Key Elements of HIV/AIDS Control in the Arab World

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Basel, den 26. Februar 2013

Prof. Dr. Jörg Schibler
Dekan

Out beyond ideas of wrong-doing and right-doing, there is a field……. I'll meet you there

Attributed to Jalāl ad-Dīn Rumi
1207-1237

To the memory of Asel Asleh
1983-2000

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SUMMARY

HIV/AIDS remains one of the most pressing health challenges more than three decades after the first documented case in 1981. In 2011, there were 34 million people living with HIV/AIDS (PLWHA) in the world, and 2.5 million *new* cases were detected that same year. The burden of the epidemic varies considerably across countries and regions. Sub-Saharan Africa is the most severely affected region with nearly 5% of the population infected with HIV; this accounts for 69% of PLWHA worldwide.

Although HIV/AIDS remains one of the leading causes of death globally, solidarity in the response to HIV/AIDS during the past decade has generated extraordinary health gains. Promotion of effective prevention tools resulted in a global decline of new infections. The introduction of antiretroviral therapy (ART) hindered the progression of the HIV virus, prolonged the life of an infected person, and transformed HIV/AIDS into manageable chronic disease. Recent scientific innovations include evidence of ART as effective prophylaxis and a clinical trial of the first vaccine candidate has begun.

The Middle East and North Africa region (MENA) is one of lowest regions in terms of HIV/AIDS prevalence. At the end of 2011 there were 300,000 PLWHA in the region (adult prevalence was estimated at 0.2%). For the same year, 37,000 people were newly infected with the HIV virus, while 23,000 deaths were AIDS-related. Low prevalence, however, does not necessarily mean low risk, and the MENA region is affected in various ways. The burden of HIV/AIDS in the region is strongly believed to be underestimated. The number of new infections in the region is on the rise despite the overall global decrease. Concentrated epidemics are emerging among high-risk groups (HRG), mainly men who have sex with men (MSM) and injecting drug users (IDU).

Soon after its discovery HIV/AIDS became a morally and politically charged issue given its association with socially 'deviant' behaviour such as drug use, homosexuality, and prostitution. This association has had a huge societal impact, both in terms of perception of the illness and as a source of stigma and discrimination. Therefore, early signs and symptoms of the psychosocial dimensions of HIV/AIDS include alienation, abandonment, and other adverse effects on PLWHA and their families.

Attitudes about HIV/AIDS in the MENA region have largely been influenced by Islamic views. Local cultural values are traditionally very strong and have a profound effect on daily life. It is widely believed that certain sociocultural values, reflected in Islamic practices, provide protection against HIV/AIDS and that people are mainly infected because of misbehaviour. Therefore, the initial response to HIV/AIDS was denial, but as the disease spread around the globe, National AIDS Programmes (NAP) were established in the MENA region aiming to maintain a low prevalence. Despite acknowledging the influence of sociocultural features on HIV/AIDS control in the region, consideration of cultural aspects on control efforts has been very limited. Furthermore, cultural values are believed by many to obstruct HIV/AIDS control.

HIV/AIDS control interventions in the region largely align with international approaches. Control measures are based on the ABC approach: Abstinence, Be faithful and use Condoms. Voluntary counselling and testing centres (VCT) are the working arms of the NAPs. VCTs promote condom use and provide anonymous counselling and HIV testing. VCTs also provide ART and medical monitoring as well as social and psychological support for PLWHA. HRGs are highly stigmatised and homosexuality, prostitution, or drug use is punishable by law in some countries of the region; both of which present a major challenge for HIV/AIDS control. Most NAPs work indirectly with HRGs through civil society organisations to avoid political sensitivities. Most countries in the MENA region impose some form of restriction on the entry, stay and residence of PLWHA and deport newly diagnosed people. In addition, HIV testing is mandatory for short- or long-term visitors, before marriage or when applying for certain jobs.

This thesis is the first to study the cultural epidemiology of HIV/AIDS in the MENA region. This study was conducted in Jordan in collaboration with the Jordan University of Science and Technology and two local non-governmental organisations (NGOs) that work with PLWHA and HRGs. The aims were, first, to gain a better understanding of the local perceptions of HIV/AIDS by assessing its priority in the local health agenda and in scientific research, and, second, to study sociocultural factors that are associated with HIV/AIDS control from the perspectives of PLWHA and HRGs. Findings presented in this thesis will likely improve the effectiveness of current interventions and contribute to the development of further interventions that are sensitive to local and regional contexts.

To address the first aim we clarified regional control policies and assessed the priority of HIV/AIDS through an exploratory observational study, involving discussions with policy

makers, and a systematic review of literature and policy documents. The second aim was addressed by using the mixed-methods approach of cultural epidemiology among PLWHA and MSM. We studied sociocultural features of HIV/AIDS in relation to control, in particular uptake of and adherence to ART among PLWHA, and condom use and HIV testing among MSM. This thesis also describes the nature of HIV/AIDS-related stigma and its role for control in the regional context.

Findings showed that approaches to control in the region focus mainly on standard international approaches such as VCT services, promoting HIV testing, and condom use. Even though cultural norms have notable implications for HIV/AIDS control in the region, their impact is neither represented in the literature nor well-integrated into control strategies. This could explain, to a great extent, the failure of control interventions in the region. Studies on HIV/AIDS in the MENA region are very limited, particularly studies that focus on sociocultural aspects of the disease. Our literature review found a low rate of reported condom use among the general population and among HRGs across the region, and a very low uptake of ART among PLWHA. The review also revealed that very little research is dedicated to PLWHA and HRGs. We consequently highlighted the need for more comprehensive academic research and political commitment and emphasised that control programmes must consider sociocultural features of HIV/AIDS with regard to priority, prevention, and treatment.

Thirty PLWHA from Jordan were interviewed to address the second aim. Thirty-three per cent were diagnosed with HIV through mandatory testing required to obtain residence permits in neighbouring countries. Forty-seven per cent sought help voluntarily and 67% were adherent to ART at the time of the study. The context in which patients are diagnosed and requirements for mandatory testing limited appropriate help-seeking and adherence to ART; voluntary testing and willingness to seek help were associated with better adherence. Side effects of prolonged medication, perceived stigma, access to treatment, anticipated ineffectiveness of treatment and religious beliefs were all found to affect adherence to ART. In addition, current policies of banning travel for PLWHA in the region have added to personal burden of illness.

PLWHA reported adverse effects of stigma on social life, medical treatment, and their work life. A few respondents referred to experience of enacted stigma, mainly arising from health care workers. Most respondents reported concerns about felt or anticipated stigma. Sadness, anxiety, reduced social status, social isolation, reduced income, and job loss were illness-

related experiences associated with higher levels of stigma. Perceived causes of HIV/AIDS associated with higher stigma included socially-mediated effects of specific behaviours such as sharing shaving blades and various sexual acts including masturbation.

A second interview survey involved a sample of 97 MSM from the four main cities of Jordan. Approximately 25% of the respondents reported using a condom during their most recent sexual intercourse, and 38% had been tested at least once for HIV. Positive determinants of condom use were higher education level, acknowledging MSM as a HRG, seeking advice from a medical doctor, and the perceived cause of sex with prostitutes. Awareness of available treatment was a positive determinant of HIV testing. Blood transfusion as a perceived cause and asking advice from friends were negative determinants.

In conclusion, control of HIV/AIDS in Jordan and the wider MENA region is generally inadequate, unsustainable, and challenged by cultural values and religious teachings. HIV/AIDS prevention and control should be higher prioritised in national and regional public health agendas in terms of both resources and political commitment. Surveillance systems should be strengthened strategically to reduce the gap in HIV/AIDS-related data in the MENA region. The HIV testing policy, which currently depends heavily on mandatory or pre-marital testing, should be reformed to reach HRGs; and travel restrictions on PLWHA should be minimised to mitigate stigma. Most importantly, the recognition of local, sociocultural illness-related features should be essential in the design of interventions to enhance HIV/AIDS control. In addition, all stakeholders, and especially religious leaders, should be involved in the design and implementation of control strategies and their implementation.

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ZUSAMMENFASSUNG

Nachdem 1981 der erste Fall dokumentiert wurde, stellt HIV/AIDS über drei Jahrzehnte später immer noch eine grosse Herausforderung dar für die öffentliche Gesundheit. Weltweit lebten im Jahr 2011 34 Millionen Menschen mit HIV/AIDS (PLWHA), während allein im gleichen Jahr 2,5 Millionen neue Fälle registriert wurden. Die Epidemie betrifft Länder und Regionen ganz unterschiedlich. Am Schlimmsten betroffen ist Afrika südlich der Sahara, wo fast 5% der Bevölkerung mit HIV infiziert sind; weltweit gesehen leben 69% der PLWHA südlich der Sahara.

Obwohl HIV/AIDS immer noch eine der Haupttodesursachen weltweit darstellt, hat eine solidarische, globale Antwort während den letzten zehn Jahren ausserordentlich gute Gesundheitsverbesserungen erzielt. Die Förderung von wirksamen Präventionsmassnahmen hat weltweit zu einer Abnahme von Neuinfektionen geführt. Die Einführung von antiretroviraler Therapie (ART) hat die Verbreitung des HI-Virus gehemmt, die Lebenserwartung von infizierten Leuten verlängert und HIV/AIDS zu einer behandelbaren Krankheit, jedoch mit chronischem Verlauf, gemacht. Die neuesten wissenschaftlichen Innovationen deuten darauf hin, dass ART auch als Prophylaxe wirksam ist; zudem haben klinische Versuche zum ersten potenziellen Impfstoff begonnen.

Die Region Mittlerer Osten und Nordafrika (MENA) ist am Wenigsten von HIV/AIDS betroffen. Ende 2011 lebten 300’000 PLWHA in der Region (mit einer Erwachsenen-Prävalenz von geschätzten 0,2%). Im selben Jahr wurden 37'000 Menschen neu mit dem HI-Virus infiziert, während 23'000 Todesfälle im Zusammenhang mit AIDS registriert wurden. Eine tiefe Prävalenz bedeutet jedoch nicht notwendigerweise ein tiefes Risiko. Die Belastung der Region mit HIV/AIDS wird allgemein unterschätzt. Und trotz dem globalen Abwärtstrend ist die Anzahl Neuinfektionen in der Region im Steigen begriffen. Konzentrierte Epidemien sind am Entstehen unter Hochrisikogruppen (HRG), vor allem Männer, die Sex mit Männern haben (MSM) und Drogenkonsumenten (IDU).

Schon bald nach der Entdeckung wurde HIV/AIDS zu einem moralisch und politisch aufgeladenen Thema, vor allem wegen der Verbindung zu sozial ‚deviantem’ Verhalten, wie Drogenkonsum, Homosexualität und Prostitution. Dies hatte einen grossen Einfluss auf die Gesellschaft in Bezug auf die Wahrnehmung der Krankheit an sich und als Quelle der

Stigmatisierung und Diskriminierung. Darum wurden schon früh psychosoziale Dimensionen wie Entfremdung, Verlassen sein und andere negative Auswirkungen von HIV/AIDS auf PLWHA und deren Familien vorhergesagt.

Die Einstellungen gegenüber HIV/AIDS in der MENA-Region sind grösstenteils durch islamische Ansichten beeinflusst. Werte sind traditionellerweise stark in der lokalen Kultur verankert und im täglichen Leben integriert. Es wird gemeinhin angenommen, dass bestimmte soziokulturelle Werte, welche islamischen Praktiken entsprechen, vor HIV/AIDS schützen, während Fehlverhalten zur Ansteckung führt. Als Reaktion darauf wurde HIV/AIDS zunächst geleugnet. Als sich aber die Krankheit immer mehr über den Erdball verbreitete, wurden in der MENA-Region Nationale Aidsprogramme (NAP) gestartet mit dem Ziel, die Prävalenz niedrig zu halten. Obwohl der Einfluss von soziokulturellen Werten auf die Bekämpfung von HIV/AIDS in der Region anerkannt ist, wurden kulturellen Aspekte bisher zu wenig miteinbezogen. Zudem werden kulturelle Werte vielfach als Hindernis in der HIV/AIDS-Bekämpfung angesehen.

Regionale Interventionen zur HIV/AIDS-Bekämpfung stimmen weitgehend mit internationalen Ansätzen überein. Massnahmen zur Bekämpfung und Eindämmung basieren auf dem so genannten ABC-Ansatz: Abstinenz, Treue und Gebrauch von Kondomen. Beratungsstellen, die das freiwillige Testen fördern (VCT), sind die Arbeitsinstrumente der NAPs. VCTs fördern den Gebrauch von Kondomen, bieten anonyme Beratung an und führen HIV-Tests durch. Zudem wird in den VCTs ART und medizinisches Monitoring angeboten und PLWHA erfahren auch sozialen und psychologischen Support. HRGs werden in hohem Masse stigmatisiert während Homosexualität, Prostitution und Drogenkonsum strafbar ist in einigen Ländern der Region; beides stellt eine grosse Herausforderung dar für die HIV/AIDS-Bekämpfung. Die meisten NAPs arbeiten indirekt über zivilgesellschaftliche Organisationen mit HRGs zusammen, um politische Empfindlichkeiten zu vermeiden. Die meisten MENA-Länder verhängen irgendeine Form von Restriktion bei der Einreise, beim Aufenthalt oder der Niederlassung von PLWHA und schaffen Menschen nach erstmaliger Diagnose aus. HIV-Tests sind zudem obligatorisch für Kurz- oder Langzeitaufenthalte, und werden auch vor der Heirat und bei der Bewerbung für bestimmte Arbeitsstellen verlangt.

Diese Arbeit hat als Erste die Kulturelle Epidemiologie von HIV/AIDS in der MENA-Region untersucht. Die Studie wurde in Jordanien in Zusammenarbeit mit der Jordan University of Science and Technology und zwei lokalen Nichtregierungsorganisationen (NGOs), welche mit PLWHA und HRG zusammenarbeiten, durchgeführt. Die Ziele bestanden erstens darin,

ein besseres Verständnis der lokalen Wahrnehmung von HIV/AIDS zu erhalten, indem deren Priorität in der lokalen Gesundheitsagenda und in der wissenschaftlichen Forschung untersucht wurde, und, zweitens, diejenigen soziokulturelle Faktoren aus Sicht von PLWHA und HRGs zu studieren, die in der Bekämpfung von HIV/AIDS ein Rolle spielen könnten. Die hier präsentierten Ergebnisse werden voraussichtlich die Wirksamkeit von aktuellen Interventionen erhöhen und auch zur Entwicklung von weiteren Interventionen, die bestmöglich an die lokalen und regionalen Begebenheiten angepasst sind, beitragen.

Für das erste Ziel untersuchten und beschrieben wir regionale Bekämpfungsstrategien und beurteilten die Priorität von HIV/AIDS anhand einer explorativen Beobachtungsstudie und einer systematische Übersicht der Literatur und von Strategiedokumenten, und nach Diskussionen mit Entscheidungsträgern. Für das zweite Ziel wurde der Mixed-Methoden-Ansatz der Kulturellen Epidemiologie verwendet, um PLWHA und MSM zu studieren. Wir untersuchten die für die Bekämpfung von HIV/AIDS relevanten soziokulturellen Merkmale in Bezug auf den Gebrauch und die Adhärenz von ART bei PLWHA und in Bezug auf den Gebrauch von Kondomen und das HIV-Testen bei MSM. Diese Arbeit beschreibt auch die Art und Weise wie Stigma im Zusammenhang mit HIV/AIDS wirkt und was es für eine Rolle spielt im Kontext der regionalen Bekämpfung.

Die Ergebnisse zeigten auf, dass Ansätze zur Bekämpfung der Epidemie in der Region hauptsächlich auf internationalen Standardvorgehensweisen basieren, d.h. Dienstleistungen durch VCTs und Förderung von HIV-Tests und den Gebrauch von Kondomen. Obwohl lokale kulturelle Normen einen bedeutenden Einfluss auf die HIV/AIDS-Bekämpfung in der Region nehmen können, ist dies weder in der Literatur beschrieben noch in den Strategien zur Bekämpfung integriert. Dies könnte hauptsächlich erklären, warum Massnahmen zur Bekämpfung in der Region gescheitert sind. Studien zu HIV/AIDS aus der MENA-Region sind rar, insbesondere jene, die soziokulturelle Aspekte der Krankheit betreffen. Unsere Literaturübersicht ergab eine tiefe, auf Eigenangabe beruhende Kondombenützungsrate in der allgemeinen Bevölkerung und in HRGs in der Region und eine sehr tiefe ART-Benützungsrate unter PLWHA. Zudem zeigte die Literaturübersicht auf, dass sehr wenig zu PLWHA und HRG geforscht wird. Als Konsequenz davon weisen wir auf den Bedarf an umfassender Forschung und auf mehr politisches Engagement hin und betonen, dass soziokulturelle Charakteristiken der Krankheit hinsichtlich der Priorisierung, Prävention und Behandlung von HIV/AIDS in Bekämpfungsprogrammen berücksichtigt werden müssen.

Dreissig PLWHA wurden für das zweite Ziel dieser Studie interviewt. Dreiunddreissig Prozent waren wegen Tests, die obligatorisch zur Erlangung einer Aufenthaltsbewilligung in Nachbarländern verlangt werden, mit HIV diagnostiziert worden. Siebenundvierzig Prozent hatten freiwillig Hilfe gesucht und 67% waren zum Zeitpunkt der Studie ART-adhärent. Die Umstände, unter denen Patienten diagnostiziert wurden, sowie die verlangten obligatorischen Tests, limitierten die Suche nach passenden Hilfsangeboten und beeinträchtigten die ART-Adhärenz. Freiwilliges Testen und die Bereitschaft, Hilfe zu suchen, korrelierten mit verbesserter Adhärenz. Nebenwirkungen einer ausgedehnten Behandlung, wahrgenommenes Stigma, Zugang zur Behandlung, antizipierte Wirkungslosigkeit der Behandlung und religiöse Überzeugungen beeinflussten die ART-Adhärenz. Zudem erhöhen aktuelle Vorschriften, die PLWHA von Reisen in der Region abhalten, die persönliche Bürde der Erkrankten.

Gemäss den PLWHA verursachte Stigma nachteiligen Auswirkungen auf deren Sozial- und Arbeitsleben sowie deren medizinische Behandlung. Einige Teilnehmende wiesen darauf hin, dass sie vor allem von Gesundheitspersonal aufgrund ihrer Krankheit stigmatisiert wurden. Die meisten Teilnehmenden fühlten sich stigmatisiert oder erwarteten deren Stigmatisierung. Die folgenden krankheitsbedingten Merkmale waren mit erhöhtem Stigma verknüpft: Traurigkeit, Sorge, reduzierter sozialer Status, soziale Isolation, reduziertes Einkommen und Verlust der Arbeitsstelle. Im Zusammenhang mit erhöhtem Stigma wurden als angebliche Ursachen von HIV/AIDS sozial bedingte Auswirkungen von spezifischen Handlungen, d.h. das Teilen von Rasierklingen und verschiedene sexuelle Praktiken (inkl. Masturbation), gemessen.

Für die zweite Umfrage wurde eine Stichprobe von 97 MSM aus den vier grössten Städten Jordaniens interviewt. Annähernd 25% der Teilnehmer gaben an, während dem jüngsten Geschlechtsverkehr ein Kondom benützt zu haben, und 38% waren zumindest einmal auf HIV getestet worden. Positive Determinanten für den Kondomgebrauch waren eine bessere Ausbildung, Eingeständnis, dass MSM zu HRG gehören, Rat suchen beim Arzt, und die Idee, dass Sex mit Prostituierten zur Ansteckung führt. Das Bewusstsein über die Verfügbarkeit von Behandlungen erhöhte die Bereitschaft zum Testen auf HIV, während Bluttransfusionen als angebliche Krankheitsursache, sowie Rat suchen von Freunden, negativ auf die Test-Rate wirkte.

Zusammenfassend kann gesagt werden, dass die HIV/AIDS-Bekämpfung in Jordanien und der erweiterten MENA-Region im Allgemeinen mangelhaft und nicht nachhaltig ist und

wegen kulturellen Werten und der vorherrschenden religiösen Lehre zusätzlich herausgefordert wird. Der Prävention und Bekämpfung von HIV/AIDS sollte mehr Beachtung geschenkt werden in der nationalen und regionalen öffentlichen Gesundheitspolitik, insbesondere mit Blick auf Ressourcen und politisches Engagement. Überwachungssysteme sollten als strategische Massnahme verstärkt werden, um die Datenlücken zu HIV/AIDS in der MENA-Region zu vermindern. Um HRGs besser zu erreichen, sollte die HIV-Teststrategie, die momentan für viele obligatorisch ist oder als Bedingung fürs Verheiraten gilt, reformiert werden. Zudem sollten Reiseeinschränkungen für PLWHA gelockert werden, um die Stigmatisierung dieser Gruppe abzumildern. Die lokalen soziokulturellen Merkmale der Erkrankung sollten in jedem Fall beim Design von Massnahmen zur Verbesserung der HIV/AIDS-Bekämpfung miteinbezogen werden. Zusätzlich sollten alle Akteure, und Religionsführer im Speziellen, beim Design und in der Ausführung von Bekämpfungsstrategien involviert sein.

الخلاصة

بعد أكثر من ثلاثة عقود من اكتشاف أول حالة في عام 1981، يبقى فيروس نقص المناعة البشرية/ متلازمة العوز المناعي المكتسب (الايدز) واحداً من أكثر التحديات الصحية العالمية. في عام 2011، كان 34 مليون شخص يعيشون مع فيروس نقص المناعة البشرية/الإيدز في العالم، وتم الكشف عن 2.5 مليون حالة جديدة في نفس العام. الوباء يختلف اختلافاً كبيرا بين البلدان والمناطق؛ حيث نجد ان جنوب صحراء أفريقيا هي الأكثر تأثرا، مع ما يقرب من 5% من السكان متعايشين مع فيروس نقص المناعة البشرية/الإيدز، وتشكل ما نسبته 69 % من مجموع المتعايشين في العالم.

على الرغم من أن فيروس نقص المناعة البشرية/الإيدز يظل أحد الأسباب الرئيسية للوفاة، الا ان التضامن في التصدي لفيروس نقص المناعة البشرية/الإيدز خلال العقد الماضي قد حقق مكاسب صحية غير عادية. مثال ذلك: تعزيز أدوات الوقاية الفعالة قد أدى إلى انخفاض عالمي في عدد الإصابات الجديدة، ظهور العلاج المضاد للفيروسات الرجعية أدى الى وقف تطور فيروس نقص المناعة البشرية، وإطالة أمد الحياة للمصابين وبالتالي تحول فيروس نقص المناعة البشرية/الإيدز إلى مرض مزمن يمكن التحكم به. بالاضافة الى الاكتشافات العلمية الأخيرة و التي تتضمت أدلة على استخدام العلاج المضاد للفيروسات الرجعية للوقاية من العدوى وبدأت أيضا في تجارب سريرية لأول لقاح مرشح.

تظل منطقة الشرق الأوسط وشمال أفريقيا (مينا) واحدة من المناطق الأقل تأثرا بفيروس نقص المناعة البشرية/الإيدز. وقدر انتشار الفيروس بين البالغين اقليميا بمعدل 0.2%. في نهاية عام 2011، كان هناك 300 الف متعايشا في المنطقة. و 37 ألف شخص أصيبوا خلال تلك السنة بفيروس نقص المناعة البشرية بينما كانت هناك 23 الف حالة وفاة مرتبطة بالإيدز لنفس الفترة.

ان معدل الاصابات المنخفض في منطقة المينا لا يعني بالضرورة خطرا ضئيلا. ويعتقد بأن عبء فيروس نقص المناعة البشرية/الإيدز في المنطقة هوأمرلا يمكن الاستهانة به. الإصابات الجديدة في المنطقة آخذة في الازدياد على الرغم من الانخفاض العالمي. كما ان دراسات جديدة قدمت ادلة على انتشار مركز بينبعض الفئات المعرضة للخطرو منهم الرجال الذين يمارسون الجنس مع الرجال(مثلييي الجنس) و متعاطي المخدرات عن طريق الحقن.

بعد فترة وجيزة من اكتشافه، أصبح فيروس نقص المناعة البشرية/الإيدز قضية أخلاقية وسياسية نظراً لارتباطه ببعض السلوكات المنبوذة اجتماعيا مثل تعاطي المخدرات و المثلية الجنسية والدعارة. هذه الرابطة كان لها تأثير كبير في المجتمع، سواء في معنى المرض و كانت ايضا مصدرا لوصمة العار والتمييز. ولذلك، تم التنبؤ بالأبعاد النفسية والاجتماعية لفيروس نقص المناعة البشرية/الإيدز والآثار السلبية على المصابين وأسرهم في وقت مبكر.

في منطقة المينا، معظم المعتقدات حول فيروس نقص المناعة البشرية/الإيدز تتأثرإلى حد كبير بوجهة النظر و التعاليم الإسلامية. ويعتقد على نطاق واسع أن بعض القيم الاجتماعية والثقافية في المنطقة، بما في ذلك الممارسات الإسلامية،

توفر الحماية ضدانتشار فيروس نقص المناعة البشرية/الإيدز، وأن الناس مصابون أساسا بسبب سوء سلوكياتهم. لذلك كان اول رد فعل لفيروس نقص المناعة البشرية/الإيدز هوالانكار. ومع تقدم هذا المرض حول العالم، أنشئت البرامج الوطنية لمكافحة الإيدز في منطقة الشرق الأوسط في محاولة للإبقاء على الانتشار المنخفض.

القيم الثقافية المحلية في منطقة الشرق الأوسط تقليديا قوية جداً وتشكل أحد جوانب الحياة اليومية. على الرغم من الاعتراف بتأثير الميزات الاجتماعية والثقافية المعنية بمكافحة فيروس نقص المناعة البشرية/الإيدز في المنطقة، الا ان عملية إدماج هذه الجوانب الثقافية والقيم الثقافية في الجهود المبذولة لمكافحة الفيروس هي محدودة للغاية.

التدخلات لمكافحة فيروس نقص المناعة البشرية/الإيدز في المنطقة في معظمها مماثلة للنهج العالمي. حيث ان اساليب المكافحة تستند الى نهج عالمي معروف (ABC approach)، من خلال: الامتناع عن الجنس، الإخلاص لشريك واحد واستخدام الواقي الذكري. مراكز المشورة والفحص الطوعي، تعتبر الاذرعة العاملة لبرامج مكافحة الايدز الوطنية. حيث تقدم هذه المراكز عدة خدمات، منها تنظيم استخدام الواقي الذكري، تقديم المشورة والفحوص الطوعية، توفير العلاج والفحص الطبي و كذلك الدعم النفسي والاجتماعي للمتعايشين مع الفيروس.

تتأثر الفئات الاكثر خطرا للاصابة بالوصمة الاجتماعية كما ان لبعض الفئات وضع غير قانوني في بعض دول المنطقة، مما يشكل تحديا رئيسيا في السيطرة على المرض. لتجنب الحساسيات السياسية، تعمل معظم البرامج الوطنية بشكل غير مباشر مع هذه الفئة من خلال منظمات المجتمع المدني. تفرض معظم البلدان في منطقة المينا شكلاً من أشكال القيود على الدخول والإقامة للمصابين، وترحيل الأشخاص الذين يتم تشخيصهم حديثا.

هذه الأطروحة هي أول دراسة على وجه الحصرفي علم أوبئة فيروس نقص المناعة البشرية/الإيدز في منطقة المينا. أجريت هذه الدراسة في الأردن بالتعاون مع جامعة العلوم والتكنولوجيا الاردنية واثنتين من المنظمات غير الحكومية المحلية التي تعمل مع المتعايشين والفئات الاكثر خطرا للاصابة. كان الهدف منها هو الحصول على فهم أفضل للمفاهيم المحلية لفيروس نقص المناعة البشرية/الإيدز، وذلك بتقييم اولوية المرض في الاجندة الصحية المحلية و الاقليمية، وفي مجال البحث العلمي، ودراسة العوامل الاجتماعية والثقافية المرتبطة بمكافحة فيروس نقص المناعة البشرية/الإيدز من منظور فئة المتعايشين والفئة الاكثر خطرا للاصابة. النتائج المعروضة في هذه الأطروحة ستساعد في تعزيز فعالية اساليب المكافحة الحالية والإسهام في تطوير المزيد من الاساليب المراعية للثقافة المحلية والإقليمية.

لمعالجة الهدف الأول، قمنا باستعراض الاولوية و السياسات الإقليمية لمراقبة فيروس نقص المناعة البشرية/الإيدز من خلال دراسة رصدية استكشافية وعقد اجتماعات مع صناع القرار واستعراض منهجي للمنشورات و الابحاث العلمية والسياسية. الهدف الثاني تم تحقيقة من خلال دراسات و و اجراء مقابلات مع المتعايشين، والأشخاص المثليين حيث قمنا بدراسة السمات الاجتماعية والثقافية لفيروس نقص المناعة البشرية/الإيدز فيما يتعلق في السيطرة على الفيروس، والالتزام بالعلاج بالنسبة للمتعايشين. واستخدام الواقي الذكري، والفحص لفيروس نقص المناعة البشرية بين الاشخاص المثليين. وتصف هذه الدراسة أيضا طبيعة الوصمة المرتبطة بفيروس نقص المناعة البشرية/الإيدز ودورها في مكافحة المرض.

أظهرت النتائج فيما يتعلق بالهدف الأول أن نهج المكافحة في المنطقة مستمد أساسا من المقاييس الدولية، مثل مراكز خدمات المشورة والفحص الطوعية، تشجيع القيام بالفحص، واستخدام الواقي الذكري. كما ان العناصر الثقافية لها آثار

اساسية ملحوظة في مكافحة فيروس نقص المناعة البشرية/الإيدز في المنطقة، ولكن هذا الأثر ليس لا يرتبط بعنصر المكافحة الحالية، الامر الذي قد يفسر، إلى حد كبير، فشل اساليب المكافحة الحالية. من جهة اخرى الدراسات المتعلقة بفيروس نقص المناعة البشرية/الإيدز في المنطقة محدودة للغاية، ولا سيما الدراسات التي تركز على الجوانب الاجتماعية والثقافية للمرض. من خلال استعراضنا للاساليب السائدة، نجد انخفاض نسبة استخدام الواقي الذكرى في المنطقة بين عامة السكان والفئات الأكثر خطرا، اضافة الى الإقبال المنخفض على العلاج من قبل المتعايشين. ومن خلال المراجعة وجدنا أيضا بان دراسات قليلة جدا بحثت فئة المتعايشين والفئات الأكثر خطرا. وأكدت المراجعة على الحاجة إلى بحوث أكاديمية والى الالتزام السياسي بمكافحة المرض، وأن برامج المكافحة ينبغي أن تركز أكثرعلى السمات الاجتماعية والثقافية لفيروس نقص المناعة البشرية/الإيدز فيما يتعلق بالأولوية والوقاية والعلاج.

اما بالنسبة للهدف الثاني، فقد أجريت مقابلات مع 30 متعايش من الأردن. تم تشخيص 33% منهم من خلال الاختبارات الإلزامية المطلوبة للحصول على تصاريح إقامة في البلدان المجاورة. 67% التزموا بالعلاج خلال وقت الدراسة و 47% طلبوا مساعدة صحية طوعيا. ان ظروف التشخيص ومتطلبات الفحص الإلزامي تحد من طلب المساعدة والالتزام بالعلاج. بالمقابل فان الفحص الطوعي والرغبة في التماس مساعدة ساعد على التقيد بشكل أفضل. الآثار الجانبية للأدوية على مدى فترات طويلة، الوصمة الاجتماعية، الوصول إلى العلاج، توقع عدم فعالية العلاج، اضافة الى المعتقدات الدينية كلها عوامل يمكنها ان تؤثر على التمسك بأخذ العلاج والالتزام به. وبالإضافة إلى ذلك، السياسات الحالية لحظر السفر على المصابين في المنطقة اضافت إلى عبء المرض.

يعاني المتعايشين مع المرض في الاردن آثارا سلبية نتيجة:الوصمة الاجتماعية، أخذ العلاج الطبي، الحياة العملية وايجاد فرص عمل. عدد قليل من المتعايشين عانوا من الوصمة الاجتماعية و التمييز الفعال من قبل العاملين في القطاع الطبي، اما الاغلبية فقد توقعوا معاناتهم من الوصمة الاجتماعية. كان هناك عدة تجارب ذات صلة بالمرض ترتبط بمستويات عالية من :الوصمة الاجتماعية: الحزن، القلق، العزلة الاجتماعية، اضافة الى انخفاض مستوى الدخل، وفقدان الوظيفة. اما الأسباب المتصورة لفيروس نقص المناعة البشرية/الإيدز والمرتبطة بالوصمة الاجتماعية فقد شملت عدة آثار لسلوكيات محددة: مثل تبادل شفرات الحلاقة، وتعدد العلاقات الجنسية و الاستمناء.

شملت الدراسة الاستقصائية الثانية على 97 شخص مثلي الجنس من أربع مدن رئيسية في الاردن، ذكرت حوالي 25% من هذه الفئة استخدام الواقي الذكرى في آخر تجربة جنسية، و 38% حالة قامت باجراء فحص الايدز على الاقل مرة واحدة. المقومات الإيجابية لاستخدام الواقي الذكري ترتبط بمستوى التعليم العالي، الاعتراف بمثليي الجنس بأنهم فئة الأكثر خطرا في المجتمع، التماس المشورة من الطبيب، الاعتقاد بأن ممارسة الجنس مع عاملات الجنس هو احد أسباب الاصابة. وكان الوعي بالعلاج المتاح عاملاً إيجابيا لاختبار فيروس نقص المناعة البشرية. انتقال الفيروس من خلال نقل الدم، والاستفسار من الأصدقاء كانت من العوامل السلبية.

وفي الختام، السيطرة على فيروس نقص المناعة البشرية/الإيدز في الأردن ومنطقة المينا غير كافية، ولا يمكن تجاهل المرض و ابعاده. يجب ان يتلقى فيروس نقص المناعة البشرية/الإيدز المزيد من الأولوية في جداول الأعمال الصحة العامة الوطنية والإقليمية، من حيث الموارد والالتزام السياسي. ينبغي تعزيز نظم المراقبة استراتيجيا بهدف تقليص الفجوة في البيانات المتصلة بفيروس نقص المناعة البشرية/الإيدز في منطقة الشرق الأوسط. كما ان السياسات المتبعة حاليا

لفحص الايدز والتي تعتمد اعتمادا كبيراعلى الفحص الالزامي أو الفحص الطوعي، يجب العمل على تغييرها، بحيث تصل الى الفئات الاكثر خطرا. اضافة الى ذلك ينبغي تقليل قيود السفر المفروضة على المتعايشين للحد من الوصمة الاجتماعية. الأهم من ذلك، ينبغي أن تكون السمات الاجتماعية والثقافية هي جوهر الاساليب المصممة لتعزيز مكافحة فيروس نقص المناعة البشرية/الإيدز. وبالإضافة إلى ذلك، ينبغي إشراك جميع أصحاب القرار، والزعماء الدينيين خاصة، في عملية التصميم والتنفيذ.

ABBREVIATIONS

4-H disease	Haitians, Homosexuals, Haemophiliacs, and Heroin Users Disease
ABC approach	Abstinence, Be faithful, and Condom use
AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral Therapy
DALY	Disability-Adjusted Life-Year
DHS	Demographic and Health Surveys
EKBB	Ethics Committee of Basel, Switzerland
EMIC	Explanatory Model Interview Catalogue
EMRO	Eastern Mediterranean Regional Office (World Health Organisation)
FSW	Female Sex Workers
GFATM	Global Fund to fight AIDS, Tuberculosis and Malaria
GNI	Gross National Income
GRID	Gay-related Immune Deficiency
HCW	Health Care Worker
HIV	Human Immunodeficiency Virus
HRG	High-Risk Group
IBBS	Integrated Bio-Behavioural Surveillance Survey
JUST	Jordan University of Science and Technology
KABP	Knowledge, Attitudes, Behaviour, and Practice
LBGT	Lesbian, Bisexual, Gay and Transgender
MENA	Middle East and North Africa
MICS	Multiple Indicator Cluster Survey

MOH	Ministry of Health
MSM	Men who have Sex with Men
NAP	National AIDS Programmes
NGO	Non-Governmental Organisation
PC	Perceived Cause
PD	Pattern of Distress
PLWHA	People Living with HIV/AIDS
RANAA	Regional Arab Network Against AIDS
STI	Sexually Transmitted Infections
Swiss TPH	Swiss Tropical and Public Health Institute
UAE	United Arab Emirates
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNDP	United Nations Development Programme
UNGASS	United Nations General Assembly Special Session on HIV/AIDS
UNHCR	United Nations High Commissioner for Refugees
UNICEF	United Nations International Children's Emergency Fund
UNRWA	United Nations Relief and Work Agency for Palestine Refugees in the Near East
USA	United States of America
USAID	United States Agency for International Development
USD	United States Dollar
VCT	Voluntary Counselling and Testing Centre
WHO	World Health Organisation

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Introduction

1.1 Global context

The first evidence of HIV/AIDS came from Los Angeles, California, USA. In 1981 health experts observed a cluster of cases of Kaposi's sarcoma, and an opportunistic pneumonia, caused by *Pneumocystis carinii* (now *Pneumocystis jiroveci*) among men who have sex with men (MSM) (CDC, 1982). By the end of 2011, the Joint United Nations Programme on HIV/AIDS (UNAIDS) estimated the number of people living with HIV/AIDS (PLWHA) to be approximately 34.0 million [estimates ranging from 31.4 million–35.9 million], with a global prevalence estimated at 0.8% of adults aged 15-49 years. In 2011, 2.5 million [estimates ranging from 2.2 million–2.8 million] people were newly infected and 1.7 million [estimates ranging from 1.5 million–1.9 million] died from AIDS-related illnesses (UNAIDS, 2012a).

The burden of HIV/AIDS varies considerably across countries and regions. Sub-Saharan Africa remains the most severely affected region, with nearly a 4.9% adult prevalence rate, accounting for 69% of PLWHA worldwide. Following Sub-Saharan Africa are the Caribbean, Eastern Europe and Central Asia, where 1.0% of adults were living with HIV/AIDS in 2011(Figure 1-1). On the other hand, in the Middle East and North Africa (MENA) region, the adult prevalence rate was 0.2% in 2011 (UNAIDS, 2012a).

Figure 1-1: Number of people living with HIV/AIDS at the end of 2011

Source: (UNAIDS, 2012a)

Worldwide, the number of people newly infected with, and the deaths due to, HIV/AIDS continue to fall. The 2011 global incidence rate was 22% lower than that recorded in 2001. Likewise AIDS-related deaths in 2011 were 11% lower than 2001. However, epidemiological trends vary by geographic region. The sharpest declines in HIV infection incidence rates since 2001 have occurred in the Caribbean (42% fewer) and sub-Saharan Africa (25% fewer). In other regions, HIV acquisition rate estimates are cause for concern. HIV incidence in Eastern Europe and Central Asia increased in the late 2000s after having remained relatively stable for several years. In the MENA region, the incidence rate has increased by 37% since 2001 (UNAIDS, 2012a).

Over the last 30 years optimism concerning HIV/AIDS control has steadily grown, influenced by a series of scientific breakthroughs and increased public health attention to the global epidemic (Havlir and Beyrer, 2012). Recently, randomised clinical trials showed partial efficacy of oral and topical chemoprophylaxis (Abdool et al., 2010; Grant et al., 2010), and new evidence for the HIV vaccine candidate has been reported (Rerks-Ngarm et al., 2009).

1.2 Regional context

The MENA region, known also as the "Arab World", consists of 22 countries. Different classifications of the region exist. For the purpose of this thesis we use the UNAIDS regional classification of MENA which consist of the same 22 countries of the "Arab World" but excluding Mauritania and Comoros and including Iran and Afghanistan. Therefore our definition of MENA includes: Afghanistan, Algeria, Bahrain, Djibouti, Egypt, Iran, Iraq, Jordan, Kuwait, Lebanon, Libya, Morocco, Oman, Palestine, Qatar, Saudi Arabia, Sudan, Somalia, Syria, Tunisia, United Arab Emirates, and Yemen.

Early studies in the region suggested a near absence of HIV/AIDS in most countries (Galal et al., 1988; Arbesser et al., 1987; Nassar, 1987; Toukan and Schable, 1987). According to the latest UNAIDS report there are 300,000 PLWHA with a regional adult estimated prevalence of 0.2% [0.1-0.2]. In 2010 there were 435,000 PLWHA in the MENA; however, the difference in number was the contribution of South Sudan which after independence is listed in the Sub-Saharan African region (UNAIDS 2007).The incidence rate for 2011 was 37,000 [29,000-46,000] cases, and there were 23,000 [18,000-29,000] AIDS-related deaths that same year.

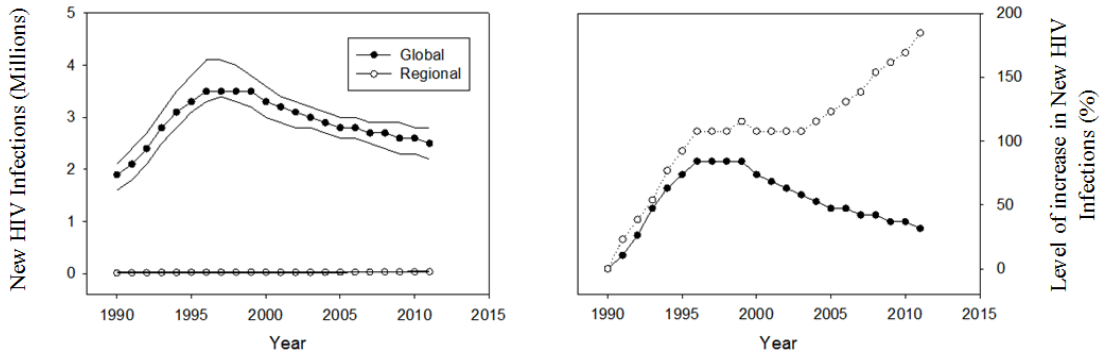
Overall, MENA is one of only two regions in the world with an increasing HIV/AIDS epidemic. Since 2001, the number of people newly infected in the MENA region has increased by 37%, despite the global decrease in incidence rates. AIDS-related deaths in this region have increased by 53% from 2001 to 2011, counter to a global decline. Figures 1-2, 1-3 and 1-4 show the change in numbers of new infection, AIDS-related deaths and PLWHA in the global and MENA region level and the fold change for each indicator since 1990. Although absolute numbers in the region are small compared to the global burden, rate of change is dramatic.

Within the region, the dynamics and profile of HIV/AIDS vary. While most of the countries have low prevalence, some have reached levels of a generalised epidemic[1], namely Djibouti with [1.1% - 2.0%] prevalence and some parts of Somalia [0.4% - %1.0] (UNAIDS, 2011; Abu-Raddad et al., 2010a). Geographic and socio-economic variations in HIV/AIDS profile are also found within countries. For example, in Morocco, surveillance indicates a concentrated epidemic among injection drug users (IDU) in northern part of the country and

[1] Generalised epidemic is an epidemic in which HIV prevalence is more than 1% of the general population, and usually based on identification of pregnant women receiving antenatal care services.

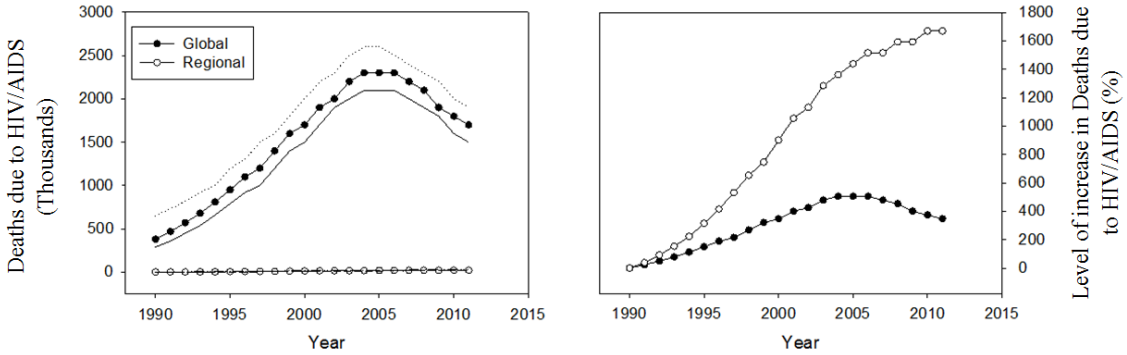
among MSM in the southern part (Morocco National AIDS Programme, 2011; Morocco National AIDS Programme, 2010).

Figure 1-2: Global and MENA regional estimates of new HIV infections



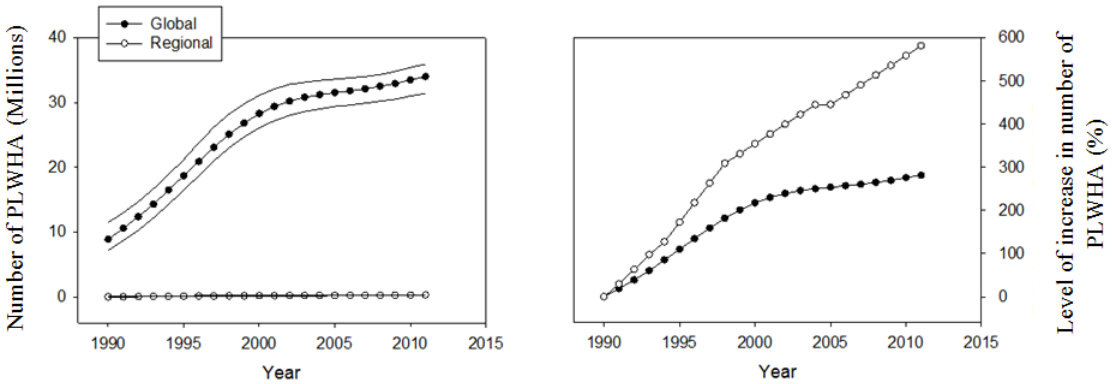
Global and MENA regional estimates of new HIV infections expressed in absolute numbers and fold change since 1990.
Level of increase = ((Year X - 1990 value)/1990 value)*100; Source: AIDS info, UNAIDS

Figure 1-3: Global and MENA regional estimates of AIDS-related deaths



Global and MENA regional estimates of AIDS-related deaths expressed in absolute numbers and fold change since 1990.
Level of increase = ((Year X - 1990 value)/1990 value)*100; Source: AIDS info, UNAIDS

Figure 1-4: Global and MENA regional estimates of number of people living with HIV/AIDS (PLWHA)



Global and MENA regional estimates of AIDS-related deaths expressed in absolute numbers and fold change since 1990.
Level of increase = ((Year X - 1990 value)/1990 value)*100; Source: AIDS info, UNAIDS

According to reported data, heterosexual transmission is believed to be the main transmission route for most countries in the region. For example it contributed to 56.3% and 63% of all

cumulative cases in Jordan and Syria, respectively (Jordan National AIDS Programme, 2012; Syria National AIDS Programme, 2012). In Egypt, heterosexual transmission accounted for 46.2% of total cases in 2010 (Egypt National AIDS Programme, 2012). Meanwhile, data from recent studies indicate that the practice of anal sex contributes considerably to HIV transmission (Mumtaz et al., 2010). In 2010, homosexual transmission contributed to 20% of cases in Egypt (Egypt National AIDS Programme, 2012), 22% in Lebanon (Lebanon National AIDS Programme, 2012) and 8% in Yemen (Yemen National AIDS Programme, 2012). IDU are largely responsible for transmission in some countries like Libya and Iran; while in other countries like Jordan and Oman, IDU contributed to 2.4% and 4.2%, respectively, of cumulative cases since 1986 (Jordan National AIDS Programme, 2012; Oman National AIDS Programme, 2012). Until 2000, contaminated blood and blood products were among the most common modes of transmission, particularly in Gulf Region. New regulations and strategies to improve blood handling practices helped to reverse this trend (Qatar Supreme Council of Health, 2012; UNAIDS/WHO, 2005; WHO, 2005; Milder and Novelli, 1992). Data on mother to child transmission is not available in most countries. Estimation is based on number of cases detected among children (Egypt National AIDS Programme, 2012).

1.2.1 High-risk groups

Some population groups are at considerably higher risk of contracting HIV due to behaviours that predispose them to acquiring HIV. They include Sex workers and their clients, MSM, prisoners, and IDU. Depending on the local settings other groups may be included. In the MENA region, female sex workers (FSW), MSM, and IDU are the high-risk groups (HRG) that receive the most attention in terms of outreach, prevention and, testing. In Saudi Arabia, however, FSW and MSM are not considered valid social categories due to socio-cultural and religious attitudes (Saudi Arabia Ministry of Health, 2012).

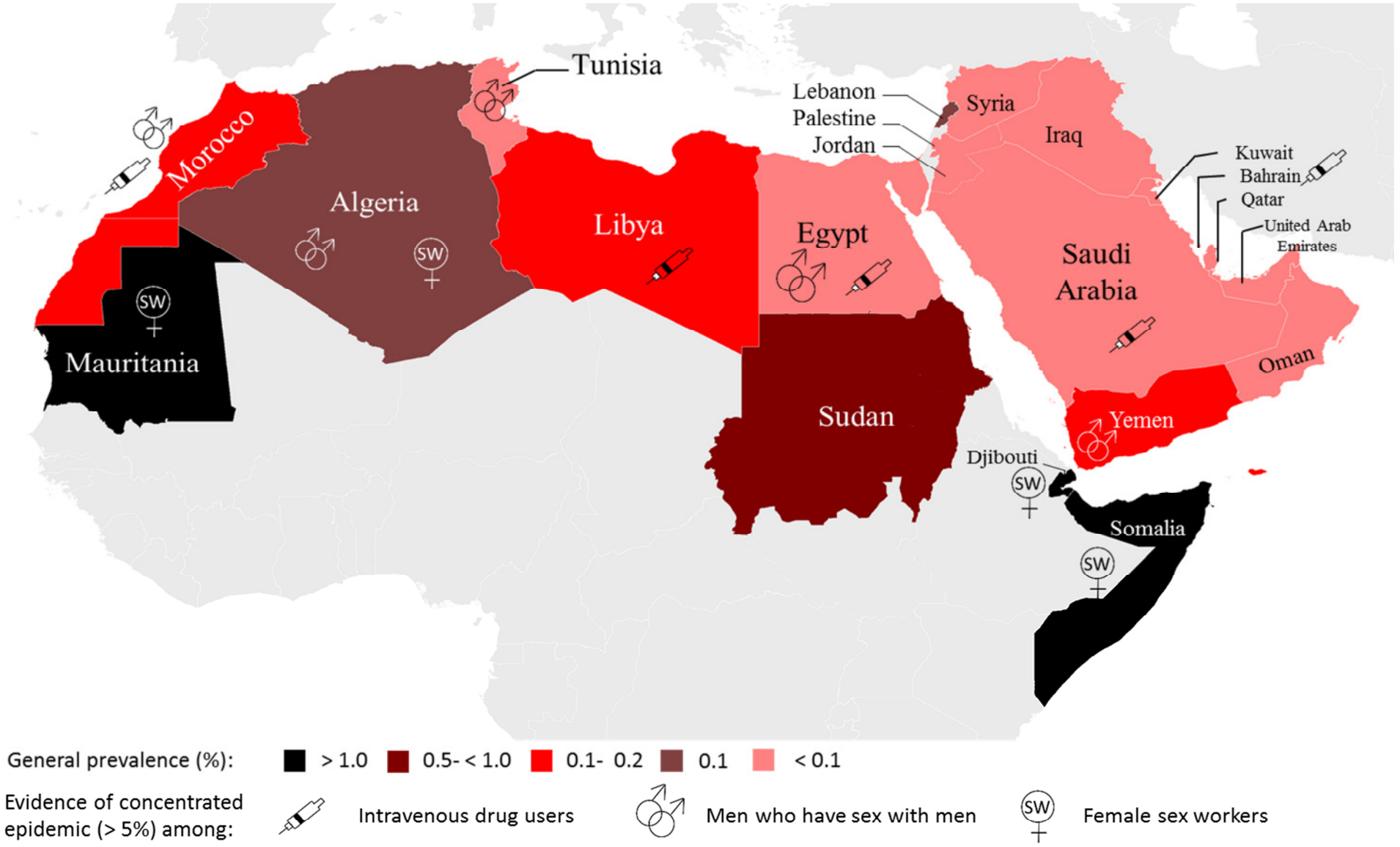
Additional sub-populations are relevant HRG for specific countries in the region based on local context or geographical location. Mobile and migrant populations are recognised HRG, particularly in the Gulf area (United Arab Emirates Ministry of Health, 2012; Saudi Arabia Ministry of Health, 2012; Martin A and UNDP, 2011). Iran, Tunisia, Egypt, Lebanon, and Morocco recognise the vulnerability of prisoners (Egypt National AIDS Programme, 2012; Iran National AIDS Programme, 2012; Lebanon National AIDS Programme, 2012; Tunisia National AIDS Programme, 2012). In Jordan university students, refugees, taxi drivers,

tourist guides, and health workers are defined as secondary HRGs (Jordan National AIDS Programme, 2008).

Recent reports suggest concentrated epidemics[2] among MSM and IDU in some areas of the region. HIV prevalence among IDU are estimated at 7% in Afghanistan (Afghanistan Ministry of Public Health, 2012), 13 % in Iran (Iran National AIDS Programme, 2010a), 22% in Libya (Mathers et al., 2008), and 7% in Egypt (Egypt National AIDS Programme, 2010a). A concentrated HIV epidemic among MSM has been observed in more than half of the countries of the MENA region (UNAIDS, 2011). Prevalence estimates from recent studies indicate a concentrated epidemic among MSM with rates reaching up to 14.8% in Iran (Eftekhar M et al., 2008), and 9.3% in Sudan (Mumtaz et al., 2010). In Egypt, the prevalence among a sample of MSM was 5.7% in Cairo and 5.9% in Alexandria (Egypt National AIDS Programme, 2010a). In Tunisia a prevalence at 5% was found among the same group in the Integrated Bio-Behavioural Surveillance survey (IBBS) (Tunisia National AIDS Programme, 2010a). Figure 1-5 summarise the regional prevalence of HIV/AIDS among general population and selected HRGs.

[2] Concentrated epidemic is an epidemic in which HIV, or another pathogen, represents > 5% in any sub-population at higher risk of infection—e.g., drug injectors, sex workers, homosexual men.

Figure 1-5: HIV/AIDS prevalence among general population and selected high risk groups in the Arab World



Sources: UNAIDS and Countries progress reports

1.3 Sociocultural features of HIV/AIDS

In the early years of the HIV/AIDS pandemic, a number of medical and popular labels were used to describe the syndrome that was eventually called AIDS. These included GRID syndrome (Gay-related Immune Deficiency), the gay plague (Fee and Krieger, 1993; CDC, 1982) and the 4-H disease (Haitians, Homosexuals, Haemophiliacs, and Heroin Users Disease) (Cohen, 2006). In the associating the condition with these socially and politically marginalised groups, HIV/AIDS came to be seen as a "social disease", even more than alcoholism, tuberculosis, or classical sexually transmitted infections (Velimirovic, 1987).

As the epidemic rapidly spread within and across countries, HIV/AIDS became characterised as "less a medical than a social-psychological and a social-political problem" (Velimirovic, 1987). In 1985 Heberele reported in Die Zeit, "the overall social consequences will be even more catastrophic than the disease itself" (Haeberle, 1985). Indeed, four decades on, social science research continues to occupy a central role for understanding the dynamics of HIV transmission, morbidity, prevention, and in HIV/AIDS control (Humble et al., 2012; Velimirovic, 1987). HIV/AIDS also became a morally- and politically- charged issue given its early association with socially 'deviant' behaviour such as drug use, homosexuality, and prostitution. The public conversation about HIV/AIDS became interwoven with cultural ideas about race, national pride, economics, and religion. For example, religious extremists and right-wing advocates spoke of divine punishment for "sinful" lifestyles (de Waal Alex, 2006). In Africa there was a virtual ban on publication of information about HIV/AIDS at the start of the epidemic. These bans prevented research from being published as well as notification of cases (Bennett, 1987). Conspiracy theorists claimed that the virus that causes HIV/AIDS was a biological weapon created in the U.S. (Bennett, 1987). Such ideological stances often justified scapegoating and selective denial by political establishments that HIV/AIDS could be a risk for all segments of society.

In the MENA region, attitudes about HIV/AIDS were largely influenced by Islamic principles which were initially manifested in denial and a distancing by society. Early in the epidemic, HIV/AIDS was described as an infection originating in sexually and morally decadent countries, or as the "disease coming from the West" (Kandela, 1993). Among the first diagnosed cases of in the region, in 1986, HIV/AIDS was labelled as the "disease of sinners" or "the others' problem" (WHO, 2007a). Even after four decades HIV/AIDS continues to be perceived as a "moral disease" (Badahdah, 2010).

HIV/AIDS first became politicised in the MENA region in the eighties after a scandal of contaminated blood shipments in Iraq and Jordan; 189 Iraqi haemophiliacs had contracted HIV from clotting agents imported from France and Austria (Zielbauer, 2006). Another well-known case is a trial in Libya "The El-Fatih epidemic". This trial is the largest documented incident of nosocomial infection of HIV in history. It infected over 400 children with the HIV virus in 1998 (Bagasra et al., 2007; Kovac and Khandjiev, 2001). In April 2001 former Libyan leader Muammar Gaddafi addressed the African summit on HIV/AIDS and said that the HIV/AIDS crisis in Benghazi was "an odious crime" and questioned who was behind it-implying the USA and Israel (Nkrumah, 2001; Rusinova, 2001). In 1997, the famous Egyptian newspaper Al-Ahram published a front page article claiming that Israel has injected 430 Palestinian kids with the HIV virus. Such cases and how they were communicated had publicity that strongly influenced public perceptions, which came to view the scourge of HIV/AIDS as a problem of political conspiracy and of immorality. Even today these attitudes are propagated through the media. Figure 1-6 show two examples of how HIV/AIDS in propagated, the first picture is a cover page of the Libyan magazine "NO". The picture refers to the incidence in the Libyan hospital and picturing skeleton infecting children with "AIDS". The second picture is a carton from Elite newspaper in Sudan, its message equal between getting HIV and death and proposing that there is no treatment for such case.

Figure 1-6: HIV/AIDS in the Middle East and North Africa region Media

The cover page of the Libyan magazine "NO", 1998. Entitled: "AIDS is among our children, who is responsible?"
picturing a Skelton injecting a child with a syringe labelled AIDS

A cartoon published in the Sudan elite newspaper, 2009
First character; This AIDS, did they find a cure for it?
Second character: Does death have a cure?

1.3.1 Stigma

Modern understanding of disease-related stigma owes much to the work of Erving Goffman, who defined stigma as the disqualification from full social acceptance, and who regarded stigma as "an attribute that is significantly discrediting'' (Goffman E, 1963). Goffman reconceptualised stigma with reference to social interactions, deviance, and exclusion. Stigma stems in part from ignorance and fear typically levied from a dominant social group against another. It often manifests in moral condemnation of others, based on cultural attitudes, that inflicts blame, victimisation and legitimation of social exclusion (Weiss, 2008). Stigma research in health has focused on the experiences of marginalised groups, such as the mentally ill and the disabled, LBGT—Lesbian, Bisexual, Gay and Transgender— drug users, and ethnic minorities.

HRGs (e.g., MSM and IDU) have been the targets of social stigma, even before the discovery of HIV/AIDS (Bennett, 1987). In the late 1980s, Jonathan Mann outlined three phases of an AIDS epidemic in any community: the unnoticed spread of HIV infection, the epidemic of AIDS itself resulting from HIV infection. The last and most explosive phase is the epidemic of stigma, discrimination, blame, and denial (Mann J, 1987)

At present stigma remains a central challenge to HIV/AIDS control (Florom-Smith and De Santis, 2012; Soliman and Almotgly, 2011; Badahdah and Sayem, 2010; Badahdah and Foote, 2010; Al-Iryani et al., 2009; Kabbash et al., 2008; Roudi-Fahimi, 2007; Parker and Aggleton, 2003). Stigma adversely affects treatment, testing, and prevention (Konkle-Parker et al., 2011; Obermeyer and Osborn, 2007; Holzemer and Uys, 2004) representing a hidden burden of HIV/AIDS (Bravo et al., 2010). Therefore measuring stigma, understanding its impact, and mitigating its social disqualification and related suffering are priorities in public health (Heijnders and Van Der Meij, 2006).

In the MENA region such stigma is often justified by normative cultural values and Islamic beliefs that forbid pre-marital sex, homosexuality, prostitution, and drug use. In this respect, many believe that HIV infections only occur in immoral people who transgress against doctrinal and cultural proscriptions (El-Feki S., 2006).

As elsewhere, stigma is enacted in various ways, ranging from verbal insults, denial of treatment in health care facilities, denial of opportunities for jobs or education, physical harm, imprisonment, or even murder (IRIN Plus News, 2012; IRIN Plus News, 2006; IRIN Plus News, 2005). Although strategies have been implemented to mitigate stigma, reports have

documented high rates across the region (Roudi-Fahimi, 2007). Stigma has been widely anticipated and endorsed, and well observed among both the general population and health care workers. For example, in Saudi Arabia 76% of surveyed college students believed that PLWHA should be isolated from the public, and 60% said PLWHA should be fired from their jobs (Badahdah, 2010).

1.4 Approaches to HIV/AIDS control

In the three decades after the first documented case in 1981 (CDC, 1982), effective control strategies have been developed, despite the political and social climate that impeded progress. Strategies include a range of different approaches which focus on prevention and treatment (Hogan and Salomon, 2005). The first recommendations issued by the US Public Health service noted that having multiple sex partners increased the risk of HIV/AIDS and recommended that members of groups at increased risk refrain from donating plasma and/or blood (CDC, 1983). After the identification of the causative agent and the adaptation of antibody testing assays, more prevention methods were developed including deferral of seropositive persons from plasma and blood donation and heat treatment of clotting factor preparations to inactivate the virus (De Cock et al., 2012). Other prevention methods for designated groups included HIV testing for MSM, informing partners of infection status, and promotion of safe sex practices. Avoidance of sharing needles and other injection equipment were recommended for IDU (CDC, 1986).

Over three decades, many additional HIV/AIDS control interventions have been integrated into global and national strategies including the well-known “ABC” approach, (A) abstinence, (B) being faithful, and (C) condom use (Green, 2003), antiretroviral therapy (ART), sexual education, HIV voluntary testing and counselling, promotion of safe sexual behaviour, and monitoring and counselling, as well as mental health care, social, and psychological support to for PLWHA and HRGs. Many factors constrain each strategy, and additional safeguards are needed to ensure the success of such interventions such as continued funding, effective programme implementation, surveillance, political commitment, and stigma mitigation.

Based largely on the success of these recommendations, in 2011 the United Nations Political Declaration on HIV and AIDS has articulated 10 specific targets for 2015 to guide collective action. The targets address reducing sexual transmission and transmission among IDU. They also target to eliminate infections among of children, to scale up ART access, to eliminate stigma and travel restrictions, as well as other targets (see Text Box 1-1) (UNAIDS, 2012a).

Text Box 1-1: The ten specific targets of the United Nations Political Declaration on HIV and AIDS for 2015

- Reduce sexual transmission by 50%.
- Reduce HIV transmission among IDU 50%.
- Eliminate new infections among children and the number of mothers dying from AIDS-related causes.
- Provide ART to 15 million people.
- Reduce the number of PLWHA who die from tuberculosis by 50%.
- Close the global AIDS resource gap and reach annual global investment of USD 22 billion to USD 24 billion in low- and middle-income countries.
- Eliminate gender inequalities and gender-based abuse and violence and increase the capacity of women and girls to protect themselves from HIV.
- Eliminate stigma and discrimination against PLWHA and people affected by HIV by promoting laws and policies that ensure the full realization of all human rights and fundamental freedoms.
- Eliminate restrictions for PLWHA on entry, stay and residence.
- Eliminate parallel systems for HIV-related services to strengthen the integration of the AIDS response in global health and development efforts

1.4.1 Condom use

Male condoms were available prior to the onset of the HIV/AIDS epidemic and are recommended to prevent transmission during sex. The effectiveness of condoms for the prevention of most other known sexually transmitted infections is well documented. The effectiveness of condoms to prevent HIV infection is estimated at 80–85% based on data from longitudinal studies, and as high as 95% for consistent use (Holmes et al., 2004; Weller and Davis, 2002; Lytle et al., 1997; Van de Perre et al., 1987). Condom use remains one of the most effective ways to reduce the sexual transmission of HIV.

To be effective, condoms should be used correctly and consistently. Nevertheless, various factors can obstruct proper use and limit their effectiveness, such as poor accessibility, high price, lack of awareness among potential users, reduced sexual pleasure, partner rejection of condom use, and cultural attitudes that paint condom use in a negative light (UNAIDS, 2000).

1.4.2 ART

Approved in 1996, ART was a milestone in the control of HIV/AIDS. ART transformed a fatal disease into a chronic manageable, although not yet curable, condition (Vella et al., 2012). ART slows the progression of HIV by reducing the viral load and the increasing CD4 count (Hogan and Salomon, 2005), thereby improving the life of those who are infected has transformed the disease into a manageable chronic condition (Bravo et al., 2010). Within a few short years after the introduction of ART, a dramatic decrease in morbidity and mortality was described worldwide (Palella, Jr. et al., 1998; Carpenter et al., 1996). Recently, ART was found to have a prophylaxis effect in limiting virus transmission (de, I, 2011; Abdool et al., 2010; Grant et al., 2010).

ART success can be hindered by many factors including late diagnosis, inadequate access to care and services, drug resistance, as well as monitoring and counselling (Stevens et al., 2004; Wainberg and Friedland, 1998). Adherence to ART is an important determinant of survival; it is strongly associated with access, uptake, and several other factors including health system capacity, health policies, and resource allocation (WHO, 2008a; Miles et al., 2007). Treatment cost also contributes to non-adherence to ART (Laniece et al., 2003). Additional relevant patient-related factors, such as stigma, illness experience, and sociocultural features, also require consideration (Deribe et al., 2008; Plummer et al., 2006; Mshana et al., 2006).

1.4.3 HIV testing

HIV testing is a key strategy in the prevention and control of HIV/AIDS (Hermez et al., 2010). Knowing HIV status can facilitate access, care, treatment, and adoption of prevention methods to prevent further transmission (UNAIDS/WHO, 2012). HIV testing indirectly increases awareness of HIV/AIDS (Lorenc et al., 2011) and reduces the practice of risky behaviours (Marks et al., 2005; Weinhardt et al., 1999). Meta-analytic evidence shows that most people who discover that they are HIV positive take preventive action, including condom use, to reduce the risk of transmission (Marks et al., 2005).

HIV testing, however, should be combined with the "3 Cs"- counselling, confidentiality, and with informed consent. Fear of HIV/AIDS and associated disclosure, low risk perception, stigma, access to health services, cost, and health policy are documented barriers to testing, (Lorenc et al., 2011; Deblonde et al., 2010; Boyd et al., 2005; Flowers et al., 2003)

1.5 Regional control

In 2012, for the first time, *all* MENA region countries submitted comprehensive reports on their national HIV/AIDS response, compared to one-third of the countries in 2006 (UNAIDS, 2012a). Member countries also endorsed the 2011 Political Declaration on HIV/AIDS and its ten specific targets. Advancement was observed in the whole region, when the priority of HIV/AIDS dramatically increased compared to the early response.

HIV/AIDS control was initially given low priority, as it was widely believed that adherence to Islamic values and norms will offer the best protection against HIV. Low prevalence appeared to support this view (UNDP, 2009; Ellis, 2008). Furthermore, most of the reported HIV/AIDS cases were among foreigners (Jordan National AIDS Programme, 2008; Traboulsi et al., 2006). Despite early denial and apparent low priority, most countries in the region established National AIDS Programs (NAP) towards the beginning of the epidemic, and most governments have worked with the WHO and UNAIDS. Maintaining the low prevalence of HIV/AIDS in the region was the primary strategy adapted by most of the countries.

With continuous discovery of new cases in the region, control strategies evolved according to the global standards (Jenkins and Robalino, 2003). Initial efforts included blood screening, preventing blood imports, training medical personnel, and developing technical capacity for HIV testing. Efforts to increase the public awareness of HIV transmission and prevention followed (Qatar National AIDS Committee, 2008). Recent involvement of the Global Fund to

fight AIDS, Tuberculosis and Malaria (GFATM)[3] and other international organisations in the region have enhanced surveillance efforts, increased local awareness about the disease, encouraged HIV voluntary testing especially for vulnerable groups, and promoted preventive methods and safe sex advocacy (USAID 2008a).

Currently NAPs act through voluntary counselling and testing centres (VCT) in the region. NAPs aim to prevent HIV/AIDS by encouraging anonymous HIV testing free of charge (Hermez et al., 2010), promote safe sex by raising awareness, encouraging abstinence, and promoting condom use. They also provide free ART, support, and care for PLWHA and their families. In addition to blood screening, NAPs address concerns with HRGs (Egypt Ministry of Health et al., 2007).

Recently, increased awareness of the importance of working with HRGs has led to more committed efforts to understand the implications of HRGs negligence and address the shortcomings of current approaches (UNAIDS, 2012a). To do so, NAPs and Ministries of Health (MOH) are establishing collaborations with civil society organisations to reach HRGs and PLWHA.

Stigma is documented in the region and considered a major obstacle in HIV/AIDS control (Jordan National AIDS Programme, 2012; Badahdah, 2010; Kabbash et al., 2008; Roudi-Fahimi, 2007). Cases of enacted stigma, including homicides against PLWHA, suicides, and discrimination in the work place, have all been reported in the region (IRIN Plus News, 2006; IRIN Plus News, 2005). NAPs acknowledge this and use different approaches for mitigation mainly through media and raising awareness (Figure 1-7). By using different types of social media, awareness campaigns target various population subgroups with the aim to raise knowledge about the disease and correct any pre-existing misconceptions.

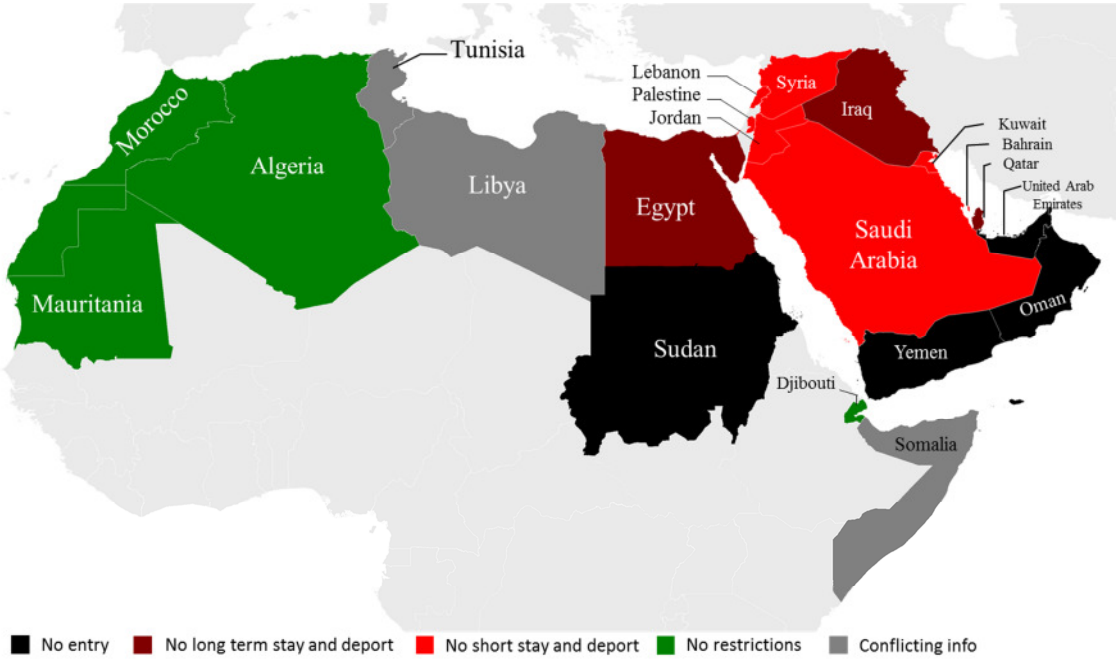
[3] In nine countries of the MENA region, GFATM provided 61% of the international financing for HIV and 39% of the overall HIV funding, both international and domestic (UNAIDS, 2010)

Figure 1-7: A poster addressing HIV/AIDS stigma in the MENA region

A poster distributed by the WHO office for the Eastern Mediterranean Region on the AIDS International World day, 2002. The message in Arabic says "Wish the lives of others what you wish for yours"

Restrictions and bans on travel are control methods that were imposed in many regions in the early years of the epidemic. In 2012, there were 45 countries with restrictions on entry, stay, and residence for PLWHA; of those, 13 were from the MENA region (UNAIDS, 2012a). Of the 20 countries with laws for deporting individuals diagnosed with HIV, 12 are from the MENA. This is particularly notable in the Gulf area, the destination for millions of migrant workers. Bahrain, Kuwait, Oman, Qatar, Saudi Arabia, and the United Arab Emirates – all mandatorily test migrants seeking employment and require them to be periodically tested for visa renewal. Figure 1-8 illustrates the different travel bans and restriction in the MENA region.

Figure 1-8: Travel ban and restrictions in the MENA region countries.



Source: (UNAIDS, 2012a)

Despite marked progress in infection control approaches, the current level of response in the MENA region is characterised by low priority. This indicates that several challenges still need to be overcome; for example, lack of access to appropriate health care measures and prevention programmes particularly among HRGs, including HIV testing. Insufficient leadership, disease-associated stigma and discrimination, and the amount of data available for evidence-based decision-making, all remain challenges for HIV/AIDS control (UNAIDS, 2011).

1.5.1 Condom use

In the MENA region, despite allocation of efforts and resources, condom use for HIV prevention continues to be limited (Khachani, 2008), particularly among MSM and IDU (Mumtaz et al., 2010; Abu-Raddad et al., 2010a). The latest UNAIDS report addressed this alarming situation among HRGs across the region. Official numbers presented in countries progress reports showed a condom use at last intercourse of 13% in Egypt (Egypt National AIDS Programme, 2010b), 38% in Iran (Iran National AIDS Programme, 2010b) among MSM, 21% in Egypt (Egypt National AIDS Programme, 2010b), and 51% in Jordan (Jordan National AIDS Programme, 2010a) among FSW. In Lebanon, 43% of IDU reported condom use at last anal intercourse (Lebanon National AIDS Programme, 2010).

In addition, meta-analytical evidence shows an overall regional rate of consistent condom use below 25% among MSM (Mumtaz et al., 2010). Among the VCT visitors in Amman city in 2008, 11.3% declared consistent condom use, 29.4% use them sometimes, and 53.7% had never used condoms before (Alkaiyat, 2009). Moreover, a sample of 73 MSM in Cairo, Egypt showed that only 19.2% have always used condoms in their frequent and multiple sexual relations (El-Sayyed et al., 2008a).

In the MENA region condoms are easily accessible, they are offered in the pharmacies and many supermarkets for 24 h/day and at affordable prices; this is in addition to the open and free access from the VCTs.

Unfortunately, the studies reported so far have largely failed to explain reasons behind low condom use in the region. A few studies (UNAIDS, 2000) have attempted to explain such low use in terms of globally recognised factors (El-Sayyed et al., 2008a; El-Sayyed et al., 2008b; Kabbash et al., 2007; Busulwa et al., 2006; Adib et al., 2002), rather than in terms of regionally-specific indicators.

On the other hand, regional campaigns led by religious and social leaders oppose condom use and disvalue their protective effect. These leaders view condom use as an encouragement of extra-marital sex, adultery, and fornication, behaviours that are forbidden in Islamic doctrine. Abstinence and early marriages are believed, by these groups, to be a better and "less harmful" means of HIV prevention (Islamic Law Scholars Association, 2008).

1.5.2 ART

In the MENA, ART is provided free-of-charge through VCTs to all registered and eligible PLWHA. Medical counselling and clinical tests required for ART monitoring are also available through many governmental and private centres. Despite this, in 2006 only 5% of those needed the ART treatment had access to it (UNDP, 2009). Table 1-1 describes different percentages of ART access in different regions.

The latest UNAIDS regional report estimated the regional coverage for 2011 at 8%, noting a nearly 20% increase in one year (UNAIDS, 2011). The same report found that most countries in the region are falling short of the goal of universal access to treatment. The coverage of ART varies widely across the region, Oman has the best estimated coverage (45%), followed by Lebanon (37%) and Morocco (30%), to 1.7% in Sudan (WHO, 2008b). In Jordan, the latest NAPs report reported an adherence to ART at 84% of enrolled PLWHA (Jordan National AIDS Programme, 2012).

Table 1-1: Access to HIV/AIDS treatment with antiretroviral therapy in low and middle-income countries, December 2003- June 2006

Countries	Access to HIV/AIDS treatment (%)
All	24%
Latin America/Caribbean	75%
Sub-Saharan Africa	23%
East/South-East Asia	16%
Europe/central Asia	13%
Middle East/North Africa	5%

Source: adapted UNAIDS and WHO 2006 (UNDP, 2009)

All estimations of ART coverage and adherence in the region are based on governmental and country progress reports. To our knowledge, no study has revealed factors that could explain the low access of ART treatment. Only a handful studies addressed questions of ART adherence, mainly in Egypt, and Morocco (Badahdah and Pedersen, 2011; Mills et al., 2006; Benjaber et al., 2005; Melbourne, 1999). Data from the MENA regional WHO office indicate that limited HIV testing, limited access, high cost of ART to the health system, and failure to reach stigmatised HRGs are the main obstacles (WHO, 2008b).

1.5.3 HIV testing

In the MENA region, most countries have policies for HIV testing, not necessarily complying with the "3Cs" recommendation. HIV testing is mandatory for application for immigration, residency visas, certain jobs, and for pre-marital testing in a few countries. A positive test usually results in denial of the request for which testing is required.

Most cases in the region are passively reported through mandatory testing. This phenomenon is observed in the published data from NAPs. In Jordan for instance, 66.4% of HIV/AIDS cases from 1986-2007 were foreigners (Jordan National AIDS Programme, 2008). In Lebanon till the end of 2005, only 8% of the reported HIV/AIDS cases were accounted for due to voluntary testing (Traboulsi et al., 2006). High percentages of HIV infections among foreigners are simply explained that the majority of screened people are foreigners who wish to stay in the region and therefore have to test for HIV. However, such reported high rates among foreigners increased the denial of the disease by attributing to the idea of "foreign disease".

Figure 1-9: HIV testing promotion in Damascus

AIDS awareness Billboard on a bus stop in Damascus in 2009: "No for AIDS, for any information or free, safe and anonymous test call 0112454028 or visit www.syria-fpa.org"

Despite increasing rates, HIV testing remains a serious challenge in the MENA region. Nearly 60% of the diagnostic HIV tests carried out between 1995 and 2008 were for migrant workers. In countries like UAE, 98% of HIV tests were mandatory among migrant workers (United Arab Emirates Ministry of Health, 2012). Testing among HRGs is limited within the MENA region (UNAIDS, 2011; Mumtaz et al., 2010), only 4% of tests were for the HRGs (UNAIDS, 2011; Hermez et al., 2010). Estimates for HIV testing among MSM are relatively low: 2-22% of MSM in Egypt, 22% in Lebanon (Mahfoud et al., 2010), and 22% in Tunisia (Mumtaz et al., 2010) have ever tested for HIV. Testing estimates among FSW and IDU are very limited. In the Country Progress Report 2010, only two countries – Iran and Tunisia – provided data on all three populations (Iran National AIDS Programme, 2010b; Tunisia National AIDS Programme, 2010b).

1.6 Overview of regional research

Data and research on HIV/AIDS in the MENA region are highly controversial. MENA stands as the only region where knowledge of the epidemic continues to be very limited (Obermeyer, 2006); "the region falls into a real hole in terms of epidemiological data" (Bohannon, 2005). In contrast, Abu-Raddad et al. (2010b) concluded in their literature review of the epidemiology of HIV/AIDS in the MENA region that there is a considerable amount of

epidemiological data. However, the authors concede that the data are fragmented and amorphous. In recent years, the quantity of data is steadily increasing, but it is still inadequate for mapping trends to guide public health policies.

Early studies from the region focused on serological status surveys that indicated a near absence of HIV cases (Burans et al., 1990; Naman et al., 1989; Toukan and Schable, 1987). Research then focused on medical diagnosis, pharmacology, virology, host-pathogen interactions and other biological aspects (Abdel-Rahman et al., 1994; Abdel-Rahman et al., 1993; Abdel-Rahman, 1991; Constantine et al., 1990). Later more attention was given to the behavioural and social context of HIV/AIDS in the region, addressed mainly through knowledge, attitudes, behaviour, and practices (KABP) studies among different "unaffected" subpopulations (Kahhaleh et al., 2009; Abdelmoneim et al., 2002; Azaiza and Ben-Ari, 2002; Petro-Nustas et al., 2002a; Jurjus, 1998; Azaiza and Benari, 1997; al-Ma'aitah et al., 1996; Elzubier et al., 1996; Abolfotouh, 1995; Mahfouz et al., 1995; Shouman and Fotouh, 1995; Faris and Shouman, 1994; Kulwicki and Cass, 1994; Farghaly and Kamal, 1991). Surveillance systems and health policies were emphasised after (Shawky et al., 2009b). Recently, research on HRGs has emerged, especially among MSM and FSW (Kabbash et al., 2012; Mahfoud et al., 2010; Mumtaz et al., 2010; El-Sayyed et al., 2008a).

1.6.1 Research gaps

Indeed the control of HIV/AIDS has improved over the last decade, a result of more and better research. The latest UNAIDS global report indicated that all the countries of the region submitted HIV/AIDS data for the first time in 2011. Nevertheless, many gaps in research certainly persist. Contextually appropriate studies and surveys are necessary to generate evidence that can be integrated into programmes specifically targeting key populations at risk (Oman National AIDS Programme, 2010). The regional WHO office released an urgent call for valid and evidence-based epidemiological information about HIV/AIDS (WHO, 2008c). The latest UNGASS report from Jordan noted the need for data on the comprehensiveness and effectiveness of various interventions (Jordan National AIDS Programme, 2012).

Another general need is to study the sociocultural context of the disease. It was not until 2006 that the WHO and regional policy makers addressed the importance of the cultural and religious factors in fighting the disease (Text Box 1-2). Only consideration of these factors would ensure the successful development and implementation of any effective, culturally

appropriate approach for identifying unknown HIV/AIDS cases, and would facilitate access to both treatment and preventative measures (WHO, 2007b).

Text Box 1-2: Importance of integrating sociocultural features into HIV/AIDS control as stated in the WHO regional office for the Eastern Mediterranean Region

> "The behaviour toward the illness is largely affected by the religion and culture. So any appropriate prevention messages should consolidate the observance of this behaviour and the factors that affect it. Preventive and curative interventions need to be adapted to the prevailing context, culture and religious beliefs"

Source: (WHO, 2006a)

Knowledge of the social aspects of HIV/AIDS in the region is still insufficient (Obermeyer, 2006; Jenkins and Robalino, 2003). A recent literature review of research conducted in Jordan related to behavioural and/or social outcomes found only 8 relevant studies (Alkhasawneh et al., 2012). The failure of current prevention methods is likely explained by the fundamental conflict between socio-cultural values and the national health care system. Detection of HIV status will remain a challenge and currently applied interventions will likely not achieve target goals, unless combined with social and cultural acceptance.

Stigma, in particular, requires further research. Studying stigma in a sociocultural, religious, and political framework will identify obstacles that contribute to the burden of HIV/AIDS. Studying stigma will inform policy makers for developing interventions that are more likely to be effective.

The needs of PLWHA should also be addressed in a comprehensive framework to better understand their needs and determinants of treatment adherence and quality of life. Access to preventative measures and care services should be studied in the context of those who require such service.

Data on HRGs remain limited despite recently increased reporting; in 2010 only 40%, 20%, and 15% of the countries reported data on FSW, MSM and IDU; respectively (UNAIDS, 2011). There is an urgent need to understand the medical and social dynamics among HRGs. Questions of access to HIV testing, condom use acceptance and adherence, knowledge of treatment, and help seeking behaviour need to be addressed.

In addition, more research is needed on HIV-related mental health. Studies on how media attention and local community leaders can influence and change behaviour toward HIV/AIDS is also lacking in the region. Research on health system policies, responses, and evidence to enhance HIV/AIDS control is also needed.

The research methodology should also be adapted to the regional needs and context. Quantitative epidemiological studies contribute to programme design and priority setting, and therefore the delivery of appropriate services. However, traditional epidemiological studies often disregard the influence of social and cultural processes. On the other hand, the anthropological studies that are lacking in the region would illuminate the social and cultural context, but such studies must be exhaustive enough to identify health priorities and inform policies. The context of HIV/AIDS in the MENA region requires studies generating evidence based on quantitative data to guide policies and explanatory studies with qualitative data to clarify the social and cultural factors and their impact on control.

1.7 Cultural epidemiology

Epidemiology is the study of the patterns, causes, and effects of health and disease conditions in defined populations (Miquel Porta, 2008). Epidemiologists are mainly concerned with study design, the collection of quantitative data, and statistical analysis in order to generate evidence-based knowledge to be implanted in public health methodology. Epidemiology stands as a cornerstone of public health, policy decision-making, and biomedical interventions by identifying risk factors for disease and possible control strategies.

Medical anthropology, on the other hand, is an interdisciplinary field that focuses on human health and disease, health care systems, health-related behaviours, and bio-cultural adaptation. It examines the ways in which culture and society are organised around, or influenced by, health-related issues (Seymour-Smith, 1990). Medical anthropologists use a variety of qualitative and quantitative methods, including participant observation, open-ended interviews, and focus groups. The overarching aim of this research has been to understand how people within a specific culture or social group perceive and experience an illness. Medical anthropology provides a deeper understanding of social, cultural, and political contexts and their effects on health from the vantage point of society or those who are affected by the illness.

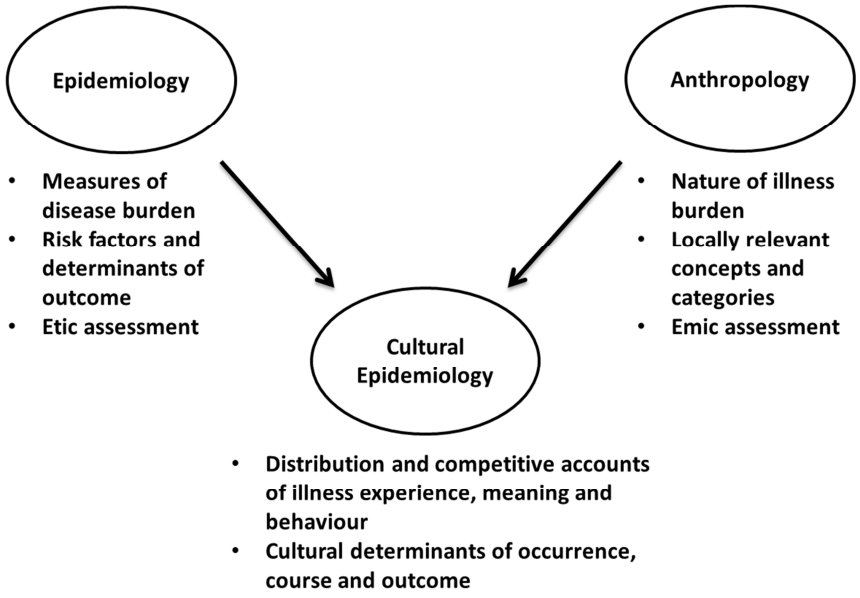
In summary, the discipline of anthropology is rooted in the ideologies of local communities, while the field of epidemiology is based on the ideologies of the professionals outside local

communities. It is important to find a suitable framework for distinguishing a 'professional' perspective from that of the local community to more specifically characterise health problems. Pike suggested the term *emic* to refer to the insiders' perspective and the term *etic* for the outsiders' perspective. Based on Pike's terminology, the discipline of anthropology uses the *emic* approach, and the field of epidemiology uses the *etic* approach (Headland et al., 1990).

Both anthropology and epidemiology contribute to public health practice. These contributions however, could be enhanced if used in concert. Attempts to connect the disciplines have been limited (Schaetti, 2012; Trostle, 2008), maybe due to differences in orientation and methodology (Weiss, 2001).

Studying the control of HIV/AIDS in the region would benefit from integrating epidemiological evidence and an outsider's, i.e. *etic*, perspective with the sociocultural context and an insider's, i.e. *emic*, perspective. In short, a cultural epidemiological approach could prove most effective. Cultural epidemiology utilises both epidemiological and anthropological methodologies to produce both quantitative and qualitative data. Therefore the results have the explanatory power yielded by epidemiology with local validity of anthropology.

Figure 1-10: Integrative framework for cultural epidemiology

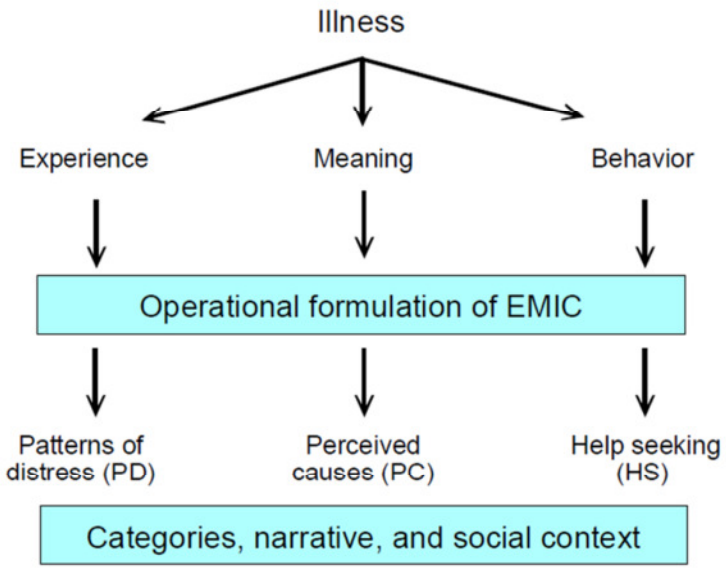


Multidisciplinary framework: contributions of epidemiology and anthropology to cultural epidemiology
Source: adapted from Weiss el al. (2008a)

Cultural epidemiology is the study of the distribution of locally valid representations of illness-related experience, meaning and behaviour (Weiss, 2001). In the framework of cultural epidemiology, one studies the sociocultural features of illness and how they affect health-related behaviour. Cultural epidemiology identifies specific illness features such as stigma, help seeking behaviour, treatment delay, and adherence; these are specified by variables, descriptions, and narratives accounting for the experience of illness, its meaning, and resultant behaviour (Trostle, 2008; Weiss, 2001).

Cultural epidemiological research uses tools based on a framework developed by Weiss (2001) called the Explanatory Models Interview Catalogue (EMIC) - a set of semi-structured survey instruments that can be locally adapted to assess representations of illness and treatment seeking behaviours from the perspective of the target population. These dimensions of health and illness are typically operationalized as pattern of distress, perceived causes, and help seeking. An EMIC interview can also be used in complementary studies with family members of people with such health problems, community residents, and other stakeholders groups such as health care providers (Weiss, 1997). EMIC interviews produce datasets with complementary quantifiable data for quantitative analysis and narrative data for qualitative analysis (Weiss, 1997).

Figure 1-11: Framework for a cultural epidemiology of illness representations



Cultural epidemiology framework; making the concepts experience, meaning and behaviour operational as patterns of distress (PD), perceived causes (PC), and help seeking (HS)
Source: adapted from Weiss (2001)

Thus cultural epidemiology is capable of providing complementary data valid in the local cultural context and yet can provide evidence and inform policies using its quantitative component. Cultural epidemiological research using EMIC interviews has been conducted in various geographic locations on topics ranging from mental health (Paralikar et al., 2011; Weiss et al., 1988), chronic disease (Kohrt et al., 2004), infectious disease (Schaetti et al., 2010; Dillip et al., 2009; Weiss et al., 2008b; Ahorlu et al., 2006; Ahorlu et al., 2005), vaccine acceptance, (Schaetti et al., 2012; Sundaram et al., 2012; Schaetti et al., 2011; Schaetti et al., 2009), stigma (Rafael et al., 2010; Coreil et al., 2010; Gosoniu et al., 2008), and gender (Atre et al., 2011; Atre et al., 2004).

In the case of HIV/AIDS in the MENA region, cultural epidemiology can address important issues from the perspective of PLWHA and HRGs. Cultural epidemiology can be used to investigate questions about the effectiveness of voluntary HIV testing and adherence to prevention measures and treatment. It also can explain features of illness experience, attributed meaning, and help-seeking behaviour in a sociocultural context, as well as the role of stigma and its impact on control.

Most of HIV/AIDS control programmes applied in the region are not evidence-based and do not adequately address local needs in terms of the social, cultural, religious, and political conditions. Unless these contexts are considered, control will remain limited and our understanding of HIV/AIDS dynamics in the region will remain incomplete.

Despite the relatively low prevalence of HIV/AIDS, many, especially health care workers, would regard HIV/AIDS as a “potential threat” in the region or “the tip of the iceberg” (El-Feki S., 2006); to either validate or disregard such assertions is controversial. The failure of most interventions such as condom use, HIV testing, and strategies to promote ART is alarming, especially in light of the fact that they are very similar to those applied in other regions where a decrease in HIV/AIDS burden have been observed.

Indeed more knowledge of the dynamics of HIV/AIDS in the MENA region is needed, particularly from those who are most affected by the epidemic- PLWHA and HRGs. Understanding the perceptions of illness-experience, meaning, and behaviour among these groups will enlighten us to possible determinants of the success or failure of interventions, and thus would facilitate tackling HIV/AIDS in the MENA region.

This thesis research aims to fill some of gaps in research on HIV/AIDS in the MENA region. The thesis assesses the priority of HIV/AIDS in this region and investigates the role of sociocultural features in control programmes. Using the cultural epidemiology framework, this thesis addresses questions of stigma, help-seeking behaviour, and ART adherence among PLWHA in Jordan. It also studies the cultural epidemiology of HIV/AIDS among Jordanian MSM with a focus on condom use and HIV testing.

2

Research aims

The overall goal of this study was to clarify elements of HIV/AIDS control in the MENA region that can be employed to enhance the effectiveness of currently applied interventions and to tailor interventions to fit local and regional contexts. This research elucidates the sociocultural and religious factors that are most likely to influence HIV/AIDS control in the region.

In preparation, we conducted a preliminary six month study in 2009 in Jordan focusing on aspects of the Jordanian health system and its HIV/AIDS control polices. The objectives of the preliminary study were to evaluate the validity and feasibility of the study and to formulate specific aims that are appropriate to the local settings and priority to HIV/AIDS control agenda. To achieve these goals, we conducted clinical observational studies at VCTs in Jordan and held a series of meetings with policy-makers and key persons involved in HIV/AIDS control in Jordan.

2.1 Broad aims for practical outcomes

This study aims to clarify specific sociocultural factors that are associated with HIV/AIDS control in the MENA region, with particular reference to condom use and HIV testing among MSM and ART uptake and adherence among PLWHA. This work also aims to describe the nature of stigma and its role in HIV/AIDS control in the regional context. This study is motivated by an effort to provide recommendations for policy makers, health workers, and national and international organisations for more effective and socially accepted interventions.

2.2 Specific aims

- Situation analysis of HIV/AIDS and its control in the MEAN region
  - Clarify the regional HIV/AIDS control policies (Chapter 3)
  - Assess the priority of HIV/AIDS as presented in the health system policy and literature (Chapter 3)
  - Identify the sociocultural features of HIV/AIDS with reference to control and perception (Chapter 3)
  - Identify research gaps in the regional literature (Chapter 3)
- Investigate social and cultural dimensions of HIV/AIDS among Jordanian PLWHA population using the cultural epidemiology framework.
  - Clarify help-seeking behaviour and ART uptake and adherence (Chapter 4)
  - Describe the nature of stigma and its impact on control among Jordanian PLWHA (Chapter 5)
- Investigate social and cultural dimensions of HIV/AIDS among Jordanian MSM using the cultural epidemiology framework with particular focus on condom use and HIV testing (Chapter 6).

2.3 Study site

Jordan, in the heart of the Middle East, had a population of 6.25 million in 2011. The majority of Jordanians (83%) live in urban areas. Amman is the capital and the largest urban centre where 38% of the Jordanian population resides, and is followed by Irbid (18%) and Zarqa (15%) (see Figure 2-1). Situated at the north-eastern tip of the Red Sea, Aqaba is Jordan's only coastal city and the home of 2.2% of the Jordanian population. Jordan's population has an expanding youth demographic; the under-30 age group comprises almost 68% of the population, with a 106.4 male-to-female ratio (Jordan Department of Statistics, 2011).

Figure 2-1: The map of Jordan

Jordan has a high literacy rate (97%) with Arabic as the main language. There are two major religions; 92% of Jordanians are Muslim, and the remainder are Christians. Jordan is classified by the World Bank as an "upper middle income country, with 4,380 USD GNI per capita in 2011(World Bank, 2012). Jordan is also classified as a country of "medium human development" with 0.698 human development index in 2011(UNDP, 2011).

Due to many political conflicts in the region, Jordan has become a destination for many refugees. More than two million Palestinian refugees have been living in Jordan since 1948, and there are approximately 30,000 Iraqi refugees. At the end of 2012 more than 117,000 Syrians had sought refuge in Jordan due to political unrest (UNHCR, 2013).

As in most MENA countries[1], Jordan is undergoing an epidemiological transition where non-communicable diseases are the leading causes of death in the region (WHO, 2002a). According to the WHO, in 2004 non-communicable diseases contributed to 72.5% of the total DALYs (disability-adjusted life years). Many improvements in health indicators have been observed in Jordan. Under-five mortality rate (probability of dying by age 5 per 1000 live births) has increased from 38 in 1990 to 22 in 2010. Adult mortality rate (probability of dying between 15 and 60 years per 1000 population) has decreased from 175 to 155 in 2010. Due to the strength of both governmental and private health systems, Jordan is considered as one on the most important medical centres for the whole region. Jordan has been a medical tourism destination in the region since the 1970s.

This study was conducted in Jordan due to its political stability and social liberty, leading role in regional scientific and medical research, and well-established heath system and HIV/AIDS control programme.

2.3.1 HIV/AIDS status in Jordan

Jordan is characterised by a low overall HIV prevalence (<0.1%), including both the general population and HRGs. The total number of HIV/AIDS cases registered from 1986-2011 was 847, of whom only 29% were Jordanians. Heterosexual contact remains the main mode of HIV transmission, accounting for 56.3% of total cases, followed blood and blood products (24.7%), and MSM (8.5%). Up to December 2011, 99 people had died of AIDS (Jordan National AIDS Programme, 2012).

In recent years Jordan has witnessed dramatic changes due to globalisation, migration from conflicted areas in the region, and the Jordanian open border policies. These changes resulted in strong political commitment to fight HIV/AIDS (Jordan National AIDS Programme, 2008) through acknowledging HIV/AIDS as a potential problem in Jordan despite the low prevalence. The latest country HIV/AIDS progress report noted that HIV/AIDS prevalence is likely underestimated and does not necessarily reflect the reality of the HIV/AIDS situation in the Jordan (Jordan National AIDS Programme, 2012).

Strategies for, and challenges in, HIV/AIDS control in Jordan are very similar to those in the region. HIV/AIDS control efforts are mostly managed by the MOH and NAP. The NAP acts through 12 VCTs distributed throughout the country. In addition, the NAP has collaborated with and received support from over 20 civil society associations, mainly working to reach

[1] Except for Sudan, Djibouti, Mauritania, and Yemen where communicable disease contribute more to causes of death.

HRGs. Jordan's work on HIV/AIDS is predominantly funded by external sources (GFATM, WHO, UNAIDS, UNDP, and USAID); the MOH is the primary recipient.

Control approaches include screening donated blood, promoting condom use, and providing condoms. ART is provided free of charge treatment for all Jordanian PLWHA. HIV/AIDS health education was included in the curriculum of secondary school students. In addition, there is continual investment in health care facilities and human resource capacity building. In 2008, the first Integrated Bio-Behavioural Surveillance survey (IBBS) survey was conducted among key populations at higher risk: FSW, MSM, and IDU; the data was analysed in 2010.

The main VCT is located in Amman. In addition to condom use promotion and ART provision, VCTs provide psychosocial support through individual counselling sessions, home based-care programme, and referrals to other social services. The Jordanian NAP ensures confidentiality when dealing with PLWHA or any VCT visitors. Therefore there is no record of VCT visitor identification. In 2010, a hospital referral system was activated through appointing a focal person at a single government hospital (Jordan National AIDS Programme, 2012).

Few other sectors are involved in HIV/AIDS management in Jordan; those that exist are working independently from the governmental and national strategy. They typically have a religious agenda that they believe will effectively prevent HIV transmission. This agenda adheres to Islamic norms such as sexual abstinence, marrying young, along with awareness and sexual education.

Despite the moderate successes in implementing HIV/AIDS prevention activities, data is scarce on the comprehensiveness and effectiveness of various awareness-raising and behavioural change interventions (Jordan National AIDS Programme, 2012).

Most available data come from governmental and international reports. Few academic or independent studies have been carried in Jordan, most of which emphasise quantitative data with minimal consideration of qualitative approaches. These studies are mainly knowledge, attitude, belief, and practice surveys (KABP) targeting different subgroups from the general population (Abu-Moghli et al., 2010; Petro-Nustas and Al-Qutob, 2002; Petro-Nustas et al., 2002a; Petro-Nustas, 2000).

2.4 Study settings

Our study design and proposal for preliminary observation was approved by the MOH and NAP in 2009. A memorandum of understanding with Jordan University of Science and Technology (JUST) and an agreement with the "Friends of PLWHA" non-governmental organisation (NGO) was established in 2010. Our study took place in multiple sites in four Jordanian cities. The PLWHA study was conducted in Amman and Irbid. MSM subjects were interviewed from four cities, Amman, Irbid, Zarqa, and Aqaba

Figure 2-2: Study settings

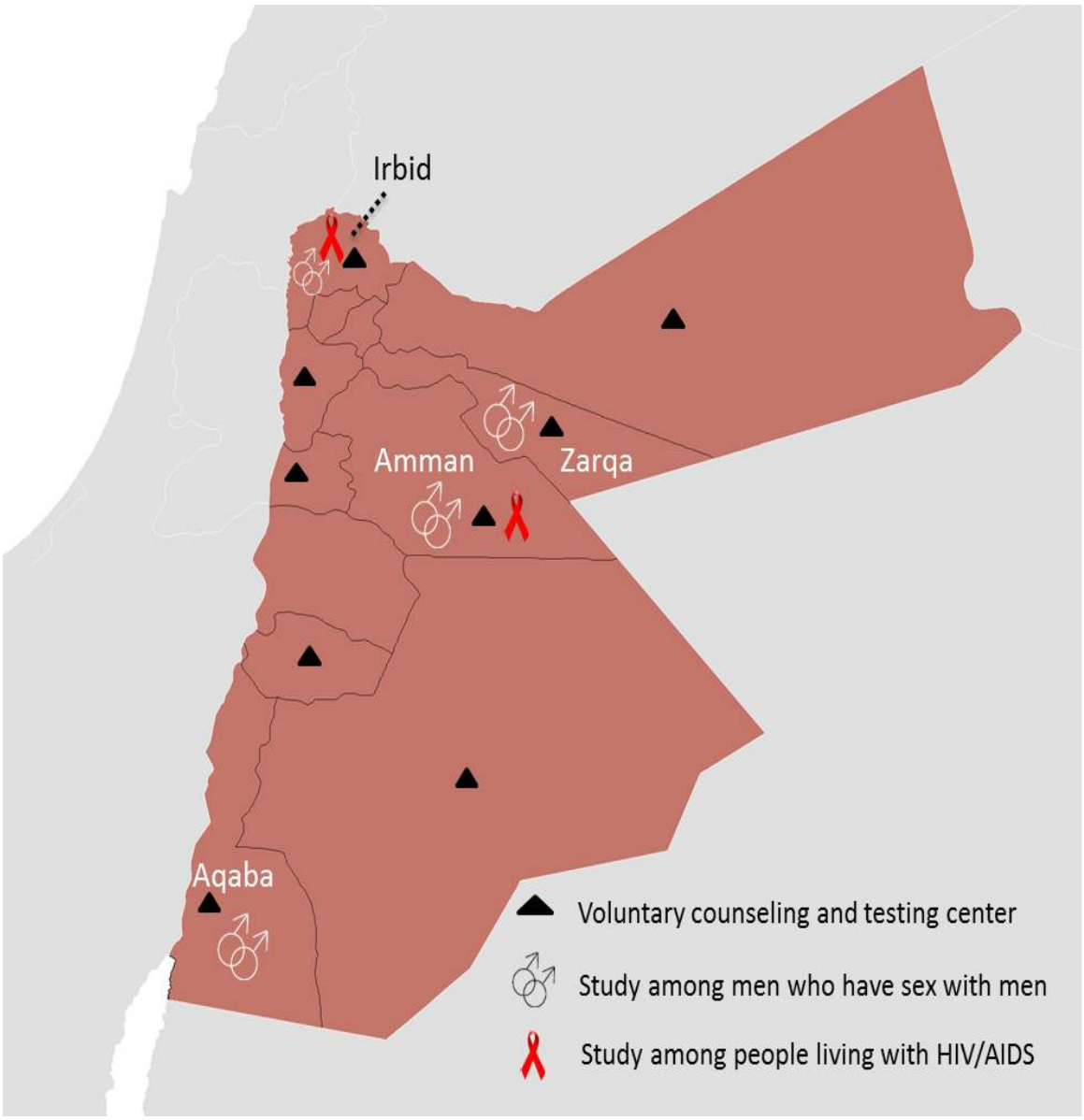


Figure 2-3: Study sites

Amman with a population of 2.4 million

Irbid with a population of 1.1 million

Zarqa with a population of 931 100

Aqaba with a population of 136 200

2.5 Methodology

Detailed descriptions of the settings, instruments, analytical approaches, and study designs are included in their respective chapters. All instruments used in the study were drafted in English, translated into Arabic, and transcribed back to English for analysis. To ensure clarity, validity, applicability, and adaptation to the local culture all instruments were pilot tested on healthy volunteers.

Quantitative categories were double-entered and cleaned with Epi Info Version 3.5.1 and processed for statistical analysis using STATA Version 10.1. MAXQDA software Version 10 was used for qualitative data management and analysis of item-related thematic codes that were compared among respondents based on variables of the dataset imported from Epi Info. RefMan 12 was used to compile and manage references. Excel was used to catalogue and filter relevant literature.

2.6 Ethics

The study was approved from the "Ethics committee of the Cantons Basel-Stadt and Basel Land" (EKBB) in August 2011. According to the Jordanian ethical panel, studies that do not involve acquisition of biological samples do not require ethical approval, but they emphasise the importance of data confidentially. In addition, the principal NGO with which we collaborated formally informed the MOH and Ministry of Civil Affairs about the study.

2.7 Organisation of the thesis chapters

The following chapters address each of the study's specific aims. A literature review on the priority, control, and socio-cultural factors of HIV/AIDS in the region is detailed in Chapter 3. The findings of the cultural epidemiology study among PLWHA are described in Chapters 4 and 5. Chapter 4 discusses in detail the local context of diagnosis, help-seeking behaviour, and ART uptake and adherence among PLWHA. Chapter 5 describes the nature and impact of perceived stigma among PLWHA as well as strategies for mitigation. Chapter 6 describes the findings of the cultural epidemiology study among MSM in Jordan and discusses determinants of condom use and HIV testing for MSM. Chapter 7 is a general discussion of implications and delineates strategies for improved HIV/AIDS control in the MENA region. The final chapter, Chapter 8, summarise the experience and lessons learned from the field work to assess future research.

3

HIV/AIDS in the Middle East and North Africa: Priority, Culture, and Control*

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Abstract

Introduction: Only 2% of people living with HIV/AIDS are in the Middle East and North Africa region. Nevertheless, with scarce data and 78.7% increase in cases number from 2001 to 2010, concerns are relevant about threat of an HIV/AIDS epidemic. National AIDS programmes were established to keep the prevalence of HIV low in most countries of the region. Control strategies include promotion of condom use for prevention and antiretroviral therapy for treatment.

Objectives: To assess the priority of HIV/AIDS in the Middle East and North Africa region and compare it with other regions. This review examines the social, cultural and religious features of HIV/AIDS in the region, and considers their role influencing, perception of risk and control approaches such as condom use and antiretroviral therapy uptake.

Methods: We screened a wide range of sources for comprehensive and reliable data, The search of PubMed, ISI Web of Science, ScienceDirect and grey literature databases were unrestricted by language and year of publication.

Results: Studies of HIV/AIDS in the region are limited, mostly, studies that focus on the social aspects of HIV/AIDS and investigate acceptance to control approaches. Findings also point to low condom use across the region among high risk groups, and the general population, and low antiretroviral therapy uptake among people with HIV/AIDS.

Conclusions: The review indicates gaps in the literature and needs for more academic engagement and political commitment. Cultural norms have notable implications for HIV/AIDS control, which are discussed, considering implications for the priority, prevention, treatment, and control of HIV/AIDS.

3.1 Introduction

Prior to 1989, several studies in the Middle East and North Africa (MENA) suggested a near absence of HIV/AIDS in most countries of this region (Galal et al., 1988; Arbesser et al., 1987; Nassar, 1987; Toukan and Schable, 1987). By the end of 2009, however, 460,000 people were living with HIV/AIDS (PLWHA), up from 180,000 in 2001. New infections have increased dramatically from 47,000 in 2001 to 84,000 in 2010. AIDS-related deaths have also increased from 22,000 in 2001 to 39,000 in 2010 (UNAIDS, 2011).

Countries of the MENA region report low prevalence (0.2%) of HIV, but many international reports questions the reliability of the data (UNAIDS, 2011; UNAIDS, 2009). Weak surveillance, limited attention to prevention, and high prevalence of sexually transmitted infections (STI) (Obermeyer, 2006), all suggest a potential crisis of HIV/AIDS in the region. MENA is presently among the top two regions in the world with the fastest growing HIV/AIDS epidemic (UNAIDS, 2011). In addition, HIV transmission among men who have sex with men (MSM) in the region is substantial, recent studies suggest that cases are concentrated among MSM in several parts of the region (Mumtaz et al., 2010)

The dynamics of HIV/AIDS in the region are not well-documented. Despite much progress on understanding HIV/AIDS globally, knowledge of the epidemic in the MENA region continues to be very limited and subject to much controversy (Obermeyer, 2006). There is a strong perception of very limited data on HIV/AIDS from the MENA (Bohannon, 2005). Nevertheless, in a recent literature review on the epidemiology of HIV/AIDS Abu-Raddad et al. indicated that there is a considerable amount of epidemiological data, although fragmented and amorphous, comparing the status of these data to “shattered glass.” (Abu-Raddad et al., 2010b). Despite much progress on data synthesis, our understanding of the sociocultural features of HIV/AIDS in the MENA region is insufficient, the social aspects, of such socially and culturally sensitive disease, are not well-understood (Badahdah, 2010; Jenkins and Robalino, 2003).

HIV/AIDS in the region is currently controlled by various measures including condom use and antiretroviral therapy (ART) (UNAIDS, 2011). Access and adherence are essential for the effectiveness of these interventions (Arnsten et al., 2001). Problems with access and adherence to prevention or treatment may result from features of health system, and social and cultural factors in the community that influence risk-related behaviour, help seeking, and adherence to treatment (Plummer et al., 2006).

Culturally, HIV/AIDS was initially dismissed as a low-priority problem affecting stigmatised groups (WHO, 2007a), and this view promoted denial of the significance of HIV/AIDS in the MENA region. People who did not identify themselves with these high-risk groups were unconcerned (El-Feki S., 2006). Furthermore, HIV/AIDS mortality seemed to validate condemnation of homosexuality and promiscuity, which are widely regarded as sinful (Francesca, 2002). Cultural values are relevant for control because they affect perceived vulnerability to HIV infection (Cheemeh et al., 2006). They are likely to influence condom use, and the uptake and adherence to ART. Strong feelings about these issues in countries of the MENA region make it necessary to consider the implications of various social, cultural, religious, and political features of HIV/AIDS (Tawil, 2008). It is therefore a challenge for both religious leaders and policy makers in the region, and an even bigger challenge now because of the changing climate of the region in the on-going "Arab Spring" (Dajani, 2011).

Despite improvement in control of HIV/AIDS and increasing acknowledged priority, data to build evidence to guide control is insufficient. One of the main issues needed is the knowledge of the social dynamics of HIV/AIDS in the region. Social studies that could explain the dynamics of HIV/AIDS in the region is insufficient. To clarify recognised implications for public health of the cultural meaning of HIV/AIDS, we review the literature on the role of the sociocultural and religious factors influencing its epidemiology and selected control measures including condom use and ART uptake. We also assess the priority of HIV/AIDS in MENA's literature by comparing the annual percentage of HIV/AIDS publications globally and regional publications cited in PubMed 1982-2011

3.2 Methods

3.2.1 Data sources and search strategy

Reports were identified through searches of PubMed (http://www.ncbi.nlm.nih.gov/), ISI Web of Knowledge (http://www.isiknowledge.com), and ScienceDirect (http://www.sciencedirect.com). Additional Arabic and English documents were identified by searching more than 50 local scientific journals, policy documents, and grey literature reports of international agencies. No restrictions were set on year or language of publications.

Several search strategies were used to identify relevant articles, and identified citations were compiled in a single dataset. We excluded duplicates, studies not specific for the MENA and studies focusing on other topics. Filters for countries of the region and topical interests of HIV/AIDS were used in the criteria for searching the literature, and details are summarised in Table 3-1.

Table 3-1: Search strategies and sources for the literature review

	Strategy	Source
1.	An electronic search with the term 'HIV' OR 'AIDS' was set in each of the local journals websites.	Local Journals websites
2.	Documents and reports were identified from the WHO, UNAIDS, UNICEF, UNDP and USAID using their global and regional websites.	WHO, UNAIDS, UNICEF, UNDP, USAID
3.	Keywords (('HIV' OR 'AIDS') AND ('Arab' OR 'Middle East' OR 'country name)) as text words were searched in PubMed and ISI web of knowledge.	PubMed, ISI web of knowledge and ScienceDirect
4.	MeSH terms 'HIV infections' OR 'Condoms' OR 'Antiretroviral Therapy, Highly Active' OR 'Anti-HIV Agents' were used with the Keywords ('Arab' OR 'Arab' OR 'Middle East' OR 'country names') as text words.	PubMed
5.	Formal and informal English and French names for each country in the region was entered as affiliation in PubMed along with 'AIDS' OR 'HIV' as text word in the title/abstract OR 'HIV infections' as MeSH term. Example: (('Countries list' [Affiliation]) AND (AIDS OR HIV [Title/Abstract])) OR ((Countries list [Affiliation]) AND ('HIV Infections' [MeSH])).	PubMed
6.	The bibliography of the identified articles and reports were screened for further possible references.	

3.2.2 Data management and analysis

References were compiled and managed with RefMan 12. Manual screening verified the relevance of the literature identified by the search strategies, excluding, for example, a few towns in the United States named "Lebanon" and universities with a "Jordan Hall." Excel was used to catalogue and filter relevant literature on condom use and uptake of ART.

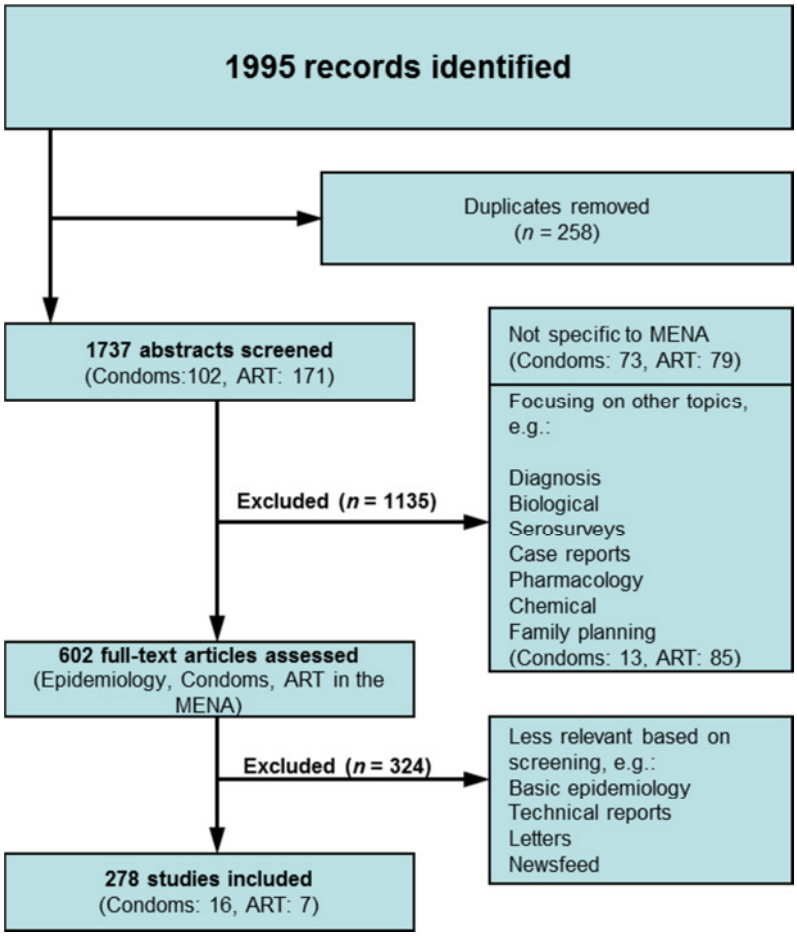
To assess the priority of HIV/AIDS in MENA and elsewhere, the MeSH term *HIV infections* was used to identify global publications in PubMed. We compared the priority reflected by the percentage of HIV-related publications retrieved for the MENA region with the global literature.

3.3 Results

3.3.1 Identified literature

Screening for relevant interest was conducted in two stages. From a total of 1995 retrieved references, 278 papers were carefully assessed after excluding those that were not directly relevant (Figure 3-1).

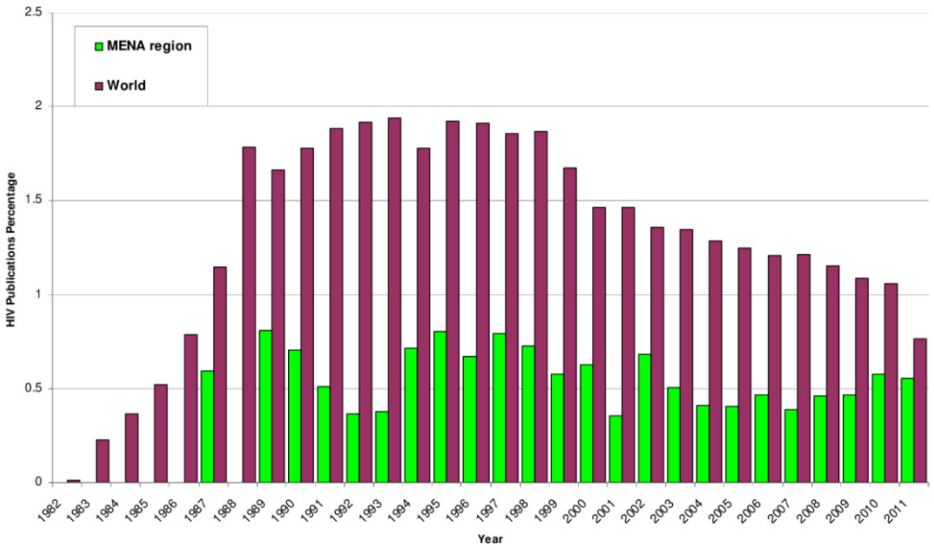
Figure 3-1: Flowchart inclusion and exclusion of identified documents



Comparing publication output of the MENA and other regions

Based on PubMed citations from 1982 to 2011, the overall percentage of HIV/AIDS related publications of the MENA region to all regional publications cited in PubMed is 0.52%, compared with 1.32% for the rest of the World. Figure 3-2 indicates the annual relative representations of HIV/AIDS consideration in the literature of the region and the World.

Figure 3-2: Overall priority of HIV/AIDS in the literature: The annual percentage of HIV/AIDS publications globally and in all MENA regional publications cited in PubMed 1982-2011



The overall percentage of PubMed citations on HIV/AIDS in the MENA region is 0.52% for publications from 1982 to 2011, compared with 1.32% for the rest of the World.

MENA Publications Profile

Medical diagnosis and treatment and biological aspects of HIV/AIDS were the main interests of the literature, with fewer epidemiological, social, and cultural studies. Early studies focused on serosurveys and pharmacology of anti-HIV agents. In the mid-1990s social and cultural interests were addressed by studies of knowledge, attitudes, behaviour, and practices (KABP), see for example (Kahhaleh et al., 2009; Elzubier et al., 1996; Faris and Shouman, 1994; Kulwicki and Cass, 1994). The focus of subsequent research shifted to surveillance systems and health policies (Shawky et al., 2009b) and then to high-risk groups (HRG), especially MSM (Mumtaz et al., 2010; El-Sayyed et al., 2008a). In some countries, few publications considered data from the region. For example, of the 19 studies on HIV/AIDS in UAE, only three included subjects from UAE while the others UAE authors conducted research outside the country (Barss et al., 2009; Al Mulla et al., 1996).

3.3.2 Islam, culture and HIV/AIDS control

Regional literature documented the importance of integrating the sociocultural and religious factors in control strategies. Several studies have evaluated the influence of Islam on HIV infection and epidemiology. Some have acknowledged that Islam and proscribed behaviour may reduce risk of HIV infection (e.g., forbidding sexual relations before and outside of marriage) (Ghalib and Peralta, 2002; Lenton, 1997; Ridanovic, 1997). Others, and fewer, argue that Islamic values may also increase the risk of HIV/AIDS (Ehsanzadeh-Cheemeh et al., 2009), for example, by allowing polygamy, and by sanctioning practice by some Islamic sects of sexual intercourse with a "temporary wife" (Cheemeh et al., 2006).

In the next sections we provide a review of the impact of sociocultural factors presented in the literature on HIV/AIDS priority, perception of risk and control measures, with focal interest on condom use and ART uptake.

3.3.3 Controversial priorities

Our review focussed on the influence of sociocultural factors represented in the literature on HIV/AIDS—considering their priority, perceptions of risk and strategies for control with particular reference to the role of condom use and ART. National priorities in the region for HIV/AIDS control appear controversial among policy makers, reflecting controversial and conflicting values of religion and public health. Notions of protection and denial of vulnerability are based on the premise that adherence to Islamic principles and values prohibiting sexual relations outside of marriage will prevent the transmission of HIV and STI (Kandela, 1993). Furthermore, policy is tempered by ideas about the benefits of conservative cultural norms, which encourage early marriages and discourage close male-female social interactions that may lead to sexual relations and HIV transmission.

Low prevalence and incidence rates in the region appear to support this view. HIV/AIDS is less prevalent than diabetes mellitus or TB (Ellis, 2008). Furthermore, most of the reported HIV/AIDS cases are among foreigners (Traboulsi et al., 2006), the focus on foreigners may deflect needed attention to the priority of HIV/AIDS among nationals. Nevertheless, these data strengthen the argument that Islamic values are protective.

3.3.4 Conflicting perceptions of risk

Some cultural and Islamic practises such as prohibiting alcohol and requiring male circumcision are likely to be protective (Templeton et al., 2010). But overreliance on

protection afforded by cultural values has also led to problematic denial. Furthermore, problems also result from stigmatising cultural practices, a social toxicity counterbalancing protection cultural values may confer. Insofar as cultural norms increase stigma and discrimination toward people with the disease, they hinder HIV testing and treatment (UNAIDS, 2010). Consequently, religious and cultural values may have little overall effect on preventing the spread of HIV/AIDS (Lenton, 1997).

Globalisation, with expanded opportunities for communication and social contacts and exposure to information and social networking on the internet, has influenced cultural and religious values and changed behaviour (Barss et al., 2009). Such changes deeply affect the structure of the society, including sexual relations, delayed marriages, and the spread of HIV/AIDS (El-Feki S., 2006; DeJong et al., 2005). Conflict within the region that leads to migration and displacement may also increase vulnerability for HIV. Therefore, low prevalence does not equate to low risks (Jenkins and Robalino, 2003).

The MENA region is the only region where knowledge of the epidemic continues to be limited, and subject to much controversy (Abu-Raddad et al., 2010a; Abu-Raddad et al., 2010b). In addition, the increase in incidence rates and deaths due to AIDS are high and rising. The weak regional surveillance systems, reliance on passive reporting of HIV/AIDS cases, the limited access to testing, and unreliability of data contribute to the potential threat (UNAIDS, 2011).

Other factors contribute to the threat of HIV, is the legal and social status of HRGs which forms a serious obstacle to assessing the real burden (Baijal and Kort, 2009). HIV infection mainly affects these groups when prevalence is low in the general population (Mills, 2000), and HIV/AIDS control has been more effective when prevention targets these groups early (Mayaud and Mabey, 2004). The low percentage of condom use in the general population (Kabbash et al., 2007), especially among HRGs (El-Sayyed et al., 2008a), and the lack of sexual education for young people (El-Feki S., 2006), are also contributing factors.

Many countries in the region have a problem of concentrated epidemic (represents > 5% in any sub-population at higher risk of infection) among HRGs. For example, the prevalence of HIV among injecting drug users (IDU) is estimated to be 11.8% in Oman, 6.5% in Morocco, and 2.6% in Egypt (Mathers et al., 2008). Prevalence estimates among MSM are 6.2% in Egypt (Shawky et al., 2009b), and 4.0% in Morocco (UN et al., 2009). Among female sex workers (FSW) in Yemen, the estimated prevalence rate ranged from 1.3% to 7.0% in

multiple studies (UNAIDS, 2009). Other countries may have reached this level, but it could be difficult to acknowledge because of economic consequences and possible conflict with Islamic and cultural values. Anecdotal evidence supports that assertion.

3.3.5 HIV/AIDS Control in the Region

The WHO and UNAIDS have been working in the region since the 1980s to control HIV/AIDS. National AIDS Programmes (NAP) were established to formulate goals and strategies (WHO, 2002b). Priorities of the NAPs have been to prevent HIV/AIDS transmission and maintain low prevalence. Over the years, policies of the NAPs have been modified and developed (Jenkins and Robalino, 2003). Initial efforts were directed toward training medical personnel and developing technical capacity for HIV testing. Efforts to increase the public awareness of HIV transmission and prevention followed. Later, the NAPs have implemented different strategies to track the epidemic and strengthen the surveillance system (Qatar National AIDS Committee, 2008).

In the MENA region, NAPs aimed to prevent HIV/AIDS by encouraging anonymous HIV testing free of charge (Hermez et al., 2010). Testing is only mandatory in specific situations, such as application for a residency visa or certain jobs, and for pre-marital testing in a few countries. A positive test usually results in denial of the request for which testing is required. NAPs promote safe sex by raising awareness, encouraging abstinence, and promoting condom use. They also provide free ART, support, and care for PLWHA and their families. In addition to blood screening, NAPs indicate concerns with HRGs (Egypt Ministry of Health et al., 2007), raising awareness of HIV/AIDS through mass media to mitigate vulnerability.

Approaches to HIV/AIDS control across the region are similar to a great. Jordan has provided free ART since 1999, distributing condoms and offering counselling (Alkaiyat, 2009). In Egypt anonymous hotline services were set up, condoms were distributed, and partnerships with local NGOs were established ([Anon], 1995). The Saudis have established programmes targeting HRGs and promoting sexual education in schools (Madani et al., 2004). In Qatar, ART is provided free of charge and programmes were set up for HIV patients and their families (Sufian, 2004). On the other hand, in other countries like UAE, despite the fast-growing rate and diversity of population, number of HIV/AIDS cases and routes of transmission have been kept confidential and were unavailable in the UNAIDS 2005 global report, this suggests on-going existence of denial (Ganczak et al., 2007).

Figure 3-3: HIV/AIDS awareness billboard in a street in the Yemini Capital, Sana'a

AIDS awareness billboard in Yemen, which says: "Do you know? Drug use and forbidden relations cause 7 million new cases every year. Be aware of AIDS"

Condom use

Our review identified 29 articles on general condom use in the region, but few studies focused on condom use for HIV prevention. Table 3-2 identified studies in the region of condom awareness and use, including barriers to use. Several of these studies recognise the protective value of condoms, providing relevant information promoting awareness of the value of condoms to prevent transmission, targeting students (Al Mulla et al., 1996), women (Husseini and Abu-Rmeileh, 2007), men (Kabbash et al., 2007) and the general population awareness (Busulwa et al., 2006). Nonetheless, research has not yet explained the low acceptance and inconsistent use of condom use, not recommend strategies to increase its use that are effective and culturally appropriate.

Table 3-2: Condom awareness and use in MENA as measured by available studies.

(Ref year) (Study site	(Target population) Sample size	Condom awareness (%)		Condom use (%)			Reason for No/ Inconsistent use (%)
		General awareness	HIV prevention	Never	Sometimes	Always	
(Kahhaleh et al., 2009) (Lebanon)	(General population 15-49 years) 3200	87.3	84.1	ND	15.3	ND	ND
(Jurjus 1996) (Lebanon)	(General population 15-49 years) 1504	95.1	88.6	ND	32.5	ND	ND
(Barbour and Salameh, 2009) (Lebanon)	(University students) 1410	98.2	80.3	38.1	14.6	ND	ND
(El-Sayyed et al., 2008a) (Egypt)	(MSM) 73	78.1	47.9	52.1	28.8	19.2	• Ignorance (21.9). • Decreased pleasure (13.7) • Partner refusal (9.6) • Unavailability (5.5)
(El-Sayyed et al., 2008b) (Egypt)	(Industrial and tourist workers) 1256	ND	0.4	ND	ND	ND	ND
(Schoueri and Bullock, 2008) (Canada)	(Canadian Arab 18-35 years) 157	ND	ND	ND	ND	27.5	• Partner refusal (ND) • Religious reasons (ND • No need (ND)
(Kabbash et al., 2007) (Egypt)	(Males 15-49) 2304	ND	60.0	ND	23.9	ND	• No need (75.7) • Decreased pleasure (18.3) • Not comfortable (10.0) • Not effective (6.9). • Difficult to use (4.4) • Religious reasons (1.5)
(Husseini and Abu-Rmeileh, 2007) (Palestine)	(Ever married women 15-54 years) 4967	ND	43.3	ND	ND	ND	ND
(Busulwa et al., 2006) (Yemen)	(General population 15-49 years) 2534	48.5	20.7	ND	2.0	ND	• Decreased Pleasure (ND) • Not effective (ND) • Breakage of condoms (ND) • Cost (ND)
(Refaat, 2004) (Egypt)	(University students) 687	ND	ND	ND	15.6*	ND	ND
(El Nakib and Hermez, 2002) (Lebanon)	(High-risk groups: MSM, FSW) 202	ND	ND	ND	ND	11.9 (FSW) 54.4 (MSM)	ND
(Petro-Nustas et al., 2002a) (Jordan)	(Nursing students) 63	ND	30.2**	ND	ND	ND	ND
(Adib et al., 2002) (Lebanon)	(Male conscripts) 292	ND	ND	ND	49.0	51.0	• Exclusive partner (86.0) • Unavailability (40.6) • Unplanned sex (31.6) • Decreased pleasure (16.8) • Partner refusal (7.0)
(Al Mulla et al., 1996)	United Arab Emirates (University students) 298	ND	48.0	ND	ND	ND	ND
(Alkaiyat, 2009) (Jordan)	(VCT visitors) 466	ND	ND	53.7	29.4	11.3	ND

ND: No data; *In the last 12 months; **Students were asked what is needed to educated people to prevent HIV.

Efforts to promote condom use for HIV prevention seem to be failing in the MENA region (Khachani, 2008). The first round of Biological Behavioural Surveillance Study (BIO-BSS) showed low and inconsistent condom use among MSM, FSW, IDU, and street boys in Egypt, and among army student officers in Lebanon (Shawky et al., 2009b).

Condoms in the region are widely available and accessible. Even in Saudi Arabia, where the constitution is based strictly on the Islamic law, condoms are available in pharmacies. In most countries they are also available in supermarkets around the clock. Prices of condoms vary across countries of the region, from 1.0 USD in Saudi Arabia to less than 0.5 USD in Jordan per latex condom.

Figure 3-4: Condoms for sale displayed in a community pharmacy in Amman, the Jordanian capital.

ART

The MENA region has been the lowest in the world for access to ART (WHO, 2010; UNDP, 2009; Kim, 2002). In 2003, less than 5% of the eligible patients received ART (Kim, 2002). In 2009 the UNDP ranked the MENA region as the lowest in ART access for the period 2003-2006 (UNDP, 2009), but the situation appears to have improved subsequently. The WHO regional office estimated coverage to be 6.5% in 2006 (WHO, 2008b; WHO, 2007a; WHO, 2006b), and the latest UNAIDS report estimates 8% for 2010 (UNAIDS, 2011). Data from the regional WHO office indicate the main obstacles to ART; they show limited HIV

testing, limited access, high cost of ART to the health system, and failure to reach stigmatised HRGs (WHO, 2008b).

Our review identified 92 studies of ART in the region. Data on ART access and uptake were found in reports of WHO, UNDP, UNAIDS, and other international organisations. Most research, however, considers pharmacology and the therapeutic or adverse drug effects of anti-HIV agents. Only a handful studies address social and cultural aspects, such as patient-reported barriers and facilitation of ART adherence (Badahdah and Pedersen, 2011; Mills et al., 2006).

Sociocultural features impacts on ART were only noted in few reports. A noteworthy case report documents changes in the ART regimen during the fasting month of Ramadan (Melbourne, 1999). A study in Morocco investigated compliance among 92 patients on ART, 90% had good compliance despite difficulties of the ART regimen, long distance to the hospital and adverse effects (Benjaber et al., 2005). A recent study interviewed 27 HIV-positive Egyptian women who had been receiving ART for at least three months. Using qualitative methods of thematic analysis, five themes relevant for adherence were identified: fear of stigma, financial constraints, characteristics of ART, social support and reliance on faith (Badahdah and Pedersen, 2011). Other papers merely referred to free access to ART for PLWHA in most of the region (Barss et al., 2009; Remien et al., 2009; Belgacem, 2007; El-Feki S., 2006; Obermeyer, 2006).

Awareness of ART within the general population and among PLWHA is poor (Alkaiyat, 2009; Hartly, 2008; Khachani, 2008), and efforts to promote awareness and access are very limited. Questions about low awareness of ART have been considered only rarely (Al-Serouri et al., 2002). Likewise, Demographic and Health Surveys (DHS) and Multiple Indicator Cluster Survey (MICS) which are applied in almost every country in the region do not address any ART-related category. This trend is also observed when screening the websites of NAPs across the region. They provide information about transmission, prevention, and hotline numbers, but not a single sentence to explain that ART can stop the progression of HIV infection and make it a chronic manageable condition.

Countries in the region were actively engaged in the 3 by 5 initiative (Kim, 2002), which was launched in 2003 and aimed to provide treatment with ART to 3 million PLWHA in low- and middle-income countries by the end of 2005 (WHO, 2010). Most of the MENA countries provide HIV treatment and supportive care for PLWHA, and most receive funds for ART

from various foundations. GFATM provides ART for 72,600 PLWHA in the region. The Clinton HIV/AIDS initiative provided ART in Morocco. ART uptake varies considerably across countries of the region, from 1.7% in Sudan to 74.3% in Oman (WHO, 2008b).

3.4 Discussion

To our knowledge, this is the first review to focus on the sociocultural features of HIV/AIDS and to identify research gaps in the MENA region. This review has highlighted the value and need for social and cultural studies of HIV/AIDS in the region, and it has identified several research gaps in the regional literature. Although more studies in recent years are providing data for the region concerned with control of HIV/AIDS (Abu-Raddad et al., 2010b), much of this data has been derived from research that lacks coherence, quality, relevance and appropriate methods for explaining the social and cultural aspects of the condition.

Despite efforts to be comprehensive, however, our study is limited by the fact that some researchers in the region may publish in local or regional journals, which re not accessible. Some of these identified articles lacked abstracts, and they could not be accessed through links, nor could we obtain hard copies. Nevertheless, this review is a first attempt to review the sociocultural features of HIV/AIDS and its relative priority for health policy and control.

Although studies have documented low access to means for control, such as condom use and access to ART, research has not adequately explained the reasons for that. Is it rooted in the religion, a feature of local cultures, or lack of priority for health system policy and action? More relevant questions may be, how are all of these interrelated, and how can answers to these questions make control more effective? Comprehensive studies for HIV/AIDS control need to carefully examine sociocultural determinants and explanatory models of the disease and ideas about its control among different segments of the population.

Most of HIV/AIDS research in the MENA is epidemiological surveys and KABP studies. Although epidemiological and burden of disease studies are necessary, they are not sufficient to fully guide policy for HIV/AIDS control. KABP studies without a qualitative component are also inadequate for explaining HIV risk-related behaviour. KABP is normally used to assess the extent of community knowledge. Other relevant issues, such as cultural concepts of illness and risk factors (i.e., illness explanatory models), are neglected in KABP studies (Hausmann-Muela et al. 2003). Assessment of interventions addressing the role of cultural factors influencing behaviour and acceptance is crucial for charting a path forward. Needs of specific population groups, especially PLWHA and HRGs, are missing from the literature.

Also, most regional studies target men without gender-sensitive consideration of women (El-Sayyed et al., 2008b; Awad, 2002; Ghazal-Aswad et al., 2002; Petro-Nustas and Al-Qutob, 2002).

Furthermore, critical academic assessment is lacking in the literature. Currently, surveys and operational studies are carried out most by governmental departments and institutions responsible for HIV/AIDS-related health services. This research is not sufficiently critical and reflective to provide effective guidance. Capacity and engagement of a critical academic contribution to this research should be developed and supported to guide government and civil society programmes more effectively (UNAIDS, 2007; UNAIDS, 2006)

3.4.1 Culture, Islam and HIV/AIDS control

The cultural of the region is of course not solely a product of Islam. Other features of local cultures should also be considered. For example, although Quran derived laws allows a man to marry four wives, in many countries cultural patterns limit this practice. In Egypt, only 3% of all marriages in 2008 where for men who already have a wife, and among them only 2.47% and 0.1% were married to a third and fourth wife respectively (Central Agency for Public Mobilization And Statistics, 2008).

Furthermore, passages of authoritative Islamic texts, including the Holy Quran and Hadith (narrations or actions originating from Prophet Muhammad)' address questions of sexual education. The Hadith provides more detail than the Quran about sexual practices within marriage, and the Prophet himself preached sexual behaviour to both men and women. However, in most of the MENA, sexual education and discussion of sexual relations is highly sensitive issue or a complete taboo (Shawky et al., 2009a). This fact represents not so much a feature of Islam, but rather a feature of local conservative cultural norms.

Cultural ideas about the disease influence policy, awareness, social stigma, and the priority or willingness to prevent and treat HIV. The idea that AIDS comes from the West is widespread. Although no policy maker officially endorses it, this idea affects policy: foreigners may be tested and expelled if found to be HIV-positive; hotel employees and people in contact with foreign tourists may also be tested (El-Sayyed et al., 2008b; El-Sayed et al., 1996). Moreover, countries in the region regarded men travelling abroad as a HRG as identified by a seminar conducted by the Ministry of Higher Education in Jordan (Petro-Nustas, 2000).

Sociocultural values interact with religious underpinnings to shape health systems and policy making at various levels, both for better and for worse with regard to control of HIV. Efforts to implement condom use and ART are likely to benefit from sensitive consideration of religion and other cultural values.

Indeed, HIV/AIDS control based on condom use and ART uptake benefit from the partnership of health systems and religious institutions. Health systems rely on that for their stability and to make services accessible and acceptable. In most of the region health systems are functional with good infrastructure and provide medical services in urban and rural areas. Similar to developed countries, the burden of disease in most of the region reflects the epidemiological transition, and non-communicable diseases have become the leading causes of death. Sudan, Djibouti, Mauritania and Yemen are exceptions, where communicable diseases remain more common causes of death (WHO, 2002c).

Although studies have documented low access to control approaches, such as condom use and ART uptake, research has not explained the reasons for that. Is it rooted in the religion, a feature of local cultures, or lack of priority for health system policy and action? The more relevant question is how all of these are interrelated, and answers are needed to make control more effective. Comprehensive studies for HIV/AIDS control need to carefully examine sociocultural determinants and explanatory models of the disease and ideas about its control among different segments of the population.

3.4.2 Promoting condom use

Global obstacles for condom use are accessibility, price, lack of awareness, and social and cultural beliefs (Cheemeh et al., 2006). In cities like Amman, Beirut, or Cairo, condoms are easily accessible in the pharmacies and supermarkets for 24 hours, in addition to the open and free access from the NAP. The price of condoms might be an issue in countries like Djibouti and Somalia where the GDP per capita is less than USD 600, but not in most of the MENA countries where GDP is much higher.

Control guidelines from the NAPs of the MENA region nominally promote condom use, consistent with the ABC approach (**A**bstinence, **B**e faithful, or use **C**ondoms). Nevertheless, content of posters and billboards to promote awareness neglect the topic. Even though condoms may be available at low cost, reasons and correct use of them lack the required emphasis. Conflicting ideas from social, religious, cultural, and health system perspectives are likely explanations for the lack of coherence in policy and action.

Although use of condoms is permitted, they are typically promoted for birth control. Promoting their use for HIV prevention raises questions about policy encouraging culturally unacceptable sexual relations. Furthermore, some Islamic leaders promote doubt by questioning the ability of condoms to prevent HIV infection (Abdulhamed Qudah, 2007). Therefore, many policy makers and health care providers are concerned that religious leaders will oppose efforts to promote condom use for HIV prevention (Madani et al., 2004; Tawilah et al., 2002). Religious authorities also represent other views and some Islamic scholars argue that condom use should be allowed for HIV prevention. They refer to the Islamic tradition of choosing the lesser of two evils. In this case, fornication or adultery is less evil than putting another person at risk of acquiring HIV infection (Malik Badri, 2009).

Addressing the issues concerning condom use in an HIV/AIDS prevention programme from a sociocultural and religious framework should help formulate an improved approach for education and ultimately increased acceptance. Interventions based on cultural framework could also invite religious leaders to openly discuss the issue, or to support the few Islamic leaders who allow condom for HIV prevention.

3.4.3 ART: The silent treatment

Confusion and uncertainty characterise the status of ART in the region. Notwithstanding the wide range in estimates of ART coverage, it is clear that information and access to ART are inadequate in the region. In countries with limited resources and weak health systems, structural and systemic obstacles, cost, stigma, and sociocultural factors are obstacles (Crane et al., 2006; Nachega et al., 2006; Laniece et al., 2003; Weiser et al., 2003). Cost and health system factors, however, cannot fully explain underutilisation of ART in the MENA region.

Inadequate implementation and underutilization of ART may result, at least in part, due to cultural values. Insofar as HIV/AIDS is perceived as a disease of sinners only affecting people who violate religious and cultural norms that proscribe fornication and homosexuality (WHO, 2007a; El-Feki S., 2006), many regard it as an untreatable disease that is God's punishment for sinners.

Regarding HIV as an untreatable disease may also lead to self-stigmatization by PLWHA, self-denial of treatment based on the idea that the disease is a fate resulting from one's own sins. Improving uptake and adherence may therefore require attention to the cultural meaning and perceived causes of the condition.

3.4.4 Research gaps and needs

Sociocultural research in the region context, meaning and control of HIV/AIDS is a priority. Without addressing the social aspects of HIV/AIDS within the cultural and religious contexts, especially in this region, our understanding of the illness burden and effective strategies for control remain limited. HIV/AIDS research agendas need to address not only social and cultural research but also the means to facilitate such research, as indicated by the following needs:

1. Political commitment should acknowledge the importance of comprehensive integrated programme monitoring of social and cultural data, including illness meanings and perceived needs of PLWHA.
2. Local academic institutions and NGOs should play a greater role in HIV/AIDS research to increase the validity and overall scientific soundness of the data.
3. Creative methodologies that integrate qualitative and quantitative approaches are needed to explain the role of culture, religion and socioeconomic factors and their practical policy implications for risk, treatment and control.

4. Surveys should be designed to distinguish more clearly the needs, priorities and the cultural epidemiology of the general population, women and HRGs.

3.5 Conclusion

Research on HIV/AIDS in the MENA region is needed but inadequate. Our findings highlight the relevance of social and cultural concepts of illness and cultural values. Successful implementation of strategies for control, especially condom use and ART, benefit from careful consideration of the cultural epidemiology. A research agenda is suggested to acquire relevant information for effective control.

Contributors

AA did the literature search, collected and did the data analysis and drafted the initial report. MGW collaborated in planning the review, writing and revision. Both authors read and approved the final version of the report.

Conflict of interest

We declare that we have no conflict of interest

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4

Diagnosis, help seeking, treatment uptake and adherence to antiretroviral therapy for HIV/AIDS in Jordan*

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Abstract

Control of HIV/AIDS in the Middle East and North Africa region has been controversial since the early days of the epidemic. Despite free access to antiretroviral therapy (ART), levels of ART uptake in the region are the lowest in the World. Surveillance mechanisms are weak, and new cases of HIV/AIDS in the region are identified mainly by passive reporting. Financial and systemic factors, as well as community beliefs about the condition appear to have affected case-finding, help-seeking and adherence to ART. Sociocultural factors may have constrained help-seeking and testing. This study examined social and cultural factors affecting help-seeking and adherence to ART. An explanatory model interview was used in a mixed-methods design. Accounts of 30 people living with HIV/AIDS in Jordan were thematically coded to explain the context and determinants of help seeking and ART adherence.

Considering circumstances of diagnosis, 33 % of the patients were identified from testing required to obtain residence permits. Thematic analysis identified themes of enacted and anticipated stigma obstructing voluntary help-seeking. Medication side effects, perceived stigma, treatment access, anticipated ineffectiveness of treatment and religious beliefs were all found to affect adherence to ART. Voluntary testing and willingness to seek help were associated with better adherence. Requirements for testing limited appropriate help-seeking and adherence. Current policies of banning travel for people with HIV/AIDS in the region have added to the burden of their illness.

Findings suggest that Jordan and other countries of the region should implement and promote a policy of voluntary HIV testing. Mitigating HIV-related stigma and attending more carefully to the social impact of policies and strategies for HIV/AIDS control should be higher priorities. Additional sociocultural studies are needed to guide strategies for improving case finding, help-seeking, and ART uptake and adherence in the region.

4.1 Introduction

As with most countries in the Middle East and North Africa region (MENA), Jordan has a low HIV prevalence. At the end of 2009 there were 122 registered people living with HIV/AIDS (PLWHA) (Jordan National AIDS Programme, 2010a). Despite free access and commitment to the "3 by 5 initiative" launched in 2003, access to ART in the MENA region is alarmingly low. In 2009 the UNDP ranked the MENA region as the lowest in ART access for the years 2003-2006 (UNDP, 2009), and the latest UNAIDS report estimated the adherence to ART in the region at 8% (UNAIDS, 2011). The main obstacles to ART use can be identified in WHO regional data: limited HIV testing, limited access and high cost of ART to the health system, and failure to reach out to stigmatised high-risk groups (HRG) (WHO, 2008a).

Most countries in the region provide HIV/AIDS treatment and supportive care through national AIDS programs (NAPs) and voluntary counselling and testing centres (VCT). Various International foundations also provide supplementary funds for ART. Case finding in the MENA region is mainly through passive reporting. HIV testing is mandatory in specified circumstances, such as application for a residency visa and for certain jobs (Alkaiyat, 2012). Countries in the region ban PLWHA travel and deport all foreigners found to be HIV positive (with the exception of Algeria, Lebanon, Libya, and Morocco) (International AIDS Society, 2012).

ART has notably improved the life of PLWHA through a significant decrease in the morbidity and mortality rates of the disease, and it has transformed the disease into a manageable chronic condition (Bravo et al., 2010). As with treatment for many other chronic conditions, ART success is strongly associated with uptake and patients' commitment to adherence. Uptake and adherence to ART are strongly dependent on several factors: health system capacity, health policies, political will, and resource allocation (WHO, 2008a; Miles et al., 2007). Access to facilities, and therefore treatment, may be restricted due to financial and time constraints for patients and their families (Posse et al., 2008; Hardon et al., 2007). There are additional relevant patient-related factors however, such as illness experience and sociocultural concepts that also require consideration (Deribe et al., 2008; Plummer et al., 2006; Mshana et al., 2006).

Questions of adherence are moot points if the patient has not sought help at the outset. It is widely acknowledged that PLWHA need to seek help, have access to medical care, and

maintain a connection with the health system (Nguyen et al., 2010; Tobias et al., 2007; Perbost et al., 2005; Samet et al., 2001). Several studies showed that fear of a positive result and being stigmatised can limit people's willingness to seek help, even when ART is available (Day et al., 2003). The willingness of an infected person to seek medical help will certainly affect diagnosis and treatment (Sahay et al., 2011; Nam et al., 2008). Therefore, understanding case finding and help seeking behaviour are essential steps for better adherence and control.

Help seeking and case finding are influenced by a combination of policy, health system-related factors, community, family, and other personal issues (Obrist et al., 2007; Rubel and Garro, 1992). Barriers to accessing HIV/AIDS care and treatment services have been documented, including substance use and lack of support services (Tobias et al., 2007), informal HIV diagnosis (Torian et al., 2008), stigma in medical facilities, and loss of trust in health care institutions and overall system (Beer et al., 2009).

Concern for a potential crisis in the MENA region is increasing. Questions about HIV/AIDS and ART status are shrouded in ambiguity, and help seeking behaviour is not well understood, but explanations limited to health system factors, access or cost are insufficient. Sociocultural factors and religious ideas appear to influence the response to, and control policies for, HIV/AIDS in the region and are likely to more fully explain features and determinants for ART adherence.

Our study aims to clarify willingness to seek help and reasons for adherence or non-adherence to ART with reference to diagnostic context. We examine reported obstacles to help seeking and ART uptake, problems related to its use and adherence, and the level of patients' commitment to treatment. We also categorise themes that influence help seeking behaviour and ART experience.

4.2 Methods

4.2.1 Setting and study sites

This study was conducted in 2011 in Amman, Jordan's capital. ART is provided for eligible patients exclusively through the VCT (Jordan National AIDS Programme, 2010a). PLWHA were recruited through two NGOs, "Friends of PLWHA" and "Positive Life".

4.2.2 Instrument and design

We explored patients' accounts of their concerns and commitment to ART and help seeking. Integrating narrative and quantitative accounts to explore social and cultural aspects of the illness, a semi-structured explanatory model interview was developed based on the Explanatory Model Interview Catalogue (EMIC) framework for cultural epidemiology (Schaetti et al., 2010; Trostle, 2008; Weiss, 1997). The original version of the interview was drafted in English, translated into to Arabic, and then checked for validity and applicability.

Open-ended questions were followed by more detailed questions probing reasons for HIV testing, options for testing, diagnosis and support. The interview examined various features of experience with ART, including barriers to uptake and adherence. It also considered a full range of help seeking resources and the course of diagnosis. Categorical coding was elaborated by respondent narratives.

PLWHA were approached through the two aforementioned NGOs. Thirty patients provided consent and were interviewed. Data were obtained directly during the interviews and recorded on a digital recorder when permitted.

4.2.3 Data management and strategy for analysis

The qualitative software MAXQDA, version 2007, was used to manage the narrative data and to facilitate further integrated analysis of findings from the quantitative data. Quantitative data were entered twice then cleaned and verified in Epi Info software, version 3.4.3. Stata, version 10, was used for statistical analysis.

Sample characteristics, context and status of testing and diagnosis, ART treatment status, help seeking willingness, and resource use are reported as frequencies. ART adherence-related problems or barriers were also reported as frequencies. Voluntary help seeking and ART adherence based on testing and diagnosis were compared using Fisher's exact test. We report a significant difference at $p \leq 0.05$ and a borderline significant difference at $p \leq 0.1$. Patients' narrative accounts for related categories were used to clarify findings of quantitative

data. We explored, in detail, the patients' narratives of help seeking behaviour and ART experience using the thematic analysis approach.

4.3 Results

4.3.1 Sample characteristics

All patients in the study had access to ART through the VCT. Twenty PLWHA (67%) were on ART at the beginning of the study and 47% voluntarily sought help. All subjects were Muslim, with a mean age of 37.2 years (SD = 9.2 years). ART adherence was positively associated with voluntary help seeking, married marital status ($p \leq 0.05$) and level of education ($p \leq 0.1$). Sample characteristics, of respondents currently taking ART and respondents who voluntary sought help, are summarised in Table 4-1.

Table 4-1: Sample Characteristics and ART status and voluntary help seeking

	Total (N=30)		**Currently on ART (N=20)**			**Voluntary sought help (N=14)**		
Characteristic	**No.**	**%**	**No.**	**%**	***P***	**No.**	**%**	***P***
Sex					0.53			> 0.99
Male	27	90.0	17	85.0		13	92.9	
Female	3	10.0	3	15.0		1	7.1	
Education level					0.07*			0.73
Secondary or less	13	43.3	7	35.0		5	35.7	
Finished high school	9	30.0	5	25.0		5	35.7	
University	8	26.7	8	40.0		4	28.6	
Marital status					<0.01**			0.16
Never married	8	26.7	1	5.0		2	14.3	
Married	15	50.0	14	70.0		10	71.4	
Divorced	5	16.7	5	25.0		2	14.3	
Widowed	2	6.7	0	0.0		0	0.0	
Occupation					0.30			0.72
Employed	12	40.0	8	40.0		5	35.7	
Unemployed	10	33.3	5	25.0		4	28.6	
Did not declare	8	26.7	7	35.0		5	35.7	

* $p \leq 0.1$ (Fisher's exact test); ** $p \leq 0.05$ (Fisher's exact test)

4.3.2 Diagnostic context and HIV testing

Application for work and residence permits outside of Jordan was the most frequently reported reason for HIV testing (33%). Physical symptoms and blood donation screening accounted for 30% and 17% respectively. HIV diagnosis of 23% of all patients in the sample resulted from voluntary testing, and this was only carried out in cases of spousal infection or

physical symptoms. A total of 67% were diagnosed in Jordan, 60% stated they would not have tested voluntarily. Table 4-2 lists reasons for HIV testing and diagnostic circumstances.

Table 4-2: Testing reasons and diagnosis circumstances by ART status and voluntary help seeking

	Total (N=30)		Currently on ART (N=20)			Sought help voluntary (N=14)		
Category	**No.**	**%**	**No.**	**%**	***P***	**No.**	**%**	***P***
Diagnosed in Jordan	20	66.7	13	65.0	> 0.99	11	78.6	0.26
Tested Voluntary	7	23.3	7	35.0	0.04**	5	35.7	0.20
Reasons for testing								
Residence permit outside Jordan	10	33.3	8	40.0	0.42	3	21.4	0.26
Physical Symptoms	9	30.0	8	40.0	0.20	8	57.1	<0.01**
Blood Donation Screening	5	16.7	1	5.0	0.03**	0	0.0	0.05**
Spouse infection	2	6.7	2	10.0	0.54	1	7.1	> 0.99
Transfusion for Haemophilia	2	6.7	1	5.0	> 0.99	2	14.3	0.21
Prison screening	2	6.7	0	0.0	0.15	0	0.0	0.49

** $p \leq 0.05$ (Fisher's exact test)

Eighty-six per cent of the PLWHA who voluntarily sought help adhered to ART ($p<0.1$). All PLWHA who tested voluntarily were on ART ($p\leq0.05$). Blood screening was associated with less adherence ($p\leq0.05$). Physical symptoms as a reason for testing were associated with more voluntary help seeking ($p\leq0.05$), while blood donation was associated with less voluntary help seeking ($p\leq0.05$).

Narratives indicated concern and distress about the circumstances surrounding diagnosis. This was especially true for patients who were diagnosed in a neighbouring country. A man who was diagnosed in Kuwait with a test required for residence permit renewal said,

'After I did the test they called me and told me that the test result was lost, and it is important to repeat it…they were nice, but what they meant by important was that I leave the country'.

Another patient described the procedure of diagnosis for him and his partner in Bahrain by saying,

'When my friend was diagnosed with HIV they held her in clinical isolation …. I went and did the test. I was positive for HIV. They asked me to go to the lab to confirm it, but from there they took me to the airport'

4.3.3 Help seeking

About half of the PLWHA in our sample voluntarily sought help (47%). The remainder (53%) were referred to the VCT either by blood-banks or upon arrival in Jordan if the infection was diagnosed outside the country. Patients reported various help-seeking resources under two main categories, self or home care (e.g. self-care, family, and friends), and outside sources (e.g. medical doctors, VCT, and governmental clinics). Within the first category, family was most frequently reported (20%). However, 10% identified friends as the most useful resource within this category.

For outside help, 30% of the sample voluntarily sought help from a medical doctor at some stage of their illness; 13% reported doctors as the most useful help source. A total of 30% voluntarily sought help from the VCT, and 53% were referred without having a choice. More than half did not identify a most useful help source for their illness (60%). Other sources of help such as psychiatrist, religious leader and folk medicine were reported by less than 5%, and thus not listed. Table 4-3 lists the frequency of the reported total and most useful help sources.

Table 4-3: Help seeking sources and use among PLWHA in Jordan (N = 30)

Help source	How reported (%)	
	Any use	Most useful
Self/Home care		
Family	20.0	3.3
Friends	10.0	10.0
Self-care	6.7	0.0
Outside sources		
Doctor	30.0	13.3
VCT centre (by choice)	30.0	10.0
VCT centre (refereed to or required)	53.3	0.0
Governmental Clinics	10.0	3.3
Not identified	0.0	60.1

Obstacles delaying help seeking that were identified in the thematic analysis of narratives were related to the influence of diagnostic context, perceived causes and stigma. Diagnosis outside Jordan due to routine HIV testing for residence permit or work application was a common theme. Many patients described such circumstances in detail. One patient who was unknowingly referred to the VCT and diagnosed outside of Jordan said,

'..The result came that I was positive for HIV. I was in a very bad shape, and they asked me to go to the lab to confirm it but from there they took me to the isolation and on the first plane back to Jordan'

Perceived causes of HIV/AIDS and forbidden sexual behaviour and illegal drug abuse were reasons that lead many to conceal their illness. These perceived causes were obstacles to help seeking. A patient who was diagnosed through a residence permit renewal test outside Jordan and was referred to the VCT said,

'Unfortunately, this disease has a bad reputation, and people always connect it to sex so I do not like to tell anybody, nor seek help from anybody'

Discriminatory actions ranged from verbal insults to denying treatment - mainly in the form of health care workers manipulating patients. Patients from the sample described their first encounter with the medical staff. A patient who was unknowingly tested for HIV after physical symptoms said,

'The doctor did not tell me that the test which I have done is for HIV, I received the result without seeing the doctor because he refused to meet me". Another patient who was diagnosed through blood donation screening in Jordan said, "I went many times to hospitals and faced a lot of stigma there. Now I do not go anymore unless I am too weak'

Anticipation of stigma was a common theme complementing enacted stigma in the qualitative data. Shame, fear of discrimination, and scandals were predominant barriers for help seeking. Family, however, was a frequent first source of help, perhaps due to less anticipated stigma. A patient who sought help after a delay of 2 years said,

'I did not go to anybody I was ashamed even from seeing a doctor. I only told my parents and younger brother'

4.3.4 ART experience

Two-thirds of the sample were on ART at the time of this study (67%). Their mean delay from diagnosis to starting ART was 2.15 years. Medication side effects (including insomnia, dizziness, diarrhoea, headache, vomiting, nausea, and hair loss) were reported problems associated with ART and one or more of these symptoms were reported by 60% of those taking ART. Access and stigma were also problems identified with treatment, each reported by 15%, and the long duration of treatment was noted by 10%.

Five themes were identified in the analysis of narratives concerning ART experience. Medication side effects, stigma, perceived ineffectiveness, and access to medicines were problems interfering with ART adherence and uptake. The fifth, reliance on faith, was reported both as a facilitator for some and a barrier to adherence and uptake for others.

1) Medication Side Effects

Both immediate and long-term side effects of ART were the most common concerns about the experience of medication with ART. In many cases side effects were attributed to frequently changing medicines. A patient on ART for 4 years said,

'I have had side effects, such as anxiety and depression for 3 to 4 months, and then they were gone. Afterwards the medicine was changed and the side effects came again….the medicine changes many times'

Another patient stopped taking ART after 9 years of consistent treatment, explaining,

'I had bleeding everywhere even internal. I was always nervous and angry, not feeling good. I asked the VCT to put me back on my old drug, but they kept telling me the one I was taking is better...Then I stopped taking the medicine…'

2) Perceived stigma

Anticipated stigma as a result of concern that by taking treatment others would come to know that they were infected was reported by many subjects. Many patients expressed their fear of illness disclosure, were anxious, and did not want to be seen or associated with the drug. A female patient on ART for 7 years said,

'Some people wonder why I always take medications, but I never tell them'

Another patient who stopped taking ART after 10 days described the anxiety when taking the drug from the VCT by saying,

'When I used to take the medicine I put it in a dark plastic bag so nobody can see it or read the label'

3) Access to treatment

Many subjects mentioned problems accessing treatment resulting from long-distance travel and the time commitment. This was an issue mainly for patients living outside Amman, who had to travel to the VCT dispersing ART. A patient who started ART after 3 years of diagnosis and remained adherent to therapy said,

'Treatment is limited to one place, and it is not easy to go to any health centre and talk about your disease. For me it is far away from where I live'

4) Perceived ineffectiveness

Some patients who discontinued ART did so because they doubted its effectiveness for treating HIV infection. A patient who stopped ART after 6 months explained that self-help and living a healthy life is more important than the drug:

'I do not think it is effective or gives a good result; it's more important is to take care of yourself'

Another patient who stopped ART after one month doubted the value of its effect, and referred to a previous bad experience with it.

'I'm not convinced by this drug. First of all, it is a chemical substance, and I took it a year ago for a month and it caused side effects; I was not able to get out of bed. It also caused me pain in my legs and hands, and I do not think it is suitable'

5) Religious beliefs

Some patients said that religious beliefs and faith facilitated their adherence to ART. Trust in God and accepting the will of God meant to such persons that they should accept their condition and stay on treatment. A patient who had been adherent to ART for the past 5 years described the way he felt when he found out about his HIV infection:

'When they told me it is AIDS, I said thanks are to Allah … Since then I have been taking my medication'

Another patient who had been taking ART for 2 years described how his infection helped him:

'AIDS has made me trust myself more. I think God had given me this disease but makes it up to me in different aspects'

For others faith had a different meaning. Instead of facilitating medical treatment, some people regarded faith as an alternative to treatment. Motivated by such faith, they stopped treatment to show that they fully accepted the fate God had in store for them, and they fully trusted God's will. A patient who had never taken ART explained,

'I fully trust in Allah, the doctors told me I should take the medicine, but I'm afraid of committing myself to the drug; God will choose the best for me'

4.4 Discussion

This study is the first to describe problems related to ART adherence among a sample of PLWHA in Jordan, to investigate obstacles in ART uptake, and to consider contexts and determinants of help seeking behaviour in the MENA region. It yields some valuable insights despite the small sample size, which limits our out power to use multivariate analysis to explore subtle determinants of uptake and adherence behaviour relevant for controlling HIV/AIDS. Nevertheless our methods were adequate to identify themes within patients' accounts of help seeking as well as uptake and adherence to ART in the region. This exploratory study provides baseline data for further studies in a region where data about PLWHA are scarce.

Voluntary help seeking was associated with better adherence. Findings that stigma and perceived causes of HIV/AIDS related to sexual behaviours are obstacles for help seeking are consistent with findings from other regions (Lieber et al., 2006; Liu et al., 2005). However, in the MENA region, the special diagnostic circumstances and control policies, including the travel ban, also had a uniquely negative impact on voluntary help seeking.

Our findings identified features of ART experience and factors that motivate or interfere with treatment that are similar to other studies worldwide. The fear of medication side-effects was a barrier to uptake, and troublesome experience with side-effects limited ART adherence. Unpleasant side-effects of ART have been reported in studies elsewhere, including both physical discomfort, and emotional and psychological symptoms resulting in sadness and substantial depression (Badahdah and Pedersen, 2011; Beusterien et al., 2008; Stone et al., 2004). In the MENA region, however, frequently changing medication might exacerbate adverse effects. Frequent change of medication may result from dependency on international donors for ART provision.

The dual role of faith indicates that its role and impact is complex. For some patients faith was a barrier to adherence, based on a belief that having HIV/AIDS is their fate and a "justified punishment" for their behaviour; treatment cannot change fate. Other patients regarded their infection as a "test from God" which requires patience and discipline with commitment to their treatment. Badahdah et al. also found that among Egyptian women on ART, religious beliefs acted as facilitator for their adherence. A few other studies have similarly found that HIV/AIDS may either help or hinder HIV/AIDS control (Ironson et al., 2011; Kremer et al., 2009; Kremer et al., 2006; Stone et al., 2004; Ironson et al., 2002). Our

findings clearly show the danger of simplistic assumptions about the positive or negative influence of cultural determinants. Further research is needed to explain the various ways that religious and cultural values affect the experience and meaning of HIV/AIDS and their significance for public health.

Stigma, whether anticipated or enacted, is widely acknowledged as a major barrier to adherence and uptake of ART, and we observed its impact on our sample. Limited access also correlates with stigma and fear of disclosure. A large body of literature documents the adverse impact of stigma on ART uptake (Wasti et al., 2012; Rintamaki et al., 2006; Mills et al., 2006). In Jordan and the MENA region the impact of stigma is especially problematic for two reasons, because of the influence of conservative cultural norms and as an effect of current HIV/AIDS control polices.

The unique and conservative culture of the region has shaped, to a great extent, the perception and response to the epidemic (Alkaiyat, 2012). Cultural norms could increase stigma, and thus hinder HIV testing and treatment (Badahdah and Pedersen, 2011; WHO, 2008a). Stigma can also arise from cultural ideas that blame victims or legitimise exclusion (Weiss, 2008). Therefore, any initiative to mitigate stigma should be designed and carried out with careful consideration of socially acceptable and culturally sensitive framework.

The approach to HIV/AIDS control, in the region, where case findings lead not only to social exclusion but even to deportation, discourages voluntary testing and help seeking. In our sample voluntary testing and help seeking were significantly associated with better ART adherence. For many people, however, such government policies impose an extra burden on newly diagnosed patients. They are forced to leave their homes, jobs, and their country of residence. These policies impose a burden that maintains stigma, and affects every aspect of life—psychological, financial, and myriad social domains. Reformulation of control policies should address the unnecessary social toxicity of limiting access to ART to VCTs that discourages necessary help seeking and ART uptake and adherence. High-risk groups must have access to acceptable services that provide treatment and respect the dignity of patients. Sensitive appreciation of the needs of PLWHA is a prerequisite for improving uptake and adherence (Safren et al., 2006; Gebrekristos et al., 2005). Current policies, by limiting help seeking sources, may conflict with these needs. In the whole of the MENA region, patient-perceived needs are still insufficiently understood; evidence-based policy-making should acknowledge and respond accordingly.

Current polices may also encourage high-risk groups and diagnosed patients to seek confidential help from other sources. The low educational and economic profile of PLWHA in our sample raises the question: “Where do rich and educated PLWHA go for help?” Or is HIV/AIDS a “neglected disease” in the region and limited to a certain socioeconomic class? The answer is uncertain, but if people are seeking help from sources that are not covered by surveillance in national AIDS programmes, further questions arise about equity and underestimating the burden of HIV/AIDS

4.5 Conclusion

Although HIV/AIDS is a widely acknowledged global health priority, in the MENA region its profile in some ways more closely resembles that of a “neglected disease.” Our knowledge of ART adherence in Jordan and the MENA region is very humble, but our findings indicate the problems and features of limited access. Future studies should focus on barriers to help seeking and ART adherence, patients’ perceived needs, as well as innovative ways to respond to identified needs. Better understanding of help seeking behaviour is urgently needed in the region, and a greater variety of accessible services beyond VCTs is needed. Policies need to promote case finding as a way of helping people deal with a serious health threat rather than merely provide a diagnosis that adds to their burden. Revising policy and reducing stigma should be priorities on both health and political agendas. Programmes and efforts to mitigate stigma should be designed to proceed with the benefit of social and cultural studies to guide them.

5

Sociocultural features of self-perceived stigma reported by people living with HIV/AIDS in Jordan*

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Abstract

Objectives: In this study we examine the nature of self-perceived stigma among Arabs living with HIV/AIDS and its relationship with sociocultural features of HIV/AIDS in the Middle East and North Africa region.

Design: HIV/AIDS patients in Jordan were approached through two NGOs. The 30 patients who consented were interviewed with a semi-structured explanatory model interview based on the framework of the Explanatory Model Interview Catalogue (EMIC) for cultural epidemiology. The EMIC interview included a full range of stigma-related questions, illness-related experience and perceived meaning of HIV/AIDS.

Results: Thirty people living with HIV/AIDS were interviewed in Jordan. Patients reported adverse effects of stigma on social life, medical treatment, and work. A few respondents referred to experience of enacted stigma, but most reported concerns about felt or anticipated stigma. Sadness, anxiety, reduced social status, social isolation, reduced income, and job loss were illness experiences associated with higher levels of stigma. Perceived causes of HIV/AIDS associated with higher stigma included socially mediated effects of specific behaviours such as sharing shaving blades and various sexual experiences including masturbation.

Conclusion: Although cultural values may promote stigma, they may also reduce it. Our findings show how the settings, context and impact of HIV/AIDS affect stigma in the region and the importance of further research. Interventions to mitigate stigma are urgently needed. We provide practical approaches e.g., revise travel restrictions to guide control policy and decrease the burden of HIV/AIDS stigma.

Key words: Stigma, HIV/AIDS, PLWHA, Jordan, Middle East and North Africa, Cultural epidemiology

5.1 Introduction

AIDS is a major medical threat caused by the human immune deficiency virus (HIV). Commonly transmitted by sexual relations, homosexuality, and drug use, AIDS was first described as GRID syndrome (Gay-related Immune deficiency) or as the 4-H disease (Haitians, Homosexuals, Haemophiliacs, and Heroin Users Disease). These initial descriptions marked HIV/AIDS as a social disease that causes people living with HIV/AIDS (PLWHA) social, emotional, and psychological discomfort that extends beyond impaired physical health and directly affects their quality of life (Mak et al., 2007; O'Connell et al., 2003). This additional burden is mainly a result of stigma and discrimination (Bravo et al., 2010).

Though its contribution to burden of illness is veiled, stigma is an important feature of HIV/AIDS and other disease and health problems (Weiss et al., 2006). Stigma had been found to be associated with reduced well-being of PLWHA and can affect the control of HIV/AIDS Some researchers assert that stigma is as central to the challenge to control the HIV/AIDS pandemic as the biomedical obstacles (Soliman and Almotgly, 2011; Badahdah and Sayem, 2010; Badahdah and Foote, 2010; Al-Iryani et al., 2009; Kabbash et al., 2008; Roudi-Fahimi, 2007; Parker and Aggleton, 2003). It discourages people from seeking HIV testing and medical help (Liu et al., 2005), and it can also result in the delay of treatment (Lieber et al., 2006). Therefore measuring stigma and understanding the impact of social disqualification and suffering is a priority for public health (Heijnders and Van Der Meij, 2006).

With the introduction of antiretroviral therapy (ART), AIDS became a medically-manageable chronic disease (Bravo et al., 2010). ART prolonged the life of PLWHA and improved their physical status while reducing the risk of transmission (Havlir and Beyrer, 2012). However, ART may be less effective in reducing social and psychological discomforts, and PLWHA still face many emotional and social problems caused by stigma and discrimination.

The nature of stigma and its impact on social suffering for PLWHA are highly variable. Stigmatising experience ranges from verbal insults, denial of treatment in health care facilities, denial of opportunities for jobs or education, physical harm, imprisonment, or even murder in the community (IRIN Plus News, 2006; Reis et al., 2005). Such acts of discrimination may be regarded as “enacted” stigma. PLWHA may also fear such discrimination, even if they have not experienced it directly, and these concerns may be

regarded as felt stigma (Scambler, 1998). Felt stigma may be further classified as anticipated or internalised when people internalise the negative societal sentiments with loss of self-esteem (Weiss, 2008).

Felt stigma typically appears to be more troublesome in some ways for PLWHA than enacted stigma (Scambler, 1998). It is more difficult to characterise and mitigate. While enacted stigma and discrimination can be limited by legislation, enforcing existing laws and promoting human rights, anticipated and internalised stigma require careful consideration of the nature, circumstances and determinants of stigma to guide health policy (Weiss and Ramakrishna, 2006).

In Jordan and the Middle East and North Africa region (MENA), HIV/AIDS prevalence is low (UNAIDS, 2009). According to the WHO, in 2004 non-communicable diseases contributed to 72.5% of the total DALYs (disability-adjusted life years) in Jordan. However, many concerns have been raised about the actual burden of the epidemic based on the increasing number of cases, the weak surveillance systems, and challenges in reaching high-risk groups (UNAIDS, 2011). HIV testing and counselling is offered via voluntary counselling and testing centres (VCT) and hotline phones also make counselling services available. ART and personal care are available free of charge (Alkaiyat and Weiss, 2012). Except for Lebanon, Morocco, Libya, and Algeria, countries in the region ban travel of PLWHA and deport all foreigners found to be HIV positive (International AIDS Society, 2012).

The sociocultural features of the region- rooted in Islamic values and local cultural norms- have greatly shaped the perception and response to HIV/AIDS (Alkaiyat and Weiss, 2012). Stigma can arise from normative views that blame victims or legitimise exclusion (Weiss, 2008). In addition to increasing the burden of illness, stigma may also discourage HIV testing and limit opportunities for treatment and control (Badahdah and Pedersen, 2011; UNAIDS, 2010). Therefore, it is important to study the cultural meaning and experience of HIV/AIDS in the region and how they affect stigma.

As in the rest of the world, stigma toward PLWHA is documented in the region and considered a major challenge in HIV/AIDS control. The need for reducing its impact has been acknowledged (Jordan National AIDS Programme, 2012; Badahdah, 2010; Roudi-Fahimi, 2007). Cases of enacted stigma, including homicides against PLWHA, suicides, and

discrimination in the work place, have all been reported in the region (IRIN Plus News, 2006; IRIN Plus News, 2005).

Stigma studies in the region are limited in number and scope; very few have considered stigma from the perspective of PLWHA (Soliman and Almotgly, 2011), and they have not distinguished enacted, anticipated or internalised stigma, which has practical implications. Research is also needed to explain how sociocultural features of HIV/AIDS may promote or mitigate stigma. Such research is needed to guide policy and action.

The current study applies cultural epidemiological methods to examine cultural concepts of HIV/AIDS and their relationship to features of stigma. We describe the nature and types of stigma experience of PLWHA in Jordan.

5.2 Methods

The relationship between local concepts and cultural meaning of HIV/AIDS and stigma is best investigated in a sociocultural framework. Cultural epidemiology is the study of locally valid representations of illness, which are specified by variables, descriptions, and narratives accounting for the experience of illness experience and its meaning (Trostle, 2008; Weiss, 2001). In the framework of cultural epidemiology, we identify specific features of stigma, how they are experienced, and how they are affected by the explanatory model of HIV/AIDS illness, and elucidate the role of sociocultural features of a HIV/AIDS.

5.2.1 Setting and study site

VCTs were established in 1999 in Jordan. Currently 12 centres around the country provide services (Jordan National AIDS Programme, 2012). The survey was conducted in Amman, Jordan's capital in 2011. Our research team collaborated with two NGOs supporting PLWHA "Positive Life" and "Friends of PLWHA". Our study was carried out in cooperation with these two NGOs, where most of the PLWHA are registered and receiving services from a VCT.

5.2.2 Instrument

We developed a semi-structured explanatory model interview based on the framework of the Explanatory Model Interview Catalogue (EMIC) to study the views of PLWHA concerning their experience and meaning of illness and their experience of stigma.

To ensure appropriate development of the interview framework and categories therein, the EMIC for this study was developed with inputs from first-hand observational studies, consultations with PLWHA, and with the knowledge from prior studies. The initial draft of the interview was written in English, translated into Arabic, and then checked for applicability and adaptation to the local culture. The EMIC was piloted on healthy volunteers to ensure clarity and validity.

Open-ended questions were followed by probing specific relevant categories. Features of stigma was assessed in the EMIC by including a full range of stigma-related questions about illness concealment, effects on social life, family, self-esteem, and other relevant concerns. The EMIC considered illness-related experience and meaning of HIV/AIDS as perceived by PLWHA. Illness-related experience was elucidated through categories and narratives to indicate patterns of distress (PD), including physical symptoms along with relevant features of emotional, psychological, and social distress. The meaning of HIV/AIDS specified by perceived causes (PC) indicates how patients explain their illness.

5.2.3 Design

All HIV/AIDS patients that are registered in a VCT were approached through the two NGOs. The 30 patients who consented were interviewed with the EMIC. Data were collected directly during the interviews and recorded on a digital recorder when permitted.

5.2.4 Approach to analysis

Quantitative categories were double-entered, cleaned, cross checked with Epi Info Version 3.5.1 (Centre for Disease Control and Prevention, Atlanta, GA, USA), and processed for statistical analysis using STATA Version 10.1 (Stata Corp LP., College Station, TX, U.S.A.). Narratives were transcribed in the interview and recorded when possible. Hand-recorded notes and voice-recordings were then translated from Arabic into English and typed in a word processor. MAXQDA software Version 10 (Verbi Software, Berlin, Germany) was used for qualitative data management and analysis of item-related thematic codes that were compared among respondents based on variables of the dataset imported from Epi Info.

Stigma

To assess the impact of stigma on the various aspects of the life of PLWHA, a mean prominence was calculated for each stigma indicator based on the value of responses given to

each indicator (Yes = 3, Possible = 2, Uncertain = 1, No = 0). A higher mean indicates a more prominent stigma indicator.

A Stigma index was then assessed based on responses to 11 indicators; each indicator contributed a value from 0 to 3, with higher values denoting more stigma. The index was computed for each respondent by adding the responses; the theoretical maximum was 33. The stigma index was the primary outcome and was reported as mean ± standard deviation (SD). The internal consistency of all items was assessed to validate the index with the Cronbach's alpha statistic. This strategy is based on an approach previously developed for cultural epidemiology analysis of stigma (Raguram et al., 1996). Narrative accounts from the EMIC clarified the nature of perceived stigma and thereby explained quantitative findings.

Illness explanatory model

Categories of PD and PC were coded and analysed for their prominence (2 = spontaneous response, 1 = probed response, 0 = unacknowledged). An additional value of 3 was assigned if the category was considered to be the most troubling or most important. This approach based on prominence distinguishes how categories were reported, rather than the frequency of reporting. The mean prominence of each PD and PC category was summarised for each respondent (ranging from 0-5).

Grouped Sociocultural Variables

A second strategy for analysis grouped similar individual categories of PD and PC, (e.g., social-emotional, financial, and physical for PD; medical injury, sexual, religious, pathogen, and illegal drugs for PC). The prominence of the grouped categories was calculated in the same manner as the individual variables. PD and PC mean prominence and percentages of total and spontaneous mention were reported. Categorical data were further elaborated with narratives.

Correlation of the stigma index and (1) features of the illness explanatory model or (2) grouped sociocultural variables was analysed by computing the Spearman correlation coefficient. We report the Spearman coefficient (ρ) and *p* value for each bivariate correlation.

5.3 Results

5.3.1 Sample characteristics

The aims and methods of the study were explained to 50 PLWHA, 30 agreed to be recruited. All subjects in the sample were Muslims with 90% males. The mean age of the sample was 37.2 years. 50% were married, and 73.3% did not continue education after high school. 26.7% were unemployed, and 26.7% did not state the nature of their occupation. The characteristics of the sample are summarised in

Table 5-1

Table 5-1: Sample characteristics (N = 30)

Sex (%)		
	Male	90.0
Age (Years)		
	Mean ± (Standard deviation)	37.2 (9.2)
	Median (Range)	35 (27-67)
Marital status (%)		
	Never married	26.7
	Married	50.0
	Divorced	16.7
	Widowed	6.7
Occupation (%)		
	Housewife	6.7
	Non skilled worker	20.0
	Unemployed	26.7
	skilled worker	6.7
	Driver	13.3
	Did not declare	26.7
Education (%)		
	Secondary or less	43.3
	High school certificate	30.0
	Diploma	20.0
	Bachelor or higher	6.7

5.3.2 Perceived stigma

Eleven items were assessed as indicators of stigma. The internal consistency of the stigma index was acceptable, with a Cronbach alpha coefficient of 0.75. For the total sample, the mean stigma index (± SD) was 22.7 ± 6.5, with values ranging from 11–33. The lower quartile, median, and upper quartile values were 18.0, 24.0, and 23.0; respectively.

Adverse effects of stigma on work, family, social and marital life, medical treatment and patients' interpersonal contact, financial problems, and fear of social isolation were prominent in respondents' accounts. Feelings of shame and low self-esteem were reported less. Table 5-2 summarises the response pattern with frequencies and mean prominence of each stigma indicator.

Table 5-2: Indicators of stigma assessed in the EMIC interview among people living with HIV/AIDS in Jordan (N =30)

STIGMA INDICATOR [a]	Total (%) [b]				Indicator mean prominence [c]
	'Yes'	'Pos'	'Unc'	'No'	
Keep others from knowing	83.3	10.0	6.7	0.0	2.77
Negative impact on job	76.7	13.3	6.7	3.3	2.63
Negative impact on family	76.7	10.0	10.0	3.3	2.60
Negative impact on social life	70.0	20.0	6.7	3.3	2.57
Negative impact on marital life	76.7	10.0	3.3	10.0	2.53
People avoid you	66.7	20.0	6.7	6.7	2.47
People less contact with you	70.0	6.7	6.7	16.7	2.30
Negative impact on medical treatment	60.0	6.7	10.0	23.3	2.03
People less respect you	56.7	3.3	3.3	36.7	1.80
Think less of yourself	33.3	3.3	0.0	63.3	1.07
Ashamed of yourself	30.0	3.3	0.0	66.7	0.97
Cronbach alpha coefficient for Internal consistency	0.75				
Stigma index mean (±SD) [d]	22.7± 6.5				

[a] Indicators of stigma as assessed by the EMIC interview; [b] Percentage of reported responses to stigma indicators; [c] Mean prominence for the stigma indicator based on values assigned to each response (3 = Yes, 2 = Possible, 3 = Uncertain, 0 = No); [d] Stigma index is the sum of the indictors mean prominence for each respondent.

All respondents had at least some concern about disclosing their condition to others, and 83.3% clearly stated they did not want others to know. Anticipation of social ignorance, sexual content of HIV/AIDS, negative reactions of people, and anticipated stigma were the main drivers motivating concealment.

Enacted stigma was also experienced by respondents. The impact of stigma on work and financial status was mainly reported by patients who had lost their jobs in neighbouring countries when diagnosed with HIV/AIDS and sent back to Jordan. Patients narrated other experiences of enacted stigma, mainly from health care workers (HCW). Verbal insults, patient confidentiality rights violation, refusal for treatment, and harassment in health care settings were all mentioned. An example of stigma perpetrated by a HCW was reported by almost every respondent.

Felt anticipated stigma was mentioned most often, and manifested in respondents' fear to communicate with other people about their illness and their fear of becoming an outcast in the community. Some patients also reported internalising such stigma and the acceptance of, or even a feeling they deserved, this anticipated exclusion from the community. Most respondents reported all three types of stigma; for example, a patient summarised his concerns and reported enacted stigma by saying,

'I went to many hospitals and I faced a lot of humiliation there. So now I hesitate to go anymore unless I'm too sick that people carry me there. I have not worked for a year and I have no money'.

He continued to describe his anticipated stigma and fear of illness disclosure

'The main problem I have is the disease disclosure, I deal with my problem in full silence and if I tell people it is a huge problem because of society's perception of me and the humiliation that will result. I am lonely and I do not communicate with the community, because I know their reaction in advance.'

The same patient described the causes of his infection in a form of internalised stigma where he accepts the people anticipated judgment:

'I deserve how people look at me, because I was very bad before and sexual relations caused my infection so God punished me with this disease'.

5.3.3 Stigma and sociocultural features of HIV/AIDS

Illness experience: Patterns of distress (PD)

Most of the patients reported a combination of social, financial, and physical problems. Concerns about the future and the course of illness were the most frequently reported and the most prominent category of distress. Among grouped categories, socially and emotionally related categories were pervasive (reported by 93.9% with a mean prominence of 4.1), followed by financial related problems (reported by 60.0% with a mean prominence of 1.7). Physical patterns of distress were reported by 63.3% with a mean prominence of 1.2 (Table 5-3).

Table 5-3: Categories of distress and their mean prominence as reported by people living with HIV/AIDS in Jordan (N = 30)

REPORTED PROBLEMS [a]	How reported (%)			Mean Prominence [e]
	Total [b]	Spon [c]	Most troubling [d]	
Social and Emotional	**93.3**	**90.0**	**76.7**	**4.13**
Concern about of illness/ future	63.3	36.7	23.3	1.70
Reduced social status	60.0	43.3	10.0	1.33
Marital problems	53.3	40.0	13.3	1.30
Sadness, anxiety or worry	63.3	36.7	3.3	1.10
Bad treatment of Health staff	33.3	33.3	10.0	0.97
Concern about children	30.0	13.3	10.0	0.73
Social isolation	23.3	23.3	6.7	0.67
Financial	**60.0**	**46.7**	**20.0**	**1.67**
Reduced income	53.3	33.3	6.7	1.07
Loss of job and wages	36.7	30.0	13.3	1.07
Physical	**63.3**	**46.7**	**3.3**	**1.20**
Diarrhoea	23.3	20.0	3.3	0.53
Teeth Problems	23.3	23.3	0.0	0.47
Headache	30.0	13.3	0.0	0.43
Fever	30.0	10.0	0.0	0.40
Side effects of medication	20.0	16.7	0.0	0.37
Sweating	26.7	6.7	0.0	0.33
Weight loss	20.0	13.3	0.0	0.33
Vomiting	20.0	6.7	0.0	0.27
Skin rashes	16.7	10.0	0.0	0.27
Thinning of hair	20.0	3.3	0.0	0.23
Loss of appetite	20.0	0.0	0.0	0.20
Sores in mouth	10.0	3.3	0.0	0.13
Weakness	6.7	3.3	0.0	0.10
Stomach ache	6.7	3.3	0.0	0.10
Nausea	6.7	3.3	0.0	0.10

[a] Categories of distress ordered by mean prominence within each group (bold). Categories reported by less than 5% not listed; [b] Percentage of reported categories; [c] Percentage of spontaneously mentioned categories; [d] Percentage of categories identified as most troubling; [e] Mean prominence based on values assigned to each reported category (0 = not reported, 1 = reported after probing, 2 = reported spontaneously, and additional 3 if identified as most troubling).

Narrative accounts also emphasised and elaborated social and financial concerns. A 35-year-old woman, whose most prominent reported category of distress was the concern for future, said,

'Now I have no health problems, except AIDS. I have problems at work because they require a disease-free certificate; I feel everything in the World is against me. I want a good life and to eat well, but my financial situation is very hard. Every time I go for the tests or to take the medication I feel very worried that people may see me'

Physically-related experiences were less common than social or financial problems, and many respondents reported physical symptoms as a result of medication side effects. A 32-year-old man explained,

'I have diarrhoea from the medicine, I keep losing weight, but these are easy problems compared to my divorce from my wife because of the disease. I lost my income. I'm always worried about the future and what will happen to me, and I'm sad all the time when I see how people look at me'

Bivariate relationships, using the nonparametric Spearman correlation coefficient test, between the mean stigma index and the mean prominence values of PD are summarised in (Table 5-4)

PD variables most strongly correlated with stigma include reduced social status and social isolation. Sadness was correlated with higher stigma ($p \leq 0.1$), most likely as a result of such anticipated experience of stigma. Reduced income and job loss were also correlated with higher stigma, typically enacted, mainly among respondents who lost their jobs in neighbouring countries due to their HIV infection.

Table 5-4: Bivariate relationship of stigma and categories of distress

PROBLEMS REPORTED	Spearman (ρ)	*p* Value	
Social and Emotional	**0.22**	**0.25**	
Concern about of illness/ future	0.09	0.62	
Reduced social status	0.40	0.03	**
Marital problems	-0.16	0.39	
Sadness, anxiety or worry	0.34	0.07	*
Bad treatment of Health staff	-0.11	0.58	
Concern about children	-.028	0.13	
Social isolation	0.54	0.00	**
Financial	**0.23**	**0.21**	
Reduced income	0.31	0.10	*
Loss of job and wages	0.32	0.09	*
Physical	**0.19**	**0.31**	
Diarrhoea	0.34	0.07	*
Teeth Problems	-0.09	0.65	
Headache	0.18	0.33	
Fever	0.07	0.70	
Side effects of medication	0.15	0.42	
Sweating	0.08	0.68	
Weight loss	0.26	0.21	
Vomiting	0.11	0.58	
Skin rashes	0.25	0.18	
Thinning of hair	0.09	0.63	
Loss of appetite	-0.22	0.25	
Sores in mouth	0.09	0.64	
Weakness	-0.17	0.37	
Stomach ache	0.13	0.50	
Nausea	0.07	0.70	

* Borderline significant correlation ($p \leq 0.1$); ** Significant correlation ($p \leq 0.05$)

Illness meaning: Perceived causes (PC)

In the grouped categories of PC, medically-related categories were most frequently reported (60.0%), followed by sexual categories (50.0%), religious (33.3%), pathogen (13.3%), environmental (10.0%), and drug intake (10.0%). 13.3% of the sample either did not know or did not state a cause of their infection. Many patients reported several causes for their HIV infection. HIV virus was only reported by 10.0% of the sample with a mean prominence of 0.13 (Table 5-5).

Table 5-5: Perceived causes and their mean prominence as reported by people living with HIV/AIDS in Jordan (N = 30)

PERCEIVED CAUSES [a]	How reported (%)			Mean Prominence [e]
	Total [b]	Spon [c]	Most troubling [d]	
Medical/Injury	**60.0**	**60.0**	**43.3**	**2.5**
Blood transfusion	26.7	26.7	13.3	0.93
The dentist	13.3	13.3	13.3	0.67
Injury, accident, surgery	16.7	16.7	3.3	0.43
Sharing shaving blades	10.0	10.0	6.7	0.40
Contaminated Injection	6.7	6.7	6.7	0.33
Tattoo	6.7	6.7	0.0	0.13
Sexual	**50.0**	**50.0**	**33.3**	**2.00**
Sexual content(unspecified)	36.7	36.7	20.0	1.33
Through spouse	10.0	10.0	6.7	0.40
Pre-marital sex	6.7	6.7	6.7	0.33
Masturbation	6.7	3.3	0.0	0.10
Don't Know	**13.3**	**13.3**	**13.3**	**0.67**
Religious	**33.3**	**10.0**	**3.3**	**0.53**
Test from Allah	23.3	10.0	3.3	0.43
Fate or will of Allah	13.3	0.0	0.0	0.13
Pathogen	**13.3**	**3.3**	**0.0**	**0.17**
HIV virus	10.0	3.3	0.0	0.13
Illegal Drugs	**6.7**	**3.3**	**6.7**	**0.30**

[a] Perceived causes ordered by mean prominence within each group (bold). Causes reported by less than 5% not listed; [b] Percentage of reported causes; [c] Percentage of spontaneously mentioned causes; [d] Percentage of causes identified as most troubling; [e] Mean prominence based on values assigned to each reported perceived cause (0 = not reported, 1 = reported after probing, 2 = reported spontaneously, and additional 3 if identified as most troubling).

Respondents typically reported sexual causes of HIV without specifying any particular sexual behaviour. Sexual experiences that were reported more than 5% were sex with spouse, premarital sex, and masturbation. Adultery was reported less than 5%, and thus not listed in the table. Homosexuality was not reported by any respondent.

Qualitative data shows that PLWHA referred more to injury and medically-related categories among personal accounts of causes of infection. In most cases, respondents referred to sexual contact as a generic mode of transmission rather than a specific experience that was the cause of their infection, denying its role or feasibility in their own case. A 37-year-old man who reported sexual relations were the cause of his HIV infection said,

'At the beginning I was suffering from family problems as a result of my father being away from home. So my mom was taking all home responsibility. I was ignorant and the environment where I was living helped me to have sexual relations'

Religious reasons and reliance on faith, either in justifying the infection or accepting the disease, was discussed by on many respondents. Two patients, 32- and 39-year-old men, justified their condition of illness with HIV/AIDS based on faith by saying respectively,

'Sexual relations I think caused my infection. I was very bad before and God punished me with this disease'. (Respondent one)

'Perhaps blood transfusion when I was 14, or because of safe sexual relation or because of the injections the athletics take I was an athletic when I was young, or a test from Allah this is what I believe in now. A test from Allah' (Respondent two)

Bivariate relationships between mean stigma index and the mean prominence values of PC are reported in Table 5-6

Among PC variables, specifically within the sexual group category, non-specific sexual experience and masturbation were correlated with higher stigma, presumably due to the religious and sociocultural response to such behaviours. The PC group of religious reasons was also correlated with higher stigma, suggesting 'internalised stigma', where subjects believe that the illness was a justified 'punishment' for their sexual behaviour and thus internalised stigma. Sharing shaving blades had significant correlation with higher stigma. Qualitative accounts showed that sharing blades was carried out in prison.

Table 5-6: Bivariate relationship of stigma and perceived causes

PERCEIVED CAUSES	Spearman (ρ)	*p* Value	
Medical/Injury	**-0.06**	**0.77**	
Blood transfusion	0.05	0.80	
The dentist	-0.26	0.16	
Injury, accident, surgery	0.18	0.34	
Sharing shaving blades	0.41	0.02	**
Contaminated Injection	-0.11	0.57	
Tattoo	-0.23	0.22	
Sexual	**0.46**	**0.01**	**
Sexual content(unspecified)	0.47	0.01	**
Through spouse	-0.10	0.61	
Pre-marital sex	0.21	0.27	
Masturbation	0.35	0.06	**
Don't Know	**-0.20**	**0.29**	
Religious	**0.31**	**0.10**	*
Test from Allah	0.21	0.25	
Fate or will of Allah	0.27	0.15	
Pathogen	**0.08**	**0.68**	
HIV virus	0.15	0.44	
Illegal drugs	**0.04**	**0.84**	

* Borderline significant correlation ($p \leq 0.1$); ** Significant correlation ($p \leq 0.05$)

5.4 Discussion

This is the first study to measure and classify perceived stigma among PLWHA, and to evaluate sociocultural factors contributing to high levels of stigma in Jordan and the MENA region. Previous research of HIV-related stigma in the region acknowledged its impact, but studies investigating stigma in the region are few and limited in scope (Alkaiyat and Weiss, 2012). Of the available studies, most consider enacted stigma, with reference to the 'attitude' of students, HCW, and other designated groups (Ellepola et al., 2011; Hassan and Wahsheh, 2011; Badahdah and Sayem, 2010; Al-Iryani et al., 2009). Anticipated and internalised stigma have been absent in the regional literature. Classifying stigma is important to enhance our understanding of its impact, and to design more effective and more selective interventions.

Our results showed high prevalence of perceived stigma and its major adverse impacts on work, medical treatment, social life, and family dynamics. Findings of studies in different global settings have also shown similarly high prevalence of perceived stigma (Lifson et al., 2012; Van, 2010; Bogart et al., 2008; Li et al., 2007; Mak et al., 2007; O'Connell et al., 2003;

Parker and Aggleton, 2003). The results of this study should be validated and maybe similar for other countries in the region due to similar features of the profile in HIV/AIDS epidemic and its control measures, as well as the similar language, religion and culture.

We have a small sample size due to difficulties reaching PLWHA and high rate of PLWHA refusing to be interviewed. This limits our out power to use multivariate analysis and correct for confounding. Nevertheless our methods were adequate to explore salient features of stigma experience among PLWHA in the region. EMIC interviews produce datasets with complementary quantifiable data for quantitative analysis and narrative data for qualitative analysis (Weiss, 1997). Thus, this study provides valuable and needed information from the MENA region where data concerning HIV/AIDS are scarce, especially data based on study of PLWHA.

5.4.1 Perceived stigma

Enacted stigma typically arose from interactions with HCW and the work environment. Stigmatising events including HCWs insulting patients; refusal, delay, or neglect of patient care, violation of confidentiality, and avoidance of physical contact are well documented in the global literature (Rutledge et al., 2011; Reis et al., 2005; Schuster et al., 2005; Yang et al., 2005; Horsman and Sheeran, 1995). Similar patterns are expected in Jordan and the MENA region. Nevertheless, patients had anticipated sympathy and support from HCW, not stigma. This made its impact more traumatic.

The other experiences of enacted stigma were the illness experiences of reduced income and job loss, which were correlated with higher stigma (Table 5-4). In many cases, diagnosis of HIV resulted in job loss and deportation, which further increased the illness burden and stigma. The PLWHA who experienced these problems were not in the clinical phase of AIDS, they were able to work. Most of them, however, were diagnosed in neighbouring Arab countries, and they were immediately deported from these countries and sent back to Jordan. Narratives indicated their feelings of sadness, anxiety, reduced social status, and social isolation that further intensified their experience of stigma.

Felt stigma, either anticipated or internalised, was the prevailing type. It was in many ways more troublesome than enacted stigma. Respondents emphasised their social and emotional distress and fear of social isolation and rejection. Although felt stigma is well documented worldwide (Hasan et al., 2012; Yebei et al., 2008), it has not been studied in the MENA region. This neglect of felt stigma is of critical importance. In settings of low HIV

prevalence, such as the MENA, felt stigma is expected to play a major role in HIV/AIDS control on two levels. First, felt stigma discourages HIV testing and counselling. Second, diagnosed patients tend to adopt a strategy of non-disclosure which limits social support, timely treatment uptake, and adherence (Badahdah and Pedersen, 2011).

Mitigating felt stigma is therefore a priority for HIV/AIDS control in the MENA region. In order to do so effectively, sociocultural features of HIV/AIDS that contributes to felt stigma need to be highlighted and publicly challenged. Most likely PLWHA anticipate such stigma from ideas that blame victims or legitimise exclusion. The sociocultural features of HIV/AIDS in the MENA region may be the most important factor in HIV-related stigma.

5.4.2 Stigma, culture, and HIV/AIDS

Cultural norms may have greatly shaped the response to HIV/AIDS including policy, laws and, related stigma. For example, 50% of the sample reported sexual causes as a mode of HIV transmission; this is lower than the officially reported national numbers where sexual transmission accounted for 60.0% (Jordan National AIDS Programme, 2012). In our study sexual causes were mainly reported under the category 'non-specific sexual reason', which was associated with higher levels of stigma (Table 5-6). In addition, qualitative data show that in most cases sexual experiences were regarded as a generic route of transmission rather than the cause of personal infection. This tendency to depersonalise certain sexual behaviours suggests that it is the immortality of sexual behaviour, rather than the sexual transmission that patients relate to HIV/AIDS infection and stigma.

Furthermore, sexual behaviours like adultery and homosexuality were likely to be understated. Sex outside of marriage is totally forbidden in the Islamic constitution. However, punishment of forbidden sexual activity depends on marital status of the persons involved. In case of premarital sex, unmarried fornicators are punished by 100 lashes. For adultery the sentence will be death by stoning. This law is currently applied only in a few countries such as Saudi Arabia and Somalia. In other countries where Islamic law is applied less rigidly, sociocultural norms strongly stigmatise such behaviours with the support of civil law. In the Jordanian penal code, for example, men receive reduced sentences for killing their wives or female family members if they are deemed to have brought dishonour to their family, implying relatively more acceptable 'honour killings' (IRIN Plus News, 2012). Homosexuality is even more hidden and stigmatised. It is reported that gay people are often

subjected to homophobia, harassment, discrimination, and/or criminalisation (Moszynski, 2008; Symington, 2008; Helie, 2004).

Another example of the effect of sociocultural values on stigma is the correlation of masturbation and increased stigma (Table 5-6). Masturbation is commonly known in the region as the 'secret habit'. The name itself implies stigma. Masturbation is surrounded by secrecy and believed to have many negative physical, mental, and social effects (Qudah, 2008). Most Islamic schools and scholars prohibit masturbation. Although it is not a cause for HIV infection; PLWHA may associate it with HIV/AIDS due to the anticipated stigma. Likewise, stigma of imprisonment rather than stigma of HIV/AIDS explain the higher stigma related to sharing shaving blades in prison.

On the other hand, professionally recognised causes of HIV infection such as blood transfusion were not associated with high stigma. Stigma toward HIV/AIDS and PLWHA in the MENA region seems to be strongly related to locally stigmatised behaviours (e.g., imprisonment, homosexuality, adultery and masturbation). PLWHA are likely to get more social support by attributing their condition to non-sexual causes.

Such ideas about stigma and HIV/AIDS are represented in the media and popular culture. A recently featured Egyptian movie 'Asmaa' is a good example. The movie is based on a true account of a woman, Asmaa, infected with HIV by her husband, who was infected in prison. She refuses to declare the actual cause of her infection out of solidarity with her PLWHA peers, who experience condemnation.

The influence of Islamic values on HIV/AIDS in the region is notable. Religious reasons for HIV infection were also correlated with higher felt stigma in our sample (Table 5-6). Religiously and culturally, HIV/AIDS remains the 'untreatable disease' and the disease of sinners (WHO, 2007a). For most people this idea enables them to feel protected. For them, concerns about infection with HIV as condemnation for sins like homosexuality and extra-marital fornication are reassuring if they do not apply (Francesca, 2002). Therefore, HIV/AIDS as the 'untreatable disease' has a good cultural fit. It rewards good behaviour and punishes sinners. It fulfils the prophecy of the Prophet Muhammad Hadith: '[*Fahishah]* Abomination has never appeared amongst any people, and they commit it openly, but an epidemic or a disease that they have never encountered before became widespread among them'.

5.4.3 Strategic implications

In their review of interventions to reduce stigma in developing and developed countries, in which no MENA country was included, Brown et, al. highlighted limitations in the arsenal of stigma interventions (Bos et al., 2008). In the MENA region, such limitations may be even more substantial. Low prevalence, may have limited perceived needs for strategic planning, but that is changing, and it is changing rapidly in some cases like Libya, where the prevalence of HIV among a high-risk population of 624 people was recently found to be as high as 87% (UNAIDS, 2012b).

Strategies to reduce stigma in the region rely heavily on health promotion and raising awareness. Indeed, knowledge and awareness of HIV/AIDS may have a positive impact on the community attitude toward PLWHA (Bektas and Kulakac, 2007; Petro-Nustas et al., 2002a). But is that enough? For instance, raising awareness on non-sexual transmission as a strategy to mitigate stigma may divide PLWHA according to their publicly perceived cause of infection, and increase the stigma toward those whose illness is linked with sexual experiences. Therefore, the response to stigma should address a broader range of interests, based on considerations of social and cultural contexts and the variety of individual circumstances and needs (Bos et al., 2008).

Stigma in the MENA region seems to be more closely related to the behaviour believed to cause the infection rather than the disease itself. Hence the actions to mitigate stigma should acknowledge this reality. Anti-stigma programmes should be designed with due consideration of culturally and religiously sensitive settings to reach people effectively. Many would argue that the cultural values of the region conflict with public health priorities. And yet, the culture of the region is not monolithic. Culture also includes a wealth of resources that may contribute to public health, including treatment and control of HIV/AIDS. For example, anti-stigma programmes may refer to Islamic values of forgiveness for repentance, devotion and good works, represented in the following Quran verse *'Except for those who repent, believe and do righteous work. For them Allah will replace their evil deeds with good. And ever is Allah Forgiving and Merciful'.* (Quran 25:70)

The region currently has an opportunity to control HIV/AIDS. Low prevalence, highly functioning health systems, new leadership, the expected shift to democracy, an increased sense of autonomy, and the recent enthusiasm for HIV/AIDS control worldwide, create an opportunity for public health action (Havlir and Beyrer, 2012; Abdool et al., 2010; Grant et

al., 2010). Effective tools are available, and regional health systems and polices should take advantage of them. However, there is a need for political commitment to recognise and mitigate stigma, discrimination, and human rights abuses against PLWHA and people at high risk of infection. Laws to end enacted stigma should be strengthened and enforced, and programmes to counter felt stigma must be evidence-based and designed in a cultural framework.

5.5 Conclusion

Although the MENA region is forging ahead to meet international standards of healthcare, HIV/AIDS is still perceived as a shameful disease. The unique culture of the region in addition to current HIV/AIDS control policies may contribute to the growing disease burden and increased stigma.

The impact of stigma in the MENA region needs to be addressed more comprehensively in both health policy and research agendas. Complementary studies of stigma that take social and cultural features into account are necessary. Causes of stigma and discrimination should be identified, mitigated and monitored. Laws to protect PLWHA from discrimination and unfair travel regulations are needed for the region.

Reducing stigma in the region requires efforts beyond biomedical interventions for disease control. Such efforts should call attention cultural norms as well as the disease. Focusing solely on awareness of the disease may have limited effects on stigma. An effective approach to reducing stigma should be sustainable, pragmatic and multi-sectoral. Policy makers, media, HCW, religious leaders, community leaders, celebrities, high risk groups, and PLWHA should all be engaged in anti-stigma programmes planning design and implementation.

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Conflict of interest

We declare that we have no conflict of interest

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6

Condom use and HIV testing among men who have sex with men in Jordan*

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Abstract

Objective: To identify sociocultural determinants of self-reported condom use and HIV testing and examine variables related to accessibility, motivation and obstacles among men who have sex with men (MSM) in Jordan.

Design: Cross-sectional study among MSM who were identified through services of a local non-governmental organisation (NGO).

Methods: Respondents were studied with a semi-structured interview based on the Explanatory Model Interview Catalogue (EMIC) framework. The vignette-based EMIC interview considered locally relevant HIV/AIDS-related knowledge, risk perception, perceived causes, and awareness of services and sources of support.

Results: Of the 97 respondents, 27% reported that they used a condom at last intercourse; 38% had been tested at least once for HIV. Positive determinants of condom use were higher education level, acknowledging MSM as high-risk group, seeking advice from a medical doctor and the perceived causes 'sex with prostitutes' 'and sex with animals'. Awareness of available treatment was a positive determinant of HIV testing. Blood transfusion as a perceived cause and asking advice from friends were negative determinants.

Conclusions: Jordanian MSM seem to be aware of the risk of HIV infection and effective prevention methods, and they are willing to be tested for HIV. Our findings addressed the importance of the sexual meaning of HIV/AIDS on the control of HIV/AIDS among MSM. More effective engagement, of NGOs and MSM in the prevention and control of HIV/AIDS is needed, enlisting support of medical doctors and community health workers. Peer education should be strategically strengthened. Political commitment is needed to mitigate social stigma.

Key words: HIV/AIDS; MSM; Condom; HIV test; Jordan; Middle East and North Africa

6.1 Introduction

AIDS was first described as Gay-Related Immune Deficiency (GRID) syndrome, as it had initially been identified among men who have sex with men (MSM) in high-income countries. Despite huge efforts to control HIV/AIDS, rates among MSM in high-, middle- and low-income countries are increasing (Smith et al., 2009; van et al., 2009; Jaffe et al., 2007). Data on HIV/AIDS in the Middle East and North Africa (MENA), especially for HIV infections among MSM, remain inadequate or unavailable (Beyrer et al., 2012; Bohannon, 2005). Despite a modest level of documented HIV prevalence, which is probably due to underestimation and passive reporting for various social, religious and political reasons, the MENA region is currently one of two global regions where HIV incidence is increasing (UNAIDS, 2011). UNAIDS estimates report over half a million people living with HIV/AIDS (PLWHA) in the region (UNAIDS, 2011). HIV prevalence is increasing among MSM (Mumtaz et al., 2010), with concentrated epidemics in some countries of the region, namely Iran, Pakistan and Egypt (UNAIDS, 2011; Mumtaz et al., 2010).

MSM may be the most hidden and stigmatised of all groups at risk of HIV infection in the MENA region. Stigma also complicates studying MSM in the Arab world (Obermeyer, 2006). MSM are vulnerable to homophobia resulting in harassment, discrimination, and criminalisation (Moszynski, 2008; Symington, 2008; Helie, 2004). Information on characteristics and profiles of MSM populations in the MENA region are lacking for the above-mentioned reasons and their legal status, which varies from country to country. In Jordan, the Criminal Code allows adult, non-commercial, and consensual homosexual relations above the age of consent, 16 years. However, the rights of MSM are not legally protected in Jordan. No law or proposed legislation affords protection from discrimination or crimes based on sexual identity.

Control of HIV/AIDS in Jordan is implemented by the National AIDS programme (NAP) under the Ministry of Health. The NAP provides no-cost consultations, HIV testing and antiretroviral therapy through voluntary counselling and testing centres (VCTs) providing services only for HIV/AIDS. Owing to political sensitivities, however, control of HIV/AIDS among MSM in Jordan and most of the MENA region is mainly implemented by local non-governmental organisations (NGOs) collaborating with the NAP. Programmes for MSM and other high-risk groups are new in the region. Key strategies to reduce HIV transmission among them rely on promoting HIV testing and condom use. Other strategies include raising awareness of HIV/AIDS, peer education, and addressing legal, psychological and social

needs of MSM (Jordan National AIDS Programme, 2012; Abu-Raddad et al., 2010a; Lebanon National AIDS Programme, 2008).

Condoms, when used correctly and consistently, prevent infections with HIV and other sexually transmitted diseases (Workowski and Berman, 2006). Condoms are widely available in the region and are used for contraception. Condoms are also offered by VCTs free of charge. Awareness of one's HIV status through HIV testing is essential in preventing HIV transmission and promoting treatment of MSM (Stolte et al., 2007). Anonymous HIV testing at no cost is available from VCTs in Jordan and across the region.

Condom use and HIV testing, however, continue to be underutilised across the MENA region (UNAIDS, 2011; Mumtaz et al., 2010). Estimates for HIV testing are also relatively low: 2-22% of MSM in Egypt, 22% in Lebanon (Mahfoud et al., 2010), and 22% in Tunisia (Mumtaz et al., 2010) have ever tested for HIV in 2010.

In Jordan, the recent Integrated Bio-Behavioural Surveillance survey (IBBS) in 2010 is the only available study of HIV/AIDS among MSM (Jordan National AIDS Programme, 2010b). The IBBS found a laboratory-confirmed HIV prevalence of 0.2% in a sample of 468 MSM. Within the same sample, condoms were consistently used in the last six months by 19% for non-commercial and by 36% for commercial sexual intercourse. Condom use rates for last non-commercial and commercial sexual intercourse were 37% and 61%, respectively. Among MSM respondents 32% had been previously tested for HIV.

The low condom use and HIV testing rates among MSM in the MENA region might be partly explained by Islamic values and cultural norms that may compromise the effectiveness of local HIV/AIDS control programmes. The recent increase in HIV infections suggests a need to study preventive behaviours of MSM and the impact of local sociocultural features of HIV/AIDS.

We aimed to identify determinants of self-reported condom use and HIV testing among MSM in Jordan. We also studied accessibility, motivation and obstacles for condom use and HIV testing. Among potential determinants we considered HIV/AIDS-related knowledge, risk perception, perceived causes and support available to MSM.

6.2 Methods

6.2.1 Setting

The study took place over a course of five months in 2011. Respondents were recruited from four main cities of Jordan (Amman, Aqaba, Irbid and Zarqa) through a partnership with an NGO called 'Friends of PLWHA'. Although this NGO was established in 2009 with a public mandate to work with PLWHA, it also provides unpublicised consultations and supports high-risk groups including MSM and female sex workers.

The study was approved by the Ethics Committee of Basel Region (Ethikkommission beider Basel, EKBB), Switzerland. After explaining the purpose and objectives of the study, participants provided verbal informed consent prior to being interviewed.

6.2.2 Instrument

A semi-structured interview was constructed in accordance with the structure of the Explanatory Model Interview Catalogue (EMIC) (Weiss, 1997). EMIC interviews integrate quantitative and qualitative data to explain illness meaning, experience and behaviour in their local cultural context. Focus group discussions were conducted with representatives of the MSM community and with members of the NGO to inform development of the EMIC interview with reference to the context and study group. A first version of the interview was drafted in English, translated into Arabic and checked for validity and applicability in pilot interviews with five MSM; these interviews were not included in the analysis. The interviews were conducted by the first author and a trained representative from the NGO.

Participants were not asked directly about their HIV status to avoid discouraging their engagement. Questions of the EMIC interview referenced a clinical vignette depicting a person with typical somatic symptoms of AIDS. Respondents were asked to identify the condition. The interview considered locally relevant HIV/AIDS-related knowledge, risk perception, awareness of services and sources of support. The local meaning of HIV/AIDS was elicited by asking an open-ended question ("What do you think has caused the illness described in the vignette?"), followed by probing predefined categories of perceived causes (PC) related to injury, sexuality, religion, pathogens, and illicit drugs. The interview also included questions on condom use in the last sexual intercourse and the respondent's history of HIV testing. Categorical data were elaborated with narratives that constituted a complementary qualitative component of the EMIC data set to help explain quantitative findings.

6.2.3 Design and sampling

Among MSM known to the NGO, all potentially eligible men were approached by a member of their staff. Recognising the high social stigma against MSM, place and time of the interview were decided by each respondent individually. Categorical and narrative data were written down during the interviews. Interviews were also voice-recorded if respondents permitted it.

6.2.4 Data management and analysis strategy

Quantitative data were entered twice, cleaned and verified in Epi Info 3.4.3. Statistical analysis was done using Stata 10. MAXQDA 2007 was used for managing and analysing textual data.

Sample characteristics, HIV/AIDS-related knowledge, risk perception, access to services and sources and obstacles for condom use and HIV testing were reported as frequencies. Categories of PC were coded and analysed for their relative prominence (2 = reported spontaneously, 1 = reported only after probing the category, 0 = not reported). An additional value of 3 was assigned if the category was considered the most important among all reported categories, so that each category received a value ranging from 0 to 5 for each respondent. This approach based on prominence distinguishes how categories were reported from consideration only of the frequency of reporting. The mean prominence for the sample of each PC category was calculated based on the prominence ranking for each respondent.

We considered two dichotomous outcome variables: condom use and HIV testing. The variable for condom use was coded with a value of 1 if respondents had used a condom at last intercourse and a value of 0 if they had not used a condom at last intercourse. HIV testing was coded with a value of 1 if respondents had ever been tested; a value of 0 if they had never been tested for HIV.

For each outcome we conducted a bivariate logistic regression with each explanatory variable (i.e. HIV/AIDS-related knowledge, risk perception, support options and PC). All variables with a $p \leq 0.20$ in the bivariate analysis were each independently retained for further logit regression adjusted for sample characteristics that are correlated with each outcome. Condom use determinants were independently adjusted for education level. HIV testing determinants were also independently adjusted for education level and occupation. We report adjusted logit regression coefficients with 95% confidence intervals.

6.3 Results

6.3.1 Sample characteristics

Over the course of five months, 97 MSM consented to be interviewed. Sample characteristics, stratified by reported condom use and HIV testing, are summarised in Table 6-1. The majority of the interviewed MSM were single (93%), Muslims (92%) and students (56%). No one declared a positive HIV status. One-fourth reported condom use at last intercourse. Thirty-eight per cent had at least tested once for HIV. Only education was significantly associated with reported condom use at last intercourse. Education and occupation were significantly associated with HIV testing.

Table 6-1: Sample characteristics by condom use and HIV testing among MSM in Jordan, N=97

	Total		Used condom last intercourse			Ever tested for HIV		
	n	**%**	**n**	**%**	***p***	**n**	**%**	***p***
Total	**97**	**100.0**	**26**	**26.8**		**37**	**38.1**	
Age category (Years)								
17-25	73	75.3	21	21.6		27	27.8	
>25	24	24.7	5	5.2		10	10.3	
Marital status								
Single	90	92.8	24	24.7		33	34.0	
Ever married	7	7.2	2	2.1		4	4.1	
Religion								
Muslim	92	94.8	24	24.7		34	35.1	
Other	5	5.2	2	2.1		2	2.1	
Education								
Less than secondary	13	13.4	2	2.1	*	10	10.3	*
Secondary certificate	44	45.4	7	7.2	**	9	9.3	**
Diploma and higher	40	41.2	17	17.5		18	18.6	
Occupation								
Student	54	55.7	16	16.5		18	18.6	
Employed	32	33.0	6	6.2		13	13.4	
Unemployed	11	11.3	4	4.1		6	6.2	*

Unadjusted bivariate logit regression for sample characteristics categories with each outcome variable
*p≤0.20, bivariate logit regression;
**p≤0.05, bivariate logit regression

6.3.2 HIV/AIDS-related knowledge, risk perception and support

All respondents had heard about HIV/AIDS and 62% recognised it from the introductory clinical vignette (Table 6-2). Cancer, diabetes and ulcers were the most frequently identified diseases other than HIV/AIDS. Thirty-two per cent believed that treatment is available for HIV/AIDS, including energy therapy, self-help, and pain killers; but only 12% mentioned antiretroviral treatment (ART).

Seventy per cent were personally afraid of an HIV infection and 62% considered MSM as a high-risk group. A majority considered HIV/AIDS a problem in Jordan (55%) and the MENA region (70%). Major reasons were doubts about official incidence and prevalence rates, inadequate control strategies, the taboo surrounding HIV/AIDS, and globalisation.

Support (i.e. advice or help) regarding HIV/AIDS was sought by 62%, mainly to acquire information about disease prevention. Friends, including gay friends, were the most frequently mentioned source of advice (59%), followed by the internet (46%); doctors and VCTs were consulted by less than 27%.

Bivariate analysis identified the following variables associated with reported condom use at last intercourse ($p \leq 0.20$): Awareness of condoms for prevention, consideration of MSM as a high-risk group, belief that HIV/AIDS is a problem in Jordan and in the region, asking advice in general and asking advice from a doctor, friend or VCT. HIV testing was associated ($p \leq 0.20$) with awareness of condoms for prevention, awareness of biomedical or alternative treatment and asking advice from a friend and a doctor.

Table 6-2: HIV/AIDS-related knowledge, risk perception and support by condom use and HIV testing among MSM in Jordan, N=97

	Total		Used condom last intercourse			Ever tested for HIV		
	n	%	n	%	*p*	n	%	*p*
HIV/AIDS-related knowledge								
Recognise HIV/AIDS from vignette	60	61.9	16	16.5		23	23.7	
Condoms can prevent HIV/AIDS	81	83.5	25	25.8	*	27	27.8	**
Aware of any available treatment	31	32.0	7	7.2		20	20.6	**
HIV/AIDS-related risk perception								
Personally afraid of infection	68	70.1	21	21.6		27	27.8	
Consider MSM a high-risk group	60	61.9	21	21.6	**	23	23.7	
HIV/AIDS is a problem in Jordan	53	54.6	18	18.6	*	22	22.7	
HIV/AIDS is a problem in the MENA region	68	70.1	21	21.6	*	27	27.8	
Support seeking								
Asked for advice regarding HIV/AIDS	60	61.9	20	20.6	*	24	24.7	
Sources for advice								
Friends	57	58.8	18	18.6	*	16	16.5	**
Internet	45	46.4	15	15.5		19	19.6	
Doctor	26	26.8	14	14.4	**	13	13.4	*
VCT[†]	25	25.8	9	9.3	*	23	23.7	
Teachers	13	13.4	6	6.2		6	6.2	

Unadjusted bivariate logit regression for HIV/AIDS-related knowledge, risk perception and support with each outcome variable
VCT: Voluntary counselling and testing centre.
MENA: Middle East and North Africa.
[†] VCT was not included in the bivariate or multivariate testing analysis due to collinearity and high level of correlation
*p≤0.20, bivariate logit regression;
**p≤0.05, bivariate logit regression

6.3.3 Illness meaning

Unspecified sexual content was the most prominent PC, reported by 99% and identified as the most important cause by 78%. Homosexuality was identified by 2% as the most important PC. The HIV virus was reported as a cause by 69%, but mostly after probing. Some respondents explained that HIV is transmitted through pollution or through airborne or casual contact (e.g. shaking hands with an infected person).

Perceived causes related to injuries, unspecified sexual content, blood transfusion, sex with prostitutes, sex with animals, adultery and pollution were associated with reported condom use at last intercourse ($p \leq 0.20$). Unspecified sexual content, blood transfusion, intravenous drug use, the HIV virus, sex with prostitutes, sex with animals, test from Allah and prior illness were associated with HIV testing ($p \leq 0.20$).

Table 6-3: Perceived causes of HIV/AIDS by condom use and HIV testing among MSM in Jordan, N=97

	How reported (%)				Used condom last intercourse	Ever tested for HIV
Perceived causes[a]	**Total**[b]	**Spon**[c]	**Important**[d]	**Mean**[e]	***p***	***p***
Sexual content (unspecified)	99.0	93.8	78.4	4.28	*	**
Blood transfusion	91.8	87.6	12.4	2.16	*	**
Intravenous drug use	64.9	58.8	1.0	1.27		**
HIV virus	69.1	7.2	1.0	0.79		**
Homosexuality	45.4	7.2	2.1	0.59		
Injury, accident	48.5	2.1	0.0	0.51	*	
Sex with prostitutes	36.1	3.1	0.0	0.39	**	*
Pollution	20.6	5.2	2.1	0.32	*	
Sex with animals	29.9	1.0	0.0	0.31	*	*
Test from Allah	16.5	12.4	0.0	0.29		*
Fate or will of Allah	11.3	8.2	0.0	0.20		
Adultery	17.5	1.0	0.0	0.19	*	
Prior illness	14.4	1.0	0.0	0.15		*
Bad food or water	11.3	2.1	0.0	0.13		

Unadjusted bivariate logit regression for reported perceived causes of HIV/AIDS with each outcome variable
[a]Perceived causes ordered by mean prominence .Causes reported by less than 10% not listed; [b]Percentage of reported causes; [c]Percentage of spontaneously mentioned causes; [d]Percentage of causes identified as most important; [e]Mean prominence based on values assigned to each reported perceived cause (0 = not reported, 1 = reported after probing, 2 = reported spontaneously, and additional 3 if identified as most important).
*$p \leq 0.20$, bivariate logit regression;
**$p \leq 0.05$, bivariate logit regression

6.3.4 Condoms: access, sources and obstacles

One-tenth reported using condoms always, the majority used condoms sometimes (67%) or never (23%). Eighty-four per cent spontaneously mentioned condoms as a means of HIV prevention and 85% reported having easy access to condoms. Pharmacies were reported as a source for condoms by 88%; 52% reported friends as a source, and 21% obtained condoms from supermarkets. VCTs were the most infrequently reported source (9%).

Reduced pleasure was the most frequently reported reason for not using condoms (58%). Ineffectiveness of condoms was reported by 37%; in most cases this meant rupture or slipping of condoms. Forty-one per cent stated they do not need condoms because they know their partners, or because they did not practice anal course. Twenty-one per cent of MSM reported stigma as an obstacle, mainly because they felt ashamed to ask for or buy condoms. Among those who reported stigma as an obstacle, 90% were single and under 25 years. Only 4% reported cost as an obstacle to obtain condoms. Other reasons included religion and partner refusal, each mentioned by less than 5%.

6.3.5 HIV testing: access, motivation and obstacles

Sixty per cent knew that HIV testing was available in Jordan. The following testing facilities were mentioned: governmental health centres (43%), private health centres (32%), VCTs (11%) and NGOs (2%). Of those who had ever tested, 92% had done so voluntarily. Median number of tests was 1 test (range: 1-16 tests). Almost all tests (95%) were done after 2009. Testing was done by 41% out of self-motivation; recommendation by friends and by VCTs was reported by 32% and 16%, respectively. Of those who sought advice from VCT, 92% had tested for HIV.

“No need for the test” was the most frequent reason for not testing, reported by 52%. Respondents felt that they do not need the test mainly because they trusted their partners. Stigma was reported by 51% as an obstacle to testing. Qualitative data show that stigma mainly arose from interactions with health care workers, compounded by concerns about the confidentiality of testing. Because of stigma, some MSM stated that they donated blood to find out their HIV status and to bypass centres for HIV testing. Thirty-two per cent of respondents did not test since they were afraid of knowing their HIV status; 16% did not test since they were not sure about the confidentiality of test results. Costs and limited availability of tests as obstacles to testing was reported by 5% and 4%, respectively.

6.3.6 Determinants of condom use

Adjusted analysis for education level revealed that acknowledging MSM as a high-risk group and seeking advice from a medical doctor were positively correlated with condom use at p≤0.05 (Table 6-4). The perceived causes of sex with prostitutes and sex with animals were also significantly positively correlated.

Table 6-4: Determinants of condom use among MSM in Jordan, N=97

	Used condom last intercourse	
Variable	**Adjusted Coef**	**95% CI**
Consider MSM at high risk	**1.28**	**(0.09 ; 2.47)**
Asked advice from doctor	**1.95**	**(0.89 ; 3.01)**
Sex with prostitutes (PC)	**1.56**	**(0.61 ; 2.51)**
Sex with animals (PC)	**1.02**	**(0.05 ; 1.99)**

Coef: Logit regression coefficient adjusted for education level
CI: Confidence interval.
PC: Perceived cause.

6.3.7 Determinants of HIV testing

Logit regression adjusted for education level and occupation revealed that awareness of available treatments and asking advice from a medical doctor were significantly positively correlated with HIV (Table 6-5). Blood transfusion and HIV virus as perceived causes, and asking advice from friends were significantly negatively correlated with testing.

Table 6-5: Determinants of HIV testing among MSM in Jordan, N=97

	Ever tested for HIV	
Variable	**Adjusted Coef**	**95% CI**
Aware of any available treatment	**1.46**	**(0.46 ; 2.46)**
Asked advice from friend	**-1.55**	**(-2.88 ; -0.23)**
Asked advice from doctor	**1.74**	**(0.29 ; 3.19)**
Blood transfusion (PC)	**-1.05**	**(-1.80 ; -0.30)**
HIV virus (PC)	**-0.99**	**(-1.81 ; -0.19)**

Coef: : Logit regression coefficient adjusted for education level and occupation
CI: Confidence interval.
VCT: Voluntary counselling and testing centre.
PC: Perceived causes.

6.4 Discussion

Decreasing HIV incidence rates and recent research indicating use of ART as prophylaxis are reasons for optimism about prospects for HIV/AIDS control on the global level (Havlir and Beyrer, 2012; Muessig et al., 2012; Grant et al., 2010). Low prevalence rates and functioning health systems present a good opportunity to improve HIV/AIDS control in the MENA region. This is the first study to explore determinants of condom use and HIV testing among MSM in this region.

Condom use and HIV testing are two very important interventions for HIV/AIDS control. Our findings indicate low and inconsistent condom use among MSM, lower than the IBBS estimates in Jordan (Jordan National AIDS Programme, 2010b) and lower than reported numbers in Lebanon (Mahfoud et al., 2010), Tunisia, and Sudan (Mumtaz et al., 2010), but higher than in Egypt (Egypt National AIDS Programme, 2010a). The percentage of MSM who ever tested for HIV is higher than reported in the IBBS study and higher compared to other regional estimates (Mahfoud et al., 2010; Mumtaz et al., 2010).

Due to the sensitivity of the topic in the Arab world, MSM could not be randomly selected in this cross-sectional study in Jordan. This may limit the external validity of our findings since the recruitment through an NGO serving PLWHA may have biased the selection of MSM to a subset not fully representative of the target MSM population. We believe, however, that this approach to sampling through NGOs was appropriate under local circumstances and the only way to contact and talk to MSM. Making contact with MSM and encouraging them to talk openly about HIV/AIDS would not have been possible in a standard random sampling design. Moreover, the relatively small sample size limited out power to use multivariate analysis and further correction for confounding. Nevertheless, we believe the results shown here are of high importance and provide enlightenment about highly understudied and stigmatised MSM population.

Global obstacles for condom use are accessibility, price, lack of awareness, reduced pleasure, social and cultural beliefs and so forth (UNAIDS, 2000). Accessibility, costs and lack of awareness were rarely reported in our study, whereas reduced pleasure, perceived ineffectiveness of condoms, and lack of seeing a need for condoms were notable. Global and regional literature has reported similar obstacles to condom use among MSM populations, including issues related to (lack of) trust in partners (Nel et al., 2012; Wagner et al., 2012; Simoni et al., 2011; Wouters, 2009). An important finding from our study is that access-

related stigma was an obstacle to condom use, exclusively reported by young and unmarried MSM. Use of condoms as contraceptives is accepted in Jordan from a social and religious standpoint. This makes condom promotion for birth control possible, but it has been difficult to promote condom use for HIV/AIDS control because it is socially unacceptable (Abu-Ruman, 2009).

Promoting HIV testing indirectly increases awareness of HIV/AIDS (Lorenc et al., 2011). It is also well established that risky behaviours were reduced after testing (Marks et al., 2005; Weinhardt et al., 1999). Meta-analytic evidence shows that most people who discover that they are HIV positive take preventive action, including condoms, to reduce the risk of transmission to others (Marks et al., 2005). This is crucial in regions such as the MENA, where ambiguity still surrounds HIV/AIDS and many concerns regarding the actual burden persist.

Our findings showed good knowledge of HIV/AIDS, and awareness of condoms for prevention and availability of services (e.g. for HIV testing). Although risk perception was high, knowledge of available treatments and ART was low. Other studies from the region have also reported low awareness of ART within the general population and among PLWHA (Khachani et al., 2012), but efforts to promote awareness and access to ART remain limited in the MENA region (Al-Serouri et al., 2002).

Almost half of our respondents mentioned the internet as a source of advice. Past studies with MSM suggest that internet use rates for this group are higher than for other men (Sanchez et al., 2012a; Benotsch et al., 2002). Other studies indicate that the internet has important implications for HIV/AIDS interventions among MSM (Elford et al., 2004; Ross et al., 2000). Internet-based methods may reach MSM who do not attend physical venues (Sanchez et al., 2012b). By June 2012, 40% of the population in the Middle East were frequent users of the internet; the world average at the same time was 34% (Internet World Stats, 2013). These findings may likely be highly relevant for HIV/AIDS control among MSM in the region.

In our study asking advice from friends was negatively associated with testing, probably due to questions of trust. Although many studies worldwide have found significant improvements in HIV testing rates and other health care services after peer-based interventions (Simoni et al., 2011; Celletti et al., 2010; Wilton et al., 2009; Wouters, 2009), peer-to-peer education seems to be more complex in Jordan and the wider region. Gay friends may discourage MSM to test for HIV because they are afraid to be perceived as HIV positive or not trustworthy.

This finding does not suggest neglecting peer-to-peer education among MSM in the region, rather it suggests rethinking different approaches to implement it, such as adequate training of peers who could encourage testing in their community. Peer-to-peer education among MSM may be a very potent tool for interventions, especially because of the high stigma toward this group.

Consideration of MSM being at high risk of HIV/AIDS was positively associated with condom use in our study. A similar finding has recently been published about MSM in Beirut where fear and anxiety emerged as motivators for both condom use and HIV testing (Wagner et al., 2012). Such a relation between risk perception and condom use or HIV testing has also been described in South Africa (Nel et al., 2012).

Although reported by only approximately one-quarter of respondents as a source of advice, getting information from medical doctors was a determinant of condom use and HIV testing. Medical doctors play an important role in prevention and diagnosis as they deliver reliable information. They should therefore be trained more in HIV/AIDS counselling for MSM. This may also help reduce the stigma medical doctors and health care workers were found to attribute to in Jordan (Alkaiyat et al., unpublished manuscript).

Stigma was also reported as a major obstacle to HIV testing in our study. HIV testing is stigmatised in the MENA region as it is connected to fear of infection that results in social isolation of MSM (Newcomb and Mustanski, 2011). Stigma perceived by other gay men or the wider community and culture has been documented as a barrier to testing (Lorenc et al., 2011).

Whether ART was meant or not and regardless of the type or efficacy of treatment, awareness of available treatment was associated with HIV testing among MSM. Others also found a similar association, suggesting that awareness of available treatment may allay fear of positive test results (Kellerman et al., 2002). However, awareness of treatment (i.e. ART) was also found to be associated with increased high-risk behaviours such as unprotected sexual intercourse (Eaton et al., 2012). Further research is needed to investigate the role of awareness of treatment on prevention in the region.

Nearly all MSM who sought advice from VCTs, the only places that offer free testing, were tested for HIV. It remains unclear, however, if visiting VCTs encouraged MSM to test, or if MSM preferred VCTs because of cost considerations or a predetermination to testing. The former explanation seems more plausible because of two reasons: testing at VCTs has always

been offered at no cost and the majority of HIV tests in our sample were done after 2009 following a NAP policy change that supported more cooperation with MSM. Personal observation also suggests that HIV testing among MSM in general has increased in Jordan after this change. Further research needs to clarify the role of VCTs in the promotion of HIV testing in Jordan, and perhaps intensified efforts to encourage MSM to visit VCTs.

A belief that HIV tests are unnecessary was the most frequently reported reason against testing in our study. Testing for HIV seems to be more likely when individuals perceive themselves at risk of infection (de Wit and Adam, 2008). Being afraid of test results was also identified as an obstacle to testing, which has also been documented in the USA and Lebanon (Wagner et al., 2012; Kellerman et al., 2002). However, the study from Lebanon showed that fear and anxiety also motivated some MSM to get tested.

The sociocultural features and meaning of HIV/AIDS among MSM may seem to play an important role in prevention and testing. MSM-reported preventive behaviours primarily acknowledged sexual transmission of HIV. Reporting sex-related perceived causes of the illness seems to be related to higher prevention as sex with prostitutes and sex with animals were positively associated with condom use. On the other hand, the respondent-perceived non-sexual meaning attributed to blood transfusion and the HIV virus was negatively associated with HIV testing. Interventions targeting MSM should take into account the meaning and their perceived causes of HIV/AIDS for more effective prevention and control in this particularly vulnerable subgroup of the population.

6.5 Conclusion

MSM in our sample seem to be generally aware of the risk of HIV infection and effective prevention methods and are willing to be tested for HIV. While our findings indicate the importance of studying sociocultural factors to improve control of HIV/AIDS among MSM, some issues (e.g. the role of peer-to-peer education and VCTs for promotion of HIV testing) remain unclear and will benefit from further research. More effective engagement of NGOs in promoting HIV testing and prevention among MSM is needed. Medical doctors play an important role in control; reducing their discriminatory behaviour towards people with HIV and MSM could contribute to access and effectiveness of healthcare. More political commitment is also needed to mitigate social stigma of HIV/AIDS and the status of MSM, especially among healthcare workers.

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Authors' contributions

Designed the study: AA and MGW. Organised and supported data collection: AA and ML. Analysed the data: AA and CS. Drafted the initial manuscript: AA. Critically reviewed the manuscript: CS and MGW. All authors read and approved the final version of the report.

Conflict of interest

We declare that we have no conflict of interest

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7

General discussion and implications

This is the first study to exclusively investigate the cultural epidemiology and control of HIV/AIDS in the MENA region. It studies sociocultural features of HIV/AIDS, including experience of stigma among PLWHA in Jordan. It examines key elements of control with focus on condom use, ART uptake and adherence, and HIV testing. This research also compares findings from Jordan to the region at large in order to suggest practical implications at both local and regional levels.

The justification for this research stems from an urgent need for evidence to guide HIV/AIDS interventions in the MENA region. With a regional outlook, we focused our work in Jordan. In collaboration with local partners, we carried out a study among PLWHA and marginalised groups of MSM.

The objectives of this thesis were defined during a preliminary observational study and systematic literature review. The preceding thesis chapters outline the epidemiology and control of HIV/AIDS in the MENA region, and the impact of sociocultural features on the priority of HIV/AIDS and its control (Chapter 3). Help-seeking behaviour and ART uptake and adherence were investigated among PLWHA (Chapter 4), as well as the nature of stigma, its triggers, and ways of mitigation (Chapter 5). In chapter 6 this study identified locally valid determinates of condom use and HIV testing among MSM.

The lack of contextual and explanatory data and the particular challenges in regional HIV/AIDS control - such as low ART uptake and adherence, low condom use, limited HIV testing, as well as the sociocultural context, indicated a need for cultural epidemiological methodology. With emphasis on categories of distress, perceived caused, and help-seeking,

cultural epidemiology offers a window into the socio-cultural dimensions of HIV/AIDS by documenting locally valid illness-related representations of HIV/AIDS experience, meaning, and behaviour among PLWHA and MSM.

Each chapter indicates difficulties in assessing the burden of HIV/AIDS in the region, inadequacies of current control programmes and alternative strategies, while also identifying research needs. Studies on HIV/AIDS in the region are limited, especially those that focus on social dimensions. Control approaches in the region are mainly modelled on international interventions with little consideration of local needs based on distinctive features of social and cultural settings.

These findings are particularly timely, given the potential for social change and strengthening of health systems stimulated by the so-called “Arab Spring”. In addition, the recent decision of GFATM —the predominant HIV/AIDS donor in the region—to cease the call for Round 11 grants, marks an opportunity to change regional control strategies. This study provides guidance to policy makers, international organisations, donors, and local communities for better HIV/AIDS control in the MENA region.

This work is incorporated in the strategy and the principles of the Swiss TPH built around the triangle of innovation to validation and application. Innovation was achieved by conducting a cultural epidemiology study for the first time in this region, and by generating explanatory data from the perspective of PLWHA and MSM for the first time in Jordan. This thesis validated previously reported numbers on low condom use, and ART adherence. It also validates the hidden burden of stigma among PLWHA. This thesis provides practical approaches for HIV/AIDS control in the region, on both policy and community levels, such as for stigma mitigation and enhancing condom use and HIV testing among MSM.

This concluding chapter discusses HIV/AIDS in the MENA region with regard to its priority and data availability and quality. It also highlights the relevance of the sociocultural features from our findings and their impact on control; both at national and regional levels, and provides practical implications for future interventions. Finally, conclusions, research needs and recommendations for HIV/AIDS control on policy and health system levels will be addressed.

7.1 Overview of the HIV/AIDS situation in the region

The development of effective tools for prevention and treatment have led to increased optimism regarding HIV/AIDS control (Cohen et al., 2011; Abdool et al., 2010; Grant et al., 2010; Rerks-Ngarm et al., 2009). Advocates have been discussing "the beginning of the end of AIDS?" (Havlir and Beyrer, 2012) and the possibility of an "AIDS free generation" as suggested by the former United States Secretary of State Hillary Clinton in 2012. Although these slogans reflect the potential prospects for control, such statements must be viewed cautiously in settings where ending the epidemic remains a more distant goal. Even worse, such statements might breed complacency and limit resources needed by suggesting an inappropriate donor exit strategy (Horton, 2012). This could eventually transform HIV/AIDS into a "neglected disease", confined to low-income and developing regions. The MENA is a region where elimination, or even effective control, of HIV/AIDS remains a distant goal.

This region provides the least information and no more than minimal coverage of HIV/AIDS in international reports. A good deal of work is needed to better estimate the burden and improve control approaches. Based on projections based on available data in 2005, the World Bank suggested that the prevalence rate in the MENA may reach 4% by 2015 if adequate preventive methods are not taken (World Bank, 2005). Others have also strongly suggested that the HIV/AIDS epidemic in the region may still be only in an early stage (Traboulsi et al., 2006).

To date, most reported MENA country-level prevalence rates are very low, and they are far below the World Bank projections. However, low prevalence does not necessarily mean low risk (Jenkins and Robalino, 2003). Assessing the burden of HIV/AIDS in the region should be combined with careful consideration of rising rates of infections and emerging evidence of concentrated epidemics among HRGs. In addition, experience from other regions in dealing with more advanced epidemics clearly indicates how devastating it is to ignore the need for investment to prevent the spread of HIV/AIDS while prevalence rates are low.

Regardless of the reliability of available estimates, it is clear that unless there is swift action future increases in HIV/AIDS incidence in the MENA region will be dramatic. Averting prospects for such an epidemic requires guidance from study of evidence-based strategies, successful prevention methods, adequate care and treatment for those who are already infected, and easy access to preventive services for HRGs that preserve their dignity.

To better estimate the burden of HIV/AIDS and get a clearer picture of its dynamics and profile in the region, many issues have to be overcome. For example, while current control approaches are efficacious, their *effectiveness* is reduced by lack of evidence-based strategy and minimal adaptation to cultural settings. HIV/AIDS must become a higher priority in the public health agenda and data relevance, availability and quality must be improved.

7.1.1 HIV/AIDS in the MENA: a potential "neglected disease"?

Although HIV/AIDS is a widely acknowledged global health priority, the MENA regional indicators and profile closely resemble those of a "neglected disease". Available studies among PLWHA in the region, in addition to the findings of this thesis, reveal a low socioeconomic profile of those who are diagnosed with HIV/AIDS (Badahdah and Pedersen, 2011; Kabbash et al., 2008; Benjaber et al., 2005). Furthermore, failure to adequately acknowledge the epidemiological status results in low resource investment by governments (and possibly NGOs) and produces a failure to implement adequate treatment and preventative measures (UNAIDS, 2011). These typical symptoms of a "neglected disease" are characteristic of HIV/AIDS in the MENA region.

The priority of HIV/AIDS on the health agenda in the MENA is, at best, conflicted. Contradictory messages regarding the importance of HIV/AIDS control are circulated. Messages from policy-makers, as expressed for example in local newspapers, reassure the general population of low HIV prevalence and risk rates (Petra, 2012; Abdul-Alem, 2012) while official reports, such as country progress reports, cite the earlier 4% projected prevalence by the World Bank (Jordan National AIDS Programme, 2008), but these data apparently are not widely disseminated. Furthermore, while most countries report low prevalence, the majority apply and receive funds from international donors, presenting their cases as *serious* and *urgent*. By the end of 2010, USD 578 million had been approved for HIV/AIDS grants by GFATM alone. On the other hand, the region received fewer funds for tuberculosis—USD 307 million through round 10—(The Global Fund to Fight AIDS, 2011) although it is published that the number of those in the Arab countries living with tuberculosis is 400 times greater than those with HIV/AIDS (UNDP, 2009). If the priority of HIV/AIDS is increased, the actual situation could be properly assessed and such grants could be justified. Increasing the importance of HIV/AIDS at the national and regional level will help in collecting more comprehensive data to establish evidence of the threat of HIV/AIDS.

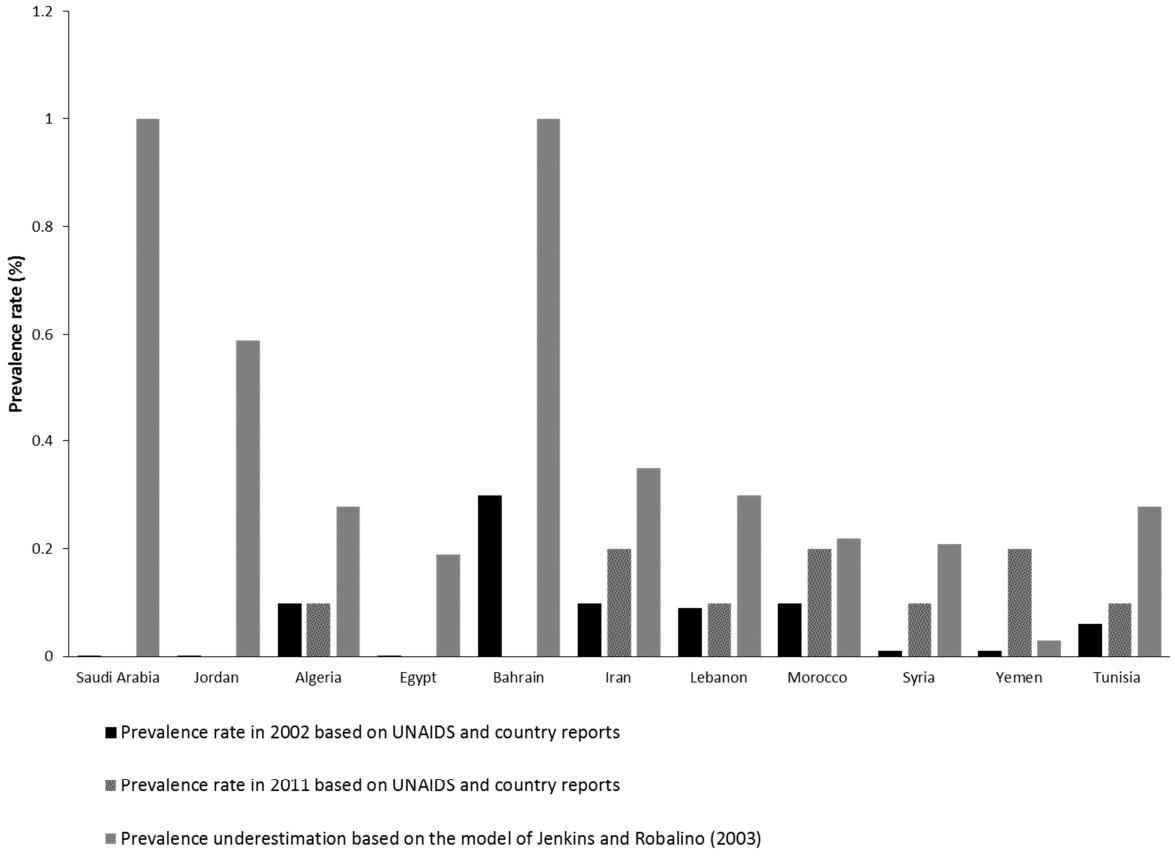
For many countries, appropriate resource allocation for HIV/AIDS remains a problem. It is unclear whether limited financial capacity or weak political will is to blame? With the on-going social and political turmoil in the region, as well as nascent democracy movements, the priority of HIV/AIDS is at a critical crossroads: the momentum can either be lost or gained. Movement from this crossroads depends on political commitment, funding, research, and strengthening surveillance systems via comprehensive and reliable data.

7.1.2 Data availability and quality

Data is needed for a more accurate picture of HIV/AIDS in the MENA region. Generating accurate and precise data is one of the main challenges for HIV/AIDS control in the region as acknowledged by countries and international agencies. Although the quantity of data is steadily increasing, it is still too limited to motivate evidence-informed decision-making. The amount of data, however, should not be the primary goal; rather ensuring data quality and its collation should be guided by the nature of the control approaches required in the MENA region. More relevant questions are: who is collecting the data, how, and for what purpose?

As discussed in Chapter 3, most of the HIV/AIDS data is published in governmental reports in the form of disease burden estimates. Ten years ago in a World Bank report, Jenkins and Robalino (2003) designed a model to assess the potential underestimation of HIV/AIDS prevalence in selected MENA countries based on data from 2002. The model predicted 0.2 to 1 per cent higher prevalence rates than official reported numbers. Alarmingly, as of 2012 most of the countries still have the same reported prevalence as in 2002, despite improvements in surveillance systems. Figure 7-1 shows the reported 2002 and 2011 prevalence rates for selected countries based on UNAIDS reports, and the potential underestimation in 2002 prevalence as predicted by Jenkins and Robalino model.

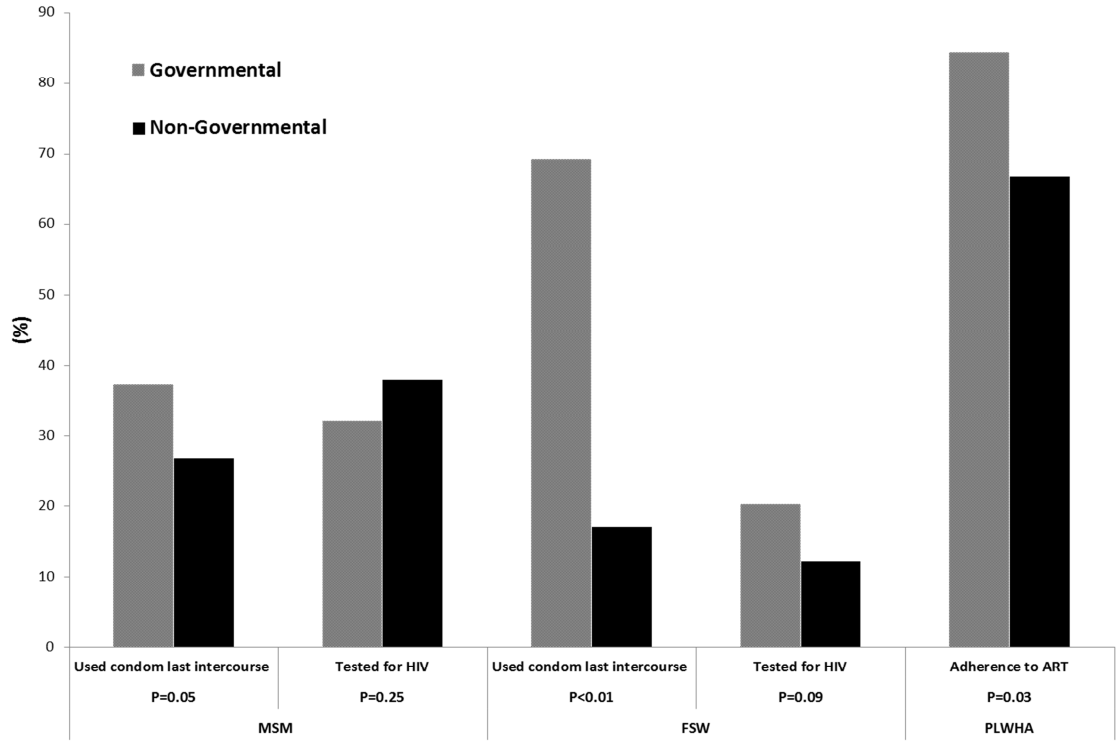
Figure 7-1: Prevalence rates in 2002 and 2011 based on UNAIDS reports, and the potential underestimation of 2002 prevalence based on a projection model in selected MENA countries



Improvements have been noted in a subset of countries such as Morocco, Tunisia, and Iran. Of course perhaps the actual prevalence has remained unchanged, but more likely it is underestimation and reflective of weakness in the surveillance data, especially in countries where concentrated epidemics are being observed, like Egypt, Bahrain and Saudi Arabia. One may argue that epidemiological data and disease burden estimates should only be provided by governments; this would ensure a global priority of central surveillance systems and therefore motivate resource allocation accordingly.

It is more troubling, however, that most studies that generate data on behaviour and access to service are also based on governmental reports. In their review Mumtaz et al. summarised (2010) studies of condom use among MSM in the MENA; 18 out of 27 sources used were retrieved from governmental and NAP reports. The results based on such reports are likely to provide misleading results. A trend of underestimation is observed when comparing some of the numbers from governmental reports in Jordan and those conducted by non-governmental institutions including data presented in this thesis (Figure 7-2).

Figure 7-2: Comparison of results between governmental and non-governmental studies among PLWHA and high-risk groups in Jordan



PLWHA: people living with HIV/AIDS; MSM: men who have sex with men; FSW: female sex workers; P-value based on Chi-squared test.
Sources: (Jordan National AIDS Programme, 2012), (Alkaiyat, 2012), Chapter 2 of the thesis, Chapter 4 of the thesis.

7.2 Relevance and priority of sociocultural features

The relevance of sociocultural features and their impact on HIV/AIDS control is well documented, and of course not exclusive to the MENA region. All around the globe HIV/AIDS is considered a social disease. Especially at the initial response to the epidemic, which was more medically oriented, the situation was described by Ankrah (1989) as *"too much epidemiology, too little social science"*.

In the MENA region, the sociocultural and religious values continue to influence the political, public health, religious institutions and community response to HIV/AIDS. Furthermore; sociocultural features effects are notable in published literature. In 2008, the Eastern Mediterranean Health Journal, —the flagship of the WHO Regional Office for the Eastern Mediterranean— published an article entitled "Risk behaviours for HIV/AIDS infection among men who have sex with men in Cairo, Egypt" (El-Sayyed et al., 2008a). The Arabic translation however, used the socially common term *Lotis* to describe MSM. *Loti* is someone who practices homosexuality. The name is based on the Quran based story of profit "Lot", who God punished his people for practicing homosexuality. Using such term might endorse specific behaviour and social response of condemnation and stigma.

This thesis has demonstrated the importance of understanding sociocultural features of HIV/AIDS in the MENA region and implications for control. Sociocultural features were observed on different aspects, from literature and policies to perceptions of PLWHA and HRG. The socially predominant idea that HIV/AIDS comes from the *West* had an influence on policies, testing tourist and hotel workers is an example. Stigma among PLWHA was engendered by stigmatised cultural behaviour. PLWHA who perceived culturally stigmatised behaviours as causes for their HIV infection (i.e., masturbation and being imprisoned) reported higher stigma, although these are not causes of HIV. Among PLWHA the most prominent categories of distress were social and emotional. Among MSM, perceived causes such as sex with prostitutes and its social context was positively correlated with condom use.

Furthermore, Religious features and their relation with HIV/AIDS were notable, in particular among PLWHA. Religious reasons were a perceived cause for HIV/AIDS, and many PLWHA perceived HIV/AIDS as a punishment for specific behaviour or a fate from God that was unpreventable. Religion influencing ART adherence was the utmost importance. Trust in God and accepting God's will meant to some PLWHA that they should accept their condition

and stay on treatment. Others regarded faith as an alternative to treatment; in this case religion was an obstruction for ART adherence.

7.2.1 Culture, Islam and HIV/AIDS

Islam is interwoven into the cultural fabric of the MENA region. Beyond spiritual doctrine and practice, Islamic law (*Sharia*) also structures on business and economic practices, governmental rule, education, family and other mundane features of day-to-day life (Lapidus, 2002). Sharia also influences concepts of public health, specifically meaning of illness and healing. It encourages healthy lifestyles and gives dimensions of health care for Muslims (Laird et al., 2007). Although some traditional Islamic values have contributed to selective denial and stigmatising toward HIV/AIDS, doctrinal prohibition of extra-marital sex and alcohol consumption and sanctioning of male circumcision may also provide buffers against HIV transmission. A review by Gray (2004) found that among 38 sub-Saharan African countries, the percentage of Muslims within each country negatively predicted HIV prevalence.

However, Islamic and cultural values are much intertwined, so relating a specific finding to Islam rather than a broader sense of culture beyond Islam maybe incorrect. When studying HIV/AIDS in a Muslim community, the influence of Islam on HIV/AIDS should be considered as an aspect of, and influence on, culture rather than a surrogate for culture.

7.2.2 Relevance and priority of sociocultural features in current control approaches

Cultural norms and religious values can play an important role not only in terms of transmission of HIV but also in terms of prevention and promotion of control programmes. Despite three decades of controversy of HIV/AIDS in the region, initiated with denial and condemnation, and despite the acknowledged importance of culture integration for effective control, the cultural impact on HIV/AIDS, to say the least, is undervalued. Attempts to integrate cultural and religious features in HIV/AIDS control in the region are more rhetorical than practical and lack the motivation, substantiality and commitment. To illustrate, the latest comprehensive UNAIDS report on HIV/AIDS in the MENA (2011) may represent such undervalue of culture role. The words, *culture, cultural and sociocultural,* were each mentioned once in the 140-page report (2011). Notwithstanding their role in bringing attention to HIV/AIDS in the MENA region, international NGOs should give more attention to the sociocultural features of the region.

On the other hand, this study found that despite the acknowledged importance of religion, in adherence to ART and as a meaning of HIV/AIDS, PLWHA and MSM were rarely reported by religious leaders or Imams as sources of help, indicating anticipated stigma. Religious leaders nonetheless are critical individuals with whom to engage. However, attempts to involve religious leaders in dealing with HIV/AIDS are very limited. In 2006, for the first time the UNDP brought together Muslim and Christian leaders from across the Arab region to discuss HIV/AIDS, some considered this meeting as a waking up to the risk of HIV/AIDS. After three days, the religious leaders signed a declaration in which they pledged to *"stand in solidarity with those who are infected and to talk about HIV/AIDS from their pulpits"* (McGirk, 2008; El-Feki S., 2006). The following year another larger meeting took place, also in Cairo. Unfortunately, no practical outcomes were achieved.

The involvement of religious leaders seems to be complicated and, for many reasons, requires further effort beyond annual meetings. First, the current approaches for HIV/AIDS control, mainly condom use, is seen by the religious institutions as a way of encouraging sexual relations outside marriage, a behaviour that all sectors of Islam, prohibit. Second, religious leaders may perceive international donations for HIV/AIDS—such those from the USAID—as a way for changing cultural norms and targeting the morality of young people in the region for political reasons. Text Box 7-1 is an excerpt of a newspaper article; it illustrates nicely the obstacles for involving of religious leaders and their perception of the current approaches to control. The article was written by Dr. Abdulhammed Qudah, an Islamic scholar, Bacteriologist and the director of HIV/AIDS and STI programme in the "Federation of the Islamic Medical Association". Dr. Qudah in this article wonders about the reasons to follow the "western" interventions to control HIV/AIDS. Instead, he assures that following the Islamic rules of abstinence will eliminate HIV/AIDS. He also addresses that the "western" methods of interventions, including condom use, comprises political agendas that target the Muslim youth and their morality.

Text Box 7-1: Newspaper article written by an Islamic scholar and published in the Jordanian newspaper "Al-Ghad" in 2009.

I wonder, why do we follow exactly what the Westerns want? Why not cut the root of the AIDS problem? Why all these prosthetic solutions? Is it not that all the applications and imitation applied in an environment and beliefs very different from our environment and our belief? What works for them does not fit our societies at all.

Thanks go to Mr Michel Sidibé, the head of UNAIDS, who was not hesitant, ashamed nor masked, when he said aloud in his first statement after being appointed: "We have to work in order for AIDS to be considered a political opportunity to bring about deep changes in the communities, for the benefit of addressing difficult topics such as sex education, and not to persecute homosexuals from a human rights perspective……

There seems to be many efforts in the world that seek to destroy the youth and corrupt them and overwhelm them with pleasures, desires, amusement and promiscuity, sometimes encouraging homosexuals and other times encouraging Satanists…!!

The best proof of this is a title of one report issued by the CIA predicting that "Sex and the moral decadence are key in the future war," whoever succeeds first in corrupting the opponents youth with sex and decadence and drugs shall win the battle…..!!

We would not, even unintentionally, be of help to them. God bless not people working to corrupt the minds and beliefs of our youth.
With all of the above, we do not deny the positive efforts and we encourage them limitlessly. But we are looking for the ideal solution leading to the satisfaction of God Almighty "and Allah has ordered, but most people do not know"

Finally, many calls from public health experts—in what seems like an alternative—have been directed to challenge cultural norms that may engender stigma or oppose prevention such as condom use. Such a stance is not likely to be successful means of behaviour change. First of all, a change in deeply embedded cultural norms could take at least a generation. In addition, experience from the region shows how devastating consequences can be by doing so. In 2009, the NAP in Jordan used an awareness poster indicating several transmission routes of HIV/AIDS, including anal and oral sex. The campaign resulted in a wave of negative reactions, it was even attacked in a main newspaper in an article entitled "AIDS Poster; the conspiracy face". The main theme of reactions was condemning the government and NAP to surrender to donors regulations that aim to change the morals of the society (Abu-Ruman, 09).

Current HIV/AIDS approaches that are based on a cultural framework are limited in the region. If not changed, HIV/AIDS will be still viewed as shameful condition. Notions of HIV/AIDS as a punishment from God, that condoms promote adultery, and that practices which spread the disease have been introduced by enemies of the Arab world will be still provoked and marketed. Especially now with the recent social and political turmoil in the region reflected by the on-going "Arab Spring", HIV/AIDS still remains a very easy issue to politicise.

7.3 Integrating the sociocultural features with HIV/AIDS control

The relevance of sociocultural features of HIV/AIDS highlights the urgency of their integration into control measures. One may ask how to integrate such conservative culture, where some values engender stigma, and how to reduce opposition to homosexuality and condom use for HIV prevention with approaches to mitigate stigma and increase access to information and services for marginalised groups to promote prevention? Some even describe such integration as the "AIDS Jihad", or a struggle (Loue, 2011). However, such development of HIV/AIDS control approaches integrating sociocultural features is critical if the low HIV prevalence to be sustained and if it is to be reduced among groups in which it is increasing. To do so, innovative interventions that are attentive and sensitive to cultural issues should be developed.

Generation of a framework for augmentation of cultural norms, including religious norms, relevant to HIV/AIDS is required for any successful treatment and prevention programme. Approaches for HIV/AIDS control will benefit if drawn from important cultural and religious precepts as a foundation (Loue, 2011). Cultural characteristics can serve as potential means of enhancing the effectiveness of health communication programs and interventions (Kreuter and McClure, 2004).

The latest breast cancer awareness camping in Jordan is a good example of potential and good prospects for such enhancement. In the MENA, breast cancer has common features with HIV/AIDS. Cancer is often communicated between people as "the unnamed disease" or "that disease", an indication of fear and severity and high mortality (Kawar, 2012). Social stigma on the other hand surrounds breast cancer in particular. Embarrassment, shyness and shame as well as worrying about husbands' approvals to receive early screening and fear of the impact of diagnosis on families negatively influence early diagnosis, resulting women to present with advanced stages of breast cancer (Arevian et al., 2011; Doumit et al., 2007; Petro-Nustas et al., 2002b).

Recently, Jordan launched a unique awareness programme for early diagnosis and screening of breast cancer (Jordan Breast Cancer Program, 2013). The main concept of the campaign was based on cultural values of family ties and the male role. The focal message of the campaign was directed to the men to encourage the women in their families to be screened. The number of women who underwent clinical examinations and screening for breast cancer tripled by the end of the campaign compared to the previous year. Although many features of

breast cancer in the local settings are different from those for HIV/AIDS, integrating the sensitivity to cultural characteristics shown by the breast cancer programme will likely benefit any HIV/AIDS control approach.

Figure 7-3: Breast Cancer awareness campaign billboard in Amman, Jordan capital

A billboard in Amman promoting breast cancer examination specifically addressing men as sons, brothers and husbands to encourage women to undergo examination emphasising the man's vital opinion

On the other hand, several Islamic-based approaches in non-Arab Muslim communities have been successful in HIV/AIDS control. Early In 1990, the Islamic Medical Association of Uganda conducted HIV/AIDS education programme to train local religious leaders. The programme resulted in an increase in awareness and significantly contributed to decrease in risky behaviours (Kagimu et al., 1998; UNAIDS, 1998). In South Africa there have been many programs based in mosques which aimed to mitigate stigma, promote protection and facilitate the life of PLWHA (Positive Muslims., 2004). In Malaysia, Muslim religious leaders have been actively involved in HIV awareness programmes and also proactively establishing care and support for PLWHA and also engaged with HRGs (Malaysia Ministry of Health, 2011). In Senegal, HIV/AIDS became a regular topic in Friday sermons in mosques, and senior religious figures talked about it on television and radio (UNAIDS, 2001).

Other successful formula for HIV/AIDS control efforts have been conducted in similar settings. In Iran for example, a programme recognised as a best practice is the triangular clinic which integrates services for treatment and prevention of sexually transmitted infections, injecting drug use and the care and support for PLWHA. Collaboration between governmental and non-governmental facilities have set up a sustainable programme which meets the needs of the country and was deigned based on its culture (Razzaghi et al., 2006).

Further examples from the MENA region come from Algeria and Morocco where engagement of civil society organisations resulted in establishing successful, well-perceived and cultural-sensitive interventions (see for example the NGOs; *El-Hayet* in Algeria and *de Lutte Contre le Sida* in Morocco). A recent Egyptian feature film, *"Asama,"* which tells a story of a woman living with HIV/AIDS received wide acclaim in part because of its depiction of a true story from the region, and mainly because it included many local cultural themes. The film is expected to make a significant contribution by positively influencing public opinion about HIV/AIDS and PLWHA (UNAIDS, 2011).

The perception of HIV/AIDS in the MENA region is a complex set of social features, cultural values and religious teachings, as well as emerging concepts communicated in Media and popular culture, and political agendas. What is clear is that HIV/AIDS is strongly associated with sociocultural features in this region, and successful strategies to enhance prevention and control must seriously take them into account.

Success stories in HIV/AIDS control from around the World indicate that creative and unorthodox approaches, where the community, PLWHA and HRG drive its conception and design, are more likely to be effective. This is particularly valid to the MENA region where HIV/AIDS is not easily observed because of the low prevalence and the sociocultural context is very challenging.

7.4 The way forward: implications for policy and control

The response to HIV/AIDS in the MENA region seems to be a mixture of denial, politics, culture, religion, health policy and funding strategy. HIV/AIDS cannot be considered merely a medical problem that can be managed with typical public health approaches. Further approaches are needed to produce the extent and type of responses necessary to reduce vulnerability of HIV/AIDS.

HIV/AIDS control in this region is a paradox between policy making and public health interest from one side and social context and religious institutions from the other side. The extent of the gap between these sides is wide and their views of control contradict each other. Each side sees the other's approach as a way of halting HIV/AIDS control or a method to politically manipulate youth and society. Regional HIV/AIDS control requires interactions across multiple social groups. In any programme, none of the stakeholders should be excluded and control should not be preferential for one stakeholder over another.

Therefore, research and advocacy should be directed to find the suitable means to reach a common platform for the different stakeholders. Religious advocates are key players in HIV/AIDS control, and means to foster their involvement in HIV/AIDS control should be developed. If donations from specific international donors e.g., the USAID will be an obstacle for such involvement, policy makers should evaluate the advantages of such donations versus the disadvantages of possibly excluding religious community members.

Furthermore, public health experts should be more accepting to interventions based on social and cultural values. Promoting condom use for HIV prevention seems to be a main struggle for religious leaders. On the other side, there is a theme among public health experts in the region that condom use is a milestone in control and opposing its use for prevention is a catastrophe for public health. Indeed condoms have saved millions of lives simply by preventing HIV transmission. In the region however, despite efforts to promote them, condom use continues to be limited. Opposing an approved intervention does not necessarily mean control failure in specific settings. In Uganda for example, there was resistance from politicians and some religious leaders toward promoting condom use (Green et al., 2006; Stoneburner and Low-Beer, 2004). A later analysis concluded that this initial antipathy toward condoms might have helped promote more fundamental changes in behaviour and played a part in the social acceptance of sexual behavioural change which led into a dramatic decline in HIV prevalence (Allen and Heald, 2004). While not endorsing opposing condom

use, perhaps focusing more on promoting social-based interventions such as abstinence and early marriages, behaviours that resonate with local norms would lead to better acceptance and thus better control.

Policy makers should be very careful how messages are perceived among general population. For many years, interventions in the region have been targeted toward awareness of HIV modes of transmission. A clear message intended to mitigate stigma was to tell that HIV can also be transmitted via non-sexual routes, so "anybody can get it". Consequently, the first question an infected person might be asked is how did you get HIV/AIDS? The answers will most likely determine an attitude of support or stigma. Such messages propagated in interventions programmes may categorise PLWHA based on what is believed their route of transmission, thus increase stigma toward those who are believed to have specific sexual behaviours.

The cause of HIV and its relation to stigma was observed in the present study finding. Blood transfusion was the most reported cause of infection by PLWHA, contradicting official numbers which show that transmission via blood and its products is minimal. PLWHA seem to report non-sexual route of transmission in an attempt to gain more social acceptance. This can also have a negative impact on surveillance where many PLWHA may claim a non-sexual route to avoid stigma among health care workers. In addition, the cause of HIV and its relation to stigma was nicely demonstrated in the aforementioned Egyptian Movie, *Asmaa*. The main character who was infected through her husband, refused to declare the cause of her infection in solidarity with other PLWHA. Maybe health systems in the region and policy makers should consider making the information about sources of transmission among diagnosed cases limited to policy makers and researchers. Limiting data in this case could be justified for public health interests. As a matter of fact Jordan in 2011 took a decision of not declaring the number of swine flu cases to avoid phobia among general population. Limiting the information about parentages might be beneficial in reducing stigma and encouraging further people to come forward and test for HIV, when they know nobody will question their source of infection or judge their behaviours

Moreover policy should take advantage of new ideas and emerging themes in the region and their influence on people, mainly youth. For example, 46% of MSM in this study reported Internet as their source of information about HIV/AIDS. Internet use including social networks has shown a big impact on youth in the region, especially lately with the rising "Arab spring". Internet and social networks could serve HIV/AIDS control not only in terms

dispensing information and increasing awareness but also in terms of providing risk assessment and counselling, particularly for HRG as it could mitigate their anticipated stigma.

In conclusion, most currently applied prevention and control measures in the region are top-down strategies devised by international actors, which risk overlooking the local context. Approaches to HIV/AIDS control which are used globally or in specific regions, are not necessarily effective in the MENA region simply due to lack of social acceptance. Using approaches that are specifically designed for the regional or local settings are most likely to be effective. To ensure this, features of the regional culture cannot always be perceived as an obstacle for HIV/AIDS control. True, many cultural norms may engender stigma and impair prevention and control. The culture of the region, however, is not monolithic. Culture also includes multitude of concepts, many of which can be fairly exploited to serve public health interests, including treatment and control of HIV/AIDS. The control of a culturally-sensitive disease, like HIV/AIDS, can be enhanced if based on cultural values, especially in a society where cultural values are very strong such as the MENA.

For example, in this study, family was the most reported nonprofessional help source by PLWHA (Chapter 3). In the MENA region, extended family constitutes the bedrock of the community life and represents a strong cultural value. Extended families have very strong relations and most have a family place to meet frequently and discuss common issues. Usually members of the extended family show a lot of support and sympathy and offer financial help for sick relatives. HIV/AIDS control can benefit from understanding how family networks operate. If a particular HIV/AIDS intervention is designed to influence families by increasing awareness and mitigating stigma, families may then support their infected relative, and be further involved in promoting prevention and testing to other extended family members, and possibly others.

On the other hand, because of the sociocultural features and the local context, the effectiveness of any HIV/AIDS intervention cannot be taken for granted simply because worked somewhere else. For example, peer-based interventions significantly improved HIV testing in several settings (Celletti et al., 2010; Wilton et al., 2009; Wouters, 2009), and therefore it is applied in Jordan as well as most countries in the region. Despite that, our findings suggested a negative association between peer-to-peer and HIV testing among MSM (Chapter 5), which suggest a more complex interaction related to the local settings of stigma

and perception of HIV/AIDS among MSM. Policy should be more considerate to the local settings before applying strategies such as peer-to-peer education.

Another example is the role of VCT in the region. VCT is an important component of HIV/AIDS prevention programs globally, several meta-analyses in developing and developed countries—none of the reviews had studies from the MENA region— show substantiated evidence that VCT services reduce risky behaviours and number of sex partners, and engaging in protected sex as well as increasing using condoms (Fonner et al., 2012; Denison et al., 2008; Wolitski et al., 1997; Higgins et al., 1991). However, the findings of this thesis suggest that VCT in Jordan may have limited efficacy in promoting behaviour change. PLWHA and MSM were not satisfied with VCT services. VCT monopolism of HIV/AIDS services increased anticipated stigma among PLWHA and caused access-related problems. Furthermore, MSM recommended services beyond VCT, to enhance access and HIV testing and reduce stigma. Without assessing their impact and their cost-effectiveness, VCT should not be considered suitable approach in the regional settings control just because it showed effectiveness somewhere else.

Working within the context of the norms and values deeply informed by Islam practices, is critical to the success of HIV/AIDS interventions. Notwithstanding the many challenges to such an approach, evidence acquired in this region and others have shown it can be done. The available tools and the relatively low HIV/AIDS prevalence in the region still provides a window of opportunity today to control and avert a catastrophic epidemic in the future, if proper response is implemented.

7.5 Generalizability of results

Cultural values vary among and within countries of the MENA region. But overall, values are a shared part of the cultural heritage of the "pan-Arab world" region which was once politically united. The region has been exposed to various colonial regimes over the years which created socioeconomic inequities as well as different forms of religious-political platforms that range from fundamentalist to liberal, pro-West.

Notwithstanding these differences, the MENA region, unlike all other regions, has many similarities across its countries. The "Arab world" in general, and the countries of the Middle East in particular, share a common cultural and religious background which is further complemented by a shared tongue, Arabic, facilitating communication and regional interaction. The common background and continuous interaction between the people have

rendered social norms and values in the region very similar. Furthermore, major social values, which are usually associated with religion, are easily spread and unified across the region.

The MENA region has a fairly uniform HIV/AIDS profile, which is characterized by low reported prevalence rate—except for Djibouti and Somalia where prevalence is much higher. PLWHA and HRG in the region share the same challenges and needs due to similar policy and community reactions. In terms of control approaches, the interventions are very similar and consist mainly of VCT, the ABC approach, and ART. Most of the few active HIV/AIDS-centred NGOs work on the regional level (i.e., regional Arab network against AIDS a.k.a. RANAA).

Despite the fact that the MENA region can be viewed as a single society, The studies presented in this thesis are case studies with some useful quantitative results which require further validation in other parts of the region. Some of the findings of this thesis support the few published studies from the region. In Egypt, Badahdah and Pedersen (2011) studied ART experience among 30 Egyptian women living with HIV/AIDS; they found common themes of stigma, access, and religious aspects. Studies among MSM in Egypt also have very similar findings with regard to condom use (El-Sayyed et al., 2008a; El-Rahman, 2004). A recent study among MSM in Biuret (Wagner et al., 2012) uncovered elements of fear and anxiety for condom use and HIV testing that are similar to the findings of this study (see Chapter 6).

The cultural epidemiological tools used in this study could be accessed easily in many MENA countries. The findings of this thesis could be extrapolated to other countries, mainly in the Middle East region, including Egypt, Lebanon, Palestine, Syria Iraq, and the countries on the Arabian Gulf.

7.6 Fieldwork challenges and lessons learned

Public health research, including HIV/AIDS, demands closer cooperation and sharing of resources within and across regions (Dawad and Veenstra, 2007; Gonzalez Block, 2006). Many benefits have been recognised with such collaboration, mainly in the framework of North-South research cooperation (Harris and Tanner, 2000). Of course, many challenges have also been identified. However, obstacles can be minimised, and advantages of such collaboration outweigh the disadvantages in most cases (Casale et al., 2011). In the MENA region collaboration for HIV/AIDS research has been limited, and on a small in scale,

including this study. The low priority of HIV/AIDS, low reported prevalence, and various cultural sensitivities are likely to explain such trend in limited collaborations.

In the MENA region, HIV/AIDS is a very sensitive issue because of its strong association with stigmatised behaviours and marginalised groups. It has been a challenge for religious leaders, policy makers, as well as researchers to work together to find appropriate solutions based on good evidence. Although the Arab Spring has the potential to open new spaces for addressing HIV/AIDS in the region, social and political instability in the short term may also turn the focus away to other issues deemed more pressing (Dajani, 2011).

Throughout the study period, we collaborated with various stakeholders representing a wide range of perspectives and interests including the MOH, NAP, VCTs, religious leaders, academic institutions, and NGOs. Despite this extensive network and the fact that the lead researcher is from the region, many challenges have been faced during the fieldwork of this study, this could, in part, be due to frequent changes in NAP administration.

As a first step, we aimed to establish a sustainable relationship with the MOH and NAP—the sole providers of HIV/AIDS services in Jordan. This was achieved by several meetings dedicated to clarifying the purpose of the study and the broad mission and principles of the Swiss Tropical and Public Health Institute. Permission to conduct the study was granted allowing data collection from VCTs across Jordan. Due to the frequent changes in NAP administration and MOH at that time - the Minister of Health was replaced three times within one year - the objectives of the project were repeatedly introduced and clarified to each new administration.

During the preliminary phase of the study, the NAP conducted a mass awareness campaign in a GFATM-funded project. The campaign was heavily criticised by religious leaders and social parties. As a result, the MOH felt threatened by the data collected from VCT records and requested a signed confidentiality statement thus prohibiting the revelation any VCT data obtained and analysed in the study. By agreeing, trust and rapport were reaffirmed.

We then established collaboration with a local academic partner, the Jordan University for Science and Technology (JUST), which provided logistical and ethical guidance and academic assistance. During our first meeting the president of the JUST advised to refrain from discussing the topics of sex or religion with informants, despite being key issues in this study. By forming collaboration with two NGOs who work on these topics, it was possible to incorporate them into the study as initially intended.

Several factors facilitated good relationships with different stakeholders. The first was to hold regular meetings with all involved parties including NGOs, MOH, academic affiliates, and religious leaders. The second was to remain neutral and not interfere with the parties' relationships. Third, was to preserve confidentiality between parties. Finally, and most importantly, was consistently reminding each stakeholder about the nature and motivation of this public health research.

During the study period we had the privilege to meet and interview marginalised people who are difficult to identify, including PLWHA and MSM. Our primary concern was to gain the trust of these groups. This was achieved by spending time at each NGO, explaining the purpose of the study, and responding to questions. Most of the time, we were accompanied by a member of the NGO. Most of PLWHA and MSM who agreed to be interviewed were very enthusiastic to be in the study.

The interview for many PLWHA was a medium to deliver a message about their suffering and daily struggles and challenges; therefore, interviews with PLWHA were relatively long. Most PLWHA would ask questions after the interview including questions about the latest advances in treatment; we documented this information. We also took care, after the first interviews, not to schedule two consecutive interviews and leave a minimum of two hours gap between interviews. During the interview it was very important to be attentive to respondent stories and concerns, but also to clarify that the goal of the research was for future rather than immediate intervention. Many of the PLWHA community complained about their experience with previous researchers making promises that were never fulfilled.

On the other hand, interviews with MSM were relatively short. MSM preferred shorter interviews which should be considered in the future. MSM in general were more stressed when interviewed, perhaps due to their experience with stigma. Some of the questions, for example, the question "Have you ever heard of HIV/AIDS?" was not perceived well as some of the MSM felt it underestimated their knowledge.

Interview sites were chosen by the subjects themselves; most of the MSM were not interested in coming to the NGO, mainly due to fear of being seen there. For many MSM, the interview was a platform to disseminate their "cause", as they believe being an Arab homosexual is a challenge and a cause to fight for. Questions followed the interviews focused on ways to seek immigration in Europe, or to be connected with MSM NGOs outside the region, we did not contribute to that knowledge, however, as it could be misinterpreted by some people.

7.6.1 Relevance of methodology

Although numerous attempts to bridge the disciplines of epidemiology and anthropology have been undertaken, culture is still undervalued in epidemiological studies (Trostle, 2008). Cultural epidemiology offers evidence that cultural concepts of illness have equal or perhaps more explanatory power than social epidemiological results in isolation (Schaetti, 2012).

To our knowledge, this is the first application of cultural epidemiology study in the MENA region. The flexibility of the EMIC allowed for adaptation to the local setting. Moreover, the EMIC interview was received well among respondents. Many PLWHA and MSM found the interview a good platform for further discussion and questions. The interview left space for PLWHA and MSM to share their experiences and perceptions, without jeopardising the integrity of the interview.

7.7 Conclusions

The work summarised in this thesis assessed the HIV/AIDS situation in the MENA region and provided suggestions for more effective control. This study produces evidence on specific sociocultural factors that are associated with HIV/AIDS control and explains how specific cultural values can be integrated into interventions that are manageable and accepted by the health system, PLWHA, HRGs, and the general population. In summary, the following set of conclusions is offered for consideration:

- The MENA region has a low HIV/AIDS prevalence, but concentrated epidemics among MSM and IDU are emerging and there are growing concerns that the HIV/AIDS disease burden recorded in the literature is dangerously underestimated;
- Priority of HIV/AIDS in the regional public health agenda is low. Data are limited and mainly provided by governmental institutes which contribute to unreliability and underestimations;
- HIV/AIDS control interventions in the region largely align with global approaches. Condom use is very low among high risk groups and the general population despite availability and awareness. ART uptake and adherence is also very low despite free provision of treatment;
- Cultural norms have considerable influence on the perception of HIV/AIDS, and direct influence on its control in the MENA region. However, integration of cultural aspects into control efforts is very limited;
- Religion plays an important role in HIV/AIDS control, both negatively and positively, in terms of illness perception, stigma and its influences on prevention and treatment. Religious leaders' involvement in HIV/AIDS control is low and is often contradictory to current interventions;
- In Jordan psychological, social, and emotional aspects account for the most troubling patterns of distress among PLWHA. PLWHA face different types of stigma. Felt and anticipated stigma are prevalent. Enacted stigma typically arose in interactions with health care workers;
- Sociocultural features of HIV/AIDS are associated with higher stigma including socially-mediated effects of specific behaviours such as prison-related associations, and various sexual experiences, including masturbation;

- Control polices of mandatory testing, travel ban, and travel restrictions engender stigma and contribute to the personal burden of HIV/AIDS;
- PLWHA and MSM had concern with the VCTs regarding access, location and stigma. Voluntary testing rates are very low and diagnosis of new cases relies heavily on mandatory testing. The context of diagnosis in the MENA region, including mandatory testing and deporting newly diagnosed patients, negatively influences help-seeking and ART uptake;
- Adherence to ART is associated with diagnostic circumstances, stigma, access to health settings represented by VCTs, as well as religious beliefs; and ART promotion is very limited in the region;
- MSM in Jordan were very knowledgeable about HIV/AIDS and were aware of risky behaviours and the importance of HIV screening;
- Condom use is low among MSM. Positive determinants of condom use were higher education level, acknowledging MSM as a high-risk group, and seeking advice from a medical doctor. Awareness of available treatment was a positive determinant of HIV testing, but asking advice from friends was negative determinant;
- More effective engagement of NGOs with MSM and support of medical doctors and community health workers are needed to increase low rates of condom use and HIV testing;

There is still a window of opportunity for HIV/AIDS control in the MENA region through concerted efforts in (i) increasing the priority of HIV/AIDS control, (ii) accurate, reliable epidemiological data collection, (iii) involvement of all stakeholders including religious leaders, civil society organisations, policy makers, and public health experts, (iv) integration of cultural and religious values into interventions, (v) political commitment to mitigate stigma, (vi) consideration of HRGs and PLWHA needs, (vii) revision of travel restriction and mandatory testing policies, and (viii) academic engagement to meet the research needs.

7.8 Recommendations for HIV/AIDS control in the MENA

Control approaches should be based on the needs of those who are affected by HIV/AIDS rather the needs of governments or international agencies, and should meet the perceptions and expectations of PLWHA and HRGs. Control approaches should be designed to be sustainable, pragmatic, and, most importantly, adaptive to the cultural settings. The following sets of points list recommendations on different levels:

7.8.1 Policy-level recommendations

- Priority of HIV/AIDS should be increased on the regional and national public health agenda, in terms of acknowledgment and resources;
- Polices for control should shift from focusing on awareness to behavioural change through engagement with HRGs- directly, indirectly, or even discreetly- through civil society organisations to avoid political sensitivities;
- Policy should ensure and facilitate the involvement of all stakeholders in HIV/AIDS control including public health experts, religious leaders, PLWHA, HRGs, civil society organisations, media actors, community leaders, and social workers;
- HIV/AIDS services should be led mainly by civil society organisations and local NGOs, not only for reaching HRGs but also for providing counselling, testing, and other services. Policy should financially and logistically support such a shift;
- Policies should reflect political commitment to mitigate stigma through:
  - Activating human rights laws that ensure access to health services that preserve a patient's dignity;
  - Travel bans and restrictions should be lifted. The international community should make sure of that, especially for countries which receive funds for HIV/AIDS from international donors—it does not make scene to invest money in control, if control measures, such as the travel ban, engender more stigma;
  - Policy should facilitate the integration of PLWHA into the community through providing job security for those who are physically fit.

7.8.2 Health system-level recommendations

- VCT—or any new HIV/AIDS service centres—should be integrated into other primary health centres to mitigate stigma.
- Mitigate stigma enacted by health care workers through:
  - Making HIV/AIDS service work optional for health care workers and volunteer workers should be welcomed and encouraged;
  - Hiring professionals from the MSM and PLWHA committees;
- Encourage interactions between PLWHA, HRGs and health care workers via social networks including counselling service and risk assessment;
- Promote ART actively through different channels;
- Rapid HIV tests should be introduced in the health system to avoid anticipated stigma through avoiding frequent visits and long waiting time to get the test results;
- Provide psychological and emotional support for PLWHA. These services should be provided by specialists, i.e., social workers, psychologist, and psychiatrists.

7.9 Future directions

Many aspects of HIV/AIDS in the MENA region require further research, however, political commitment and willingness to acknowledge the nature and extent of problems associated with HIV/AIDS is prerequisite to conducting any further research. Such commitment is needed on international, regional, and local levels.

In general, research in the region should be driven by the needs of the population rather researchers' interests. Explorative studies of HIV/AIDS in the region that focus on the social aspects of HIV/AIDS among PLWHA, HRGs, health care workers, and general population are necessary and can feed the development of further innovative research methodologies to explore priorities in HIV/AIDS control that are appropriate for the cultural settings.

Many dimensions that are critical to the regional HIV/AIDS context are not addressed in this thesis such as gender representations of sexuality and negotiation of gender roles in family, social networks, and Islamic society at large.

7.9.1 Future research

Other important aspects of HIV/AIDS control in the MENA region such as media and health system policies were acknowledged during the course of this thesis. Further research to address these two issues is planned accordingly for the near future.

HIV/AIDS and the media in the Arab World

Like many diseases, HIV/AIDS control contains a strong media component in its construction and presentation (Berridge, 1991; Reardon and Richardson, 1991). How the media represents a disease is significant not only in shaping perception and behaviour, but also in forming public and policy responses. The aim of this research is to identify and evaluate trends in media representations of HIV/AIDS with regard to public health policy and its potential influence on HIV/AIDS trends in the region. In collaboration with the Institute for Media Studies in the University of Basel, archival material containing media representations of HIV/AIDS in the region will be gathered and analysed them in terms of content, target audience, motivation, and likely impact on awareness, attitude, and behaviour.

Health Systems and HIV/AIDS in the MENA

The integration of HIV/AIDS services into national health systems and an evidence-based response to the epidemic are key factors for evaluating the situation and establishing a road map to effective control in the MENA region. In collaboration with the Health Systems

Research and Dynamical Modelling Unit at the Swiss TPH, the regional HIV international and regional grants portfolio will be summarised, and the appropriateness of funded interventions in the region with reference to the sociocultural context, the national control strategies, and the nature of the epidemic will be evaluated. The expected influence of international grants on the epidemic control and the health system response will also be investigated.

7.9.2 Current research gaps

- Cultural epidemiology studies in other countries within the region to validate the findings of this study;
- Basic epidemiological studies carried out entirely by NGOs to measure HIV prevalence among HRGs;
- Explanatory studies among HRGs to investigate obstacles for voluntary HIV testing;
- Research tools for evaluating interventions in the region, including:
  - Cost-effectiveness studies of VCT services and assessment of its role in behaviour change and prevention of HIV/AIDS;
  - Evaluation of HIV testing criteria in the MENA region and investigation of new testing policies especially among HRGs;
- Exploring religious leaders' ideologies and approaches to HIV/AIDS control in order to identify methods for their involvement in HIV/AIDS control;
- Assessment of the needs of PLWHA and their perceptions on applied interventions;
- Studies on ART uptake and adherence on a large scale to identify obstacles and build trends for interventions;
- Explanatory studies of HRGs to understand sexual behaviour and HIV/AIDS dynamics among these groups;
- Stigma research:
  - Research to identify appropriate tools and instruments to study stigma that can be easily administered and understood in the local and cultural context;
  - Qualitative studies to describe the nature and triggers of stigma among health care workers;

- Explorative studies to understand the aspects of stigma among HRG and its influence on prevention and control;
- Research on community-based stigma to identify its triggers and ways of its mitigation.

8

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9

Appendices

9.1 EMIC interview for people living with HIV/AIDS

Explanatory model interview for study of the cultural epidemiology of HIV/AIDS among PLWHA in Jordan

Swiss Tropical and Public Health Institute
Basel University
Basel, Switzerland

Jordan University of Science and Technology
Irbid, Jordan

March 2011

Introduction

Thank you very much for giving me time to talk with you. This interview has been constructed to learn about your health condition. We are interested in your ideas and opinions; therefore there are no correct or wrong answers. Our interview here is concerned only with public health therefore, everything you will tell me will remain confidential. But first I would like to ask few questions about yourself.

Background Information

1. Basic information

Subject Study No.	Date	Interview Start Time	
Nationality	Religion	Age	Sex
			M F

Current address		Urban	Rural
Place of birth	Country	City/Village	
Other spoken languages		[En,Fr,Ge,Sp,other]	
Occupation (Refer to 2.2)			
Marital status	Single Divorced	Widowed	married
If married male	Number of wives		
Number of children	Sons	Daughters	
Number of dependents			

2. Occupation

1. Business	2. House wife	3. Student	4. Teacher
5. Medical doctor	6. Pharmacist	7. Lawyer	8. Worker
9. Accountant	10. Restaurant owner	11. Shop owner	12. Unemployed
13. Skilled worker	14. Academic	15. Technician	16. Trader
17. Driver	18. Gov. employee	19. Banking	20. Other, specify

3. Education level

Years of school

1. Secondary school or less	2. High school (Tawjihi)	3. Diploma	4. Bachelor	5. Master, PhD or higher

Patterns of distress

4. At the beginning, what are the problems you have or had any point because of your illness? Please explain them to me. Subsequent

Narrative_____

Patterns of Distress	Spon	Probe	Current	Subsequent	Onset
Physical symptoms					
1. Weight loss					
2. Sores in mouth					
3. Thinning of hair					
4. Skin rashes					
5. Recurrent "flu"					
6. Weakness					
7. Loss of appetite					
8. Side effects of medication					
9. Fever					
10. Vomiting					
11. Headache					
12. Stomach ache					
13. Diarrhoea					
14. Sweating					
15. Nausea					
16. Difficulties in swallowing					
17. Other (specify)					
Social					
18. Social isolation					
19. Stigma – reduced social status					
20. Marital problems					
Financial problems					
21. Loss of job and wages					
22. Reduced income					
Psychological - Emotional					
23. Sadness, anxiety or worry					
24. Concern about of illness					
25. Concern about children					
Miscellaneous					
26. Other (specify_____)					
27. Cannot say					

5. What is/was the most troubling problem?

Code only one | |

Narrative_____

6. What was the course of each problem you described?

For each PD mentioned spontaneously or after probing ask the time period (Current, onset, subsequent).

Narrative_____

7. When was the first time you noticed this problem?

Years	Months	Weeks	Days

Narrative_____

8. At the beginning, what did you think the problem was?

Interviewer code **HIV/AIDS related:**	Yes (2)	Uncertain (1)	No(0)

Narrative_____

9. What outcome you thought this problem will have?

Full recovery	Chronic illness	Acute illness	Fatal	Could not tell

Narrative_____

10. How this problem did affect your feelings and emotions?

Narrative_____

11. How this problem did affect your social life and relations with family and friends?

Narrative_____

12. How this problem did affect your income?

Narrative_____

Help seeking behaviour

13. At the beginning of your problem did you go to or ask anybody for help?

Yes (3)	Possibly (2)	Uncertain (1)	No(0)

Narrative_____

14. To whom did you go?

Help Seeking List	Spon	Probe	Onset	Subsequent	Current
Medical					
1. General Doctor					
2. Specialised Doctor					
3. Pharmacist					
4. NGO Health clinic					
5. Private clinical					
6. VCT centre					
7. Treatment abroad					
8. Folk medicine					
9. Self-care					
Social					
10. Friends					
11. Family					
12. Imam or religious leaders					
Psychological					
13. Psychiatric					
14. Psychologist					
15. VCT counsellor					
16. Other (specify)					

Narrative_____

15. Which one of these you mentioned was the first?

16. Which one of these you found the most useful?

for each one code only

17. For those you have mentioned, can you explain to me when did you go and if you still seek help from them?

For each PD mentioned spontaneously or after probing ask the time period (Current, onset, subsequent).

Narrative_____

18. After how long did you go?

Years	**Months**	**Weeks**	**Days**

19. Why did you go to this option and not another?

Narrative_____

20. What did this person/group told you?

Narrative_____

21. Who diagnosed you with HIV?

HS Code	

22. When were you diagnosed?

Years	**Months**	**Weeks**	**Days**

23. When you knew it was AIDS what outcome you thought?

Full recovery	**Chronic illness**	**Acute illness**	**Fatal**	**Could not tell**

Narrative_____

24. ***If VCT NOT mentioned***, did you register as a patient at the VCT?

Yes (3)	**Possibly (2)**	**Uncertain (1)**	**No(0)**

Narrative_____

For the following questions if the "Help group" mentioned spontaneously or probed ask 25-27, if not ask 28-30.

25. Are you satisfied with the medical help you receive?

Strongly (4)	Very (3)	Normal (2)	Poorly (1)	Not at all (0)

Narrative_____

26. Are you satisfied with the social help you receive?

Strongly (4)	Very (3)	Normal (2)	Poorly (1)	Not at all (0)

Narrative_____

27. Are you satisfied with the psychological help you receive?

Strongly (4)	Very (3)	Normal (2)	Poorly (1)	Not at all (0)

Narrative_____

28. Why you don't seek medical help?

	No need (4)	Not available (3)	Stigma (2)	Cost (1)	No access (0)
Interviewer code					

Narrative_____

29. Why you don't seek social help?

	No need (4)	Not available (3)	Stigma (2)	Cost (1)	No access (0)
Interviewer code					

Narrative_____

30. Why you don't seek psychological help?

	No need (4)	Not available (3)	Stigma (2)	Cost (1)	No access (0)
Interviewer code					

Narrative_____

Perceived Causes

31. What you think caused your AIDS?

Narrative_____

Perceived Causes	Spon	Probe
Ingestion (food, drink, medicine)		
1. Bad food or water		
2. Western food		
3. Malnutrition		
4. Alcohol		
5. Smoking		
6. Drug consumption		
7. Illegal drug consumption		
8. Prescribed medicine		
9. Self-prescribed medicine		
10. Diet		
11. Injury, accident, surgery		
12. Prior illness		
13. blood transfusion		
14. Biological weapon		
15. Casual contact		
Pathogen		
16. HIV virus		
17. Bacteria		

Perceived Causes	Spon	Probe
Environmental		
18. Airborne		
19. Living outside		
20. Erosion		
21. Insecticide/ Herbicide		
22. Pollution		
Religious		
23. Test from Allah		
24. Fate or will of Allah		
Sexual activity		
25. Sexual content(unspecified)		
26. Pre-marital sex		
27. Adultery		
28. Sex with prostitutes		
29. Homosexuality		
30. Masturbation		
31. Sexual weakness		
32. Sex with animals		
33. Sex with foreigner		
Other (specify)		
34. Don't know/cannot tell		
35. Other, specify		

32. Among those you have mentioned, or something else, what is the most important cause?

One code only ☐

Narrative_____

Transmission, prevention and condom use

33. Can you transmit your condition to anyone?

Yes (3)	Possibly (2)	Uncertain (1)	No(0)

Narrative_____

If "Yes" or "Possibly" ask 34, if else go to 35.

34. How HIV can be transmitted?

Narrative_____

Perceived Transmission Routes	Spon	Probe
1. Sexual contact		
2. Food/ water		
3. Drug use		
4. Contact with body fluids		
5. Airborne		
6. Casual contact		
7. Blood transfusion		
8. Other (specify)		
9. Do not know		
11. None		

35. Can HIV/AIDS be prevented?

Yes (3)	Possibly (2)	Uncertain (1)	No(0)

Narrative_____

36. What measures you take to prevent the transmission to other people?

Narrative_____

Perceived Prevention Methods	Spon	Probe
1. Abstinence		
2. Condom use ***(Do not Probe)***		
3. Not sharing food/drinks		
4. Not sharing personal sharp objects		
5. None		
6. Other, specify		

37. Have you ever heard of condoms? (Asked if condoms were not mentioned spontaneously)

Yes (3)	Possibly (2)	Uncertain (1)	No(0)

Narrative_____

If yes or possibly ask 38-41, if else go to 42.

38. Can condoms prevent HIV transmission? (if condoms were not mentioned spontaneously)

Yes (3)	Possibly (2)	Uncertain (1)	No(0)

Narrative_____

39. Have you ever used a condom?

Yes (3)	Possibly (2)	Uncertain (1)	No(0)

Narrative_____

40. Did you use condoms last time you had sexual intercourse?

Yes (3)	Possibly (2)	Uncertain (1)	No(0)

Narrative_____

41. How often do you use condoms?

Always (2)	Sometimes (1)	Never (0)

Narrative_____

42. If use condoms sometimes or never, then why?

Condom use Obstacles	Spon	Probe
Cost		
Access		
Stigma related		
Not effective		
Reduced pleasure		
Religious reasons		
No need		
Other, specify		

43. Do you have access to condoms?

Yes (3)	Possibly (2)	Uncertain (1)	No(0)

Narrative_____

44. Where do you usually get them?

Condom sources	
VCT	
Pharmacy	
Supermarket	
Friends	
Other, specify	
No source	

45. Do you know what the price of condoms is?

Yes (3)	Possibly (2)	Uncertain (1)	No(0)
		Specify price if possible	

46. Do you think the price could be a problem for you?

Yes (3)	Possibly (2)	Uncertain (1)	No(0)

Narrative_____

Treatment and ART

47. Is there any drug that can cure or control your illness?

Yes (3)	Possibly (2)	Uncertain (1)	No(0)

Interviewer code: **ART related**	Yes (1)	No (0)

Narrative_____

48. Who informed you of this drug?

Help Seeking list code	
Other, specify	

Narrative_____

49. Are you now on this drug?

Yes (3)	Possibly (2)	Uncertain (1)	No(0)

Narrative_____

50. When did you start taking this drug?

Years	Months	Weeks	Days

51. Where do you get your medication?

Help seeking code	
Other, specify	

Narrative_____

52. What is your dose regimen?

Monthly	Weekly	Daily	Other, specify

Narrative_____

53. Do you always stick to your treatment schedule?

Always (2)	Sometimes (1)	Never (0)

Narrative_____

54. What kind of problems you have that are related to your treatment?

Narrative_____

ART Obstacles	Spon	Probe
10. Cost		
11. Access		
12. Stigma related		
13. Not effective		
14. Long distance		
15. Religious reasons		
16. No need		
17. Other, specify		

55. Are there any specific reasons which make you not to take this drug?

Narrative_____

ART Obstacles	Spon	Probe
18. Cost		
19. Access		
20. Stigma related		
21. Not effective		
22. Long distance		
23. Religious reasons		
24. No need		
25. Other, specify		

56. Are you currently on any other medications?

Yes (3)	Possibly (2)	Uncertain (1)	No(0)
Specify drug if possible			

Stigma and Support

57. If possible, would you prefer to prevent people from knowing about your illness?

Yes (3)	Possibly (2)	Uncertain (1)	No(0)

Narrative_____

58. Did you tell anyone about your condition, beside the person/s you seek help from?

Yes (3)	Possibly (2)	Uncertain (1)	No(0)

Narrative_____

59. Whom did you tell? Why?

Tick all apply

1. Father	
2. Spouse	
3. Mother	
4. Brother	
5. Sister	
6. Same sex friend	
7. Different sex friend	
8. Relative	
9. Health care professional	
10. Imam	
11. Other, specify	

Narrative_____

60. What was their reaction?

Positive	**Yes (3)**	**Possibly (2)**	**Uncertain (1)**	**No(0)**
Negative	**Yes (3)**	**Possibly (2)**	**Uncertain (1)**	**No(0)**

Narrative_____

61. Why you did not inform anyone about your illness?

Narrative_____

For the next questions ask in "Would" form if the subject has not told anybody, and in "Did" form if he has told people about his condition.

62. Would/Did telling anyone affect people's contact with you?

More contact	**Yes (3)**	**Possibly (2)**	**Uncertain (1)**	**No(0)**
Less contact	**Yes (3)**	**Possibly (2)**	**Uncertain (1)**	**No(0)**

Narrative_____

63. Would/Did your illness affect your job?

Positive	**Yes (3)**	**Possibly (2)**	**Uncertain (1)**	**No(0)**
Negative	**Yes (3)**	**Possibly (2)**	**Uncertain (1)**	**No(0)**

Narrative_____

64. Would/Did your illness, affect your marital status (if married), your ability to marry (if single)?

Positive	**Yes (3)**	**Possibly (2)**	**Uncertain (1)**	**No(0)**
Negative	**Yes (3)**	**Possibly (2)**	**Uncertain (1)**	**No(0)**

Narrative_____

65. Would/Did telling anyone affect your medical care?

Positive	**Yes (3)**	**Possibly (2)**	**Uncertain (1)**	**No(0)**
Negative	**Yes (3)**	**Possibly (2)**	**Uncertain (1)**	**No(0)**

Narrative_____

66. Would/Did telling anyone affect your social life and personal feelings?

Positive	**Yes (3)**	**Possibly (2)**	**Uncertain (1)**	**No(0)**
Negative	**Yes (3)**	**Possibly (2)**	**Uncertain (1)**	**No(0)**

Narrative_____

67. Would/Did telling anyone affect your decision to take/Not take ART or any treatment?

Positive	**Yes (3)**	**Possibly (2)**	**Uncertain (1)**	**No(0)**
Negative	**Yes (3)**	**Possibly (2)**	**Uncertain (1)**	**No(0)**

Narrative_____

68. Would/Did telling anyone affect your decision to use/Not use condoms treatment?

Positive	**Yes (3)**	**Possibly (2)**	**Uncertain (1)**	**No(0)**
Negative	**Yes (3)**	**Possibly (2)**	**Uncertain (1)**	**No(0)**

69. Do you think less of yourself because of this problem? Has it reduced your pride or self-respect?

Yes (3)	**Possibly (2)**	**Uncertain (1)**	**No(0)**

Narrative_____

70. Have you ever been made to feel shamed or embarrassed because of this problem, or are you concerned that might happen?

Yes (3)	**Possibly (2)**	**Uncertain (1)**	**No(0)**

Narrative_____

71. Will/Do your neighbours, colleagues or others in your community have less respect for you because of this problem, or (do you think they would if they knew about it)?

Yes (3)	**Possibly (2)**	**Uncertain (1)**	**No(0)**

Narrative_____

72. Do you feel others Will/ have avoided you because of this problem?

Yes (3)	**Possibly (2)**	**Uncertain (1)**	**No(0)**

Narrative_____

73. Would/Did telling anyone affect your family, relatives or friends either in a good way or a bad way?

Positive	**Yes (3)**	**Possibly (2)**	**Uncertain (1)**	**No(0)**
Negative	**Yes (3)**	**Possibly (2)**	**Uncertain (1)**	**No(0)**

Narrative_____

74. Would/Did telling anyone affect people's contact with your family?

More contact	**Yes (3)**	**Possibly (2)**	**Uncertain (1)**	**No(0)**
Less contact	**Yes (3)**	**Possibly (2)**	**Uncertain (1)**	**No(0)**

Narrative_____

Media related

75. What are the main sources of your knowledge about HIV?

Information sources	
1. TV	
2. Movies	
3. MOH	
4. VCT	
5. Newspapers	
6. Radio	
7. Health worker	
8. Religious leader	
9. Other, specify	

76. Of the various media you mentioned and others, how frequent do watch, read, or listen to them?

TV	**Daily**	**Weekly**	**Occasionally**	**Rarely**	**Never**
Radio	**Daily**	**Weekly**	**Occasionally**	**Rarely**	**Never**
Newspapers	**Daily**	**Weekly**	**Occasionally**	**Rarely**	**Never**
Movies	**Daily**	**Weekly**	**Occasionally**	**Rarely**	**Never**

77. Do you think that there is any programme or article that talks directly or indirectly about your illness? Can you specify one or some of them?

More contact	**Yes (3)**	**Possibly (2)**	**Uncertain (1)**	**No(0)**
Specified programs				

Narrative_____

78. What you think if their impact?

Positive	**Yes (3)**	**Possibly (2)**	**Uncertain (1)**	**No(0)**
Negative	**Yes (3)**	**Possibly (2)**	**Uncertain (1)**	**No(0)**

Narrative_____

79. Do you think media in its various forms should address HIV?

More (3)	**Same (2)**	**Less (1)**	**No(0)**

Narrative_____

80. In your opinion, is there any HIV/AIDS related focus that media should focus at?

Narrative_____

Closure

81. Can you tell me please, what are your priorities now regarding your condition and its effects on your life?

Narrative_____

82. What do you think should be done about HIV/AIDS in Jordan and the region in general?

Narrative_____

83. In your own words, is there any massage you would like to deliver?

Narrative_____

84. What was it like to talk to us?

Narrative_____

Finally I would like to thank you for your time and cooperation.

Interviewer comments: _____
_____

Interview end time | | |

9.2 EMIC interview for high risk groups

Explanatory model interview for cultural epidemiology study among selected High Risk Groups in Jordan

Swiss Tropical and Public Health Institute
Basel University
Basel, Switzerland

Jordan University of Science and Technology
Irbid, Jordan

March 2011

Introduction

Thank you very much for giving me time to talk with you. This interview has been constructed to learn about a health problem affecting people in the community. We are interested in your ideas about the problem which I will describe to you in few minutes. Our interview here is concerned with public health and everything you will tell me will remain confidential. But first I would like to ask few questions about yourself.

Background Information

1. Basic information

Subject Study No.					Date			Interview Start Time	
Nationality					Religion			Age	Sex
									M F

Current address		Urban	Rural
Place of birth	Country		City/Village
Other spoken languages		[En,Fr,Ge,Sp,other]	
Occupation (Refer to 2.2)			
Marital status	Single	Divorced	Widowed married
If married male	Number of wives		
Number of children	Sons		Daughters
Number of dependents			

2. Occupation

21. Business	22. House wife	23. Student	24. Teacher
25. Medical doctor	26. Pharmacist	27. Lawyer	28. Worker
29. Accountant	30. Restaurant owner	31. Shop owner	32. Farmer
33. Skilled worker	34. Academic	35. Technician	36. Trader
37. Driver	38. Gov. employee	39. Banking	40. Other, specify

3. Education level

Years of school

Secondary school or less	High school (Tawjihi)	Diploma	Bachelor	Master, PhD or higher

Introduction to the vignette interview process

I would like to tell you now about someone with a problem.

Vignette

Ahmad/Salam is 35 year old unmarried man/woman. He/she used to be social and active and was running a very good business. Since last year he/she started to lose a lot of weight, and then he/she was admitted to the hospital several times due to various infections. Ahmad/Salam lost a lot of weight, about 20 kg. He/she had no energy to work or to see friends. The following questions refer to the person I have just described

Illness meaning and experience

4. Can you recognise this disease? What would you call it?

Interviewer code **HIV/AIDS related:**	**Yes (2)**	**Uncertain (1)**	**No(0)**
Specify name if possible			

5. Have you ever seen anyone with this condition?

Yes (3)	**Possibly (2)**	**Uncertain (1)**	**No(0)**

Narrative_____

6. Have you ever heard about someone with this disease?

Yes (3)	**Possibly (2)**	**Uncertain (1)**	**No(0)**

Narrative_____

I can tell you now that Ahmad/Salam went for help at the beginning of their illness and he/she was diagnosed with AIDS

7. Have you ever heard about this disease?

Yes (3)	Possibly (2)	Uncertain (1)	No(0)

8. With the information you know, do you think HIV/AIDS is a big problem in Jordan?

Yes (3)	Possibly (2)	Uncertain (1)	No(0)

Narrative_____

9. With the information you know, do you think HIV/AIDS is a big problem in the region?

Yes (3)	Possibly (2)	Uncertain (1)	No(0)

Narrative_____

10. You know that some people consider you at high risk of getting HIV. Do you feel the same way?

Very high risk (4)	High risk (3)	Normal risk (2)	Low risk (1)	No risk (0)

Narrative_____

11. Are you personally afraid of getting HIV?

Yes (3)	Possibly (2)	Uncertain (1)	No(0)

Narrative_____

12. Does considering you by some as a high risk group bother you in any aspect?

Yes (3)	Possibly (2)	Uncertain (1)	No(0)

Narrative_____

Perceived Causes

13. How can somebody get AIDS? What cause it?

Narrative_____

Perceived Causes	Spon	Probe
Ingestion (food, drink, medicine)		
18. Bad food or water		
19. Western food		
20. Malnutrition		
21. Alcohol		
22. Smoking		
23. Drug consumption		
24. Illegal drug consumption		
25. Prescribed medicine		
26. Self-prescribed medicine		
27. Diet		
28. Injury, accident, surgery		
29. Prior illness		
30. blood transfusion		
31. Biological weapon		
32. Casual contact		
Pathogen		
33. HIV virus		
34. Bacteria		

Perceived Causes	Spon	Probe
Environmental		
23. Airborne		
24. Living outside		
25. Erosion		
26. Insecticide/ Herbicide		
27. Pollution		
Religious		
36. Test from Allah		
37. Fate or will of Allah		
Sexual activity		
38. Sexual content(unspecified)		
39. Pre-marital sex		
40. Adultery		
41. Sex with prostitutes		
42. Homosexuality		
43. Masturbation		
44. Sexual weakness		
45. Sex with animals		
46. Sex with foreigner		
Other (specify)		
47. Don't know/cannot tell		
48. Other, specify		

14. Among those you have mentioned, or something else, what is the most important cause?

One code only ☐

Narrative_____

Transmission and Prevention

15. Can HIV/AIDS be transmitted from one person to another?

Yes (3)	Possibly (2)	Uncertain (1)	No(0)

If "Yes" or "Possibly" ask 16, if else go to 17.

16. How HIV can be transmitted?

Narrative_____

Perceived Transmission Routes	Spon	Probe
10. Sexual contact		
11. Food/ water		
12. Drug use		
13. Contact with body fluids		
14. Airborne		
15. Casual contact		
16. Blood transfusion		
17. Other (specify)		
18. Do not know		
19. None		

17. Are there any actions that can increase the chance of getting AIDS?

Narrative_____

Risk behaviours	Spon	Probe
1. Multiple partners		
2. Unprotected sex		
3. Other, specify		

18. In the last year how many sexual partner did you have, if any?

19. On the other side, can HIV be prevented?

Yes (3)	Possibly (2)	Uncertain (1)	No(0)

Narrative_____

20. What preventive measures you personally take to prevent getting HIV?

Narrative_____

Perceived Prevention Methods	Spon	Probe
7. Abstinence		
8. Condom use (Do not Probe)		
9. Not sharing food/drinks		
10. Not sharing personal sharp objects		
11. None		
12. Other, specify		

21. Have you ever heard of condoms? (Asked if condoms were not mentioned spontaneously)

Yes (3)	Possibly (2)	Uncertain (1)	No(0)

Narrative_____

22. Can condoms prevent HIV transmission (if condoms were not mentioned spontaneously)

Yes (3)	Possibly (2)	Uncertain (1)	No(0)

Narrative_____

23. Have you ever used a condom?

Yes (3)	Possibly (2)	Uncertain (1)	No(0)

Narrative_____

If "Yes" or "Possibly" ask 24 and 25, if else go directly to 26

24. Did you use condoms last time you had sexual intercourse?

Yes (3)	Possibly (2)	Uncertain (1)	No(0)

Narrative_____

25. How often do you use condoms?

Always (2)	Sometimes (1)	Never (0)

Narrative_____

26. Why you do not use or inconsistently use condoms?

Narrative_____

Condom use Obstacles	
Cost	
Access	
Stigma related	
Not effective	
Reduced pleasure	
Religious reasons	
No need	
Other, specify	

27. Do you have access to condoms?

Yes (3)	Possibly (2)	Uncertain (1)	No(0)

Narrative_____

28. Where do you usually get them?

Condom sources	
VCT	
Pharmacy	
Supermarket	
Friends	
Other, specify	
No source	

29. Do you know what the price of condoms is?

Yes (3)	Possibly (2)	Uncertain (1)	No(0)
		Specify price if possible?	

Narrative_____

30. Do you think the price could be a problem for you?

Yes (3)	Possibly (2)	Uncertain (1)	No(0)

Narrative_____

Help-seeking

31. Have you ever sought help for HIV/AIDS?

Yes (3)	Possibly (2)	Uncertain (1)	No(0)

Narrative_____

If "Yes" or "Possibly" go to 7.2-7.5, if else go to 7.6

32. To whom did you go?

Narrative_____

Help Seeking List	Spon	Probe	Help Seeking List	Spon	Probe
Medical			***Social***		
10. General Doctor			17. Friends		
11. Specialised Doctor			18. Family		
12. Pharmacist			19. Imam or religious leaders		
13. NGO Health clinic			***Psychological***		
14. Private clinical			20. Psychiatric		
15. VCT centre			21. Psychologist		
16. Treatment abroad			22. VCT counsellor		
17. Folk medicine			23. Other (specify)		
18. Self-care					

33. Which one of these you mentioned was the first?

34. Which one of these you found the most useful?

35. What kind of helps you were offered?

Narrative_____

Help Category	Spon	Probe
Medical help		
Drug therapy		
HIV testing (Do not probe)		
Psychological help		
Financial help		
Behavioural change help		
Other,		

36. Why you never sought for help?

Narrative_____

HIV testing and Treatment

37. Have you ever tested for HIV?

Yes (3)	Possibly (2)	Uncertain (1)	No(0)

Narrative_____

If "Yes" or "Possibly" go to 38-44-, if else go to 45

38. How many times have you tested for HIV?

Narrative_____

39. How did you test for HIV?

Voluntary (3)	Compulsory (2)	Uncertain (0)

Narrative_____

40. Who recommended the test for you?

Help seeking code	
Other, specify	

Narrative_____

41. Where did you have your test/s?

Help seeking code/s			
Other, specify			

Narrative_____

42. When tested, did you have any troubles? What kind of troubles?

Yes (3)	**Possibly (2)**	**Uncertain (1)**	**No(0)**

Narrative_____

43. Will you test again for HIV?

Yes (3)	**Possibly (2)**	**Uncertain (1)**	**No(0)**

Narrative_____

44. Do you know if HIV testing is available in Jordan?

Yes (3)	**Possibly(2)**	**Uncertain (1)**	**No(0)**

Narrative_____

45. Can you name a place where the test is available?

Type of place ***(Interviewer code, private, Gov., NGO)***	

Narrative_____

46. Why you never tested for HIV?

Narrative_____

HIV Testing Obstacles	
1. Cost	
2. Access	
3. Availability	
4. Stigma related	
5. Distance to place	
6. I don't need the test	
7. I don't trust the test	
8. Other, specify	

47. Do you know if there any treatment or drug that can cure or control HIV?

		Yes (3)	Possibly(2)	Uncertain (1)	No(0)
Interviewer code	**ART related**	**Yes (2)**	**Uncertain (1)**	**No (0)**	

Narrative_____

48. With the best available treatment in the world for HIV before clinically serious AIDS, what is the most likely outcome?

1. Death within one year	
2. Death within three years	
3. Death within five years	
4. Living normal life spam with signs and symptoms	
5. Living normal life spam without signs and symptoms	
6. Complete cure	

Narrative_____

Stigma and Support

49. Are you afraid of getting AIDS?

Yes (3)	Possibly (2)	Uncertain (1)	No(0)

Narrative_____

God forbids, if you ever get HIV/AIDS regardless of the cause

50. Will you tell anyone about your condition, beside the person/s you seek help from?

Yes (3)	Possibly (2)	Uncertain (1)	No(0)

Narrative_____

51. Who would you tell? Why?

Help seeking code/s			
Other, specify			

Narrative_____

52. If people know about your illness do you think will have more or less contact with you?

More contact	**Yes (3)**	**Possibly (2)**	**Uncertain (1)**	**No(0)**
Less contact	**Yes (3)**	**Possibly (2)**	**Uncertain (1)**	**No(0)**

Narrative_____

53. Would telling anyone about your condition affect your medical condition?

Positive	**Yes (3)**	**Possibly (2)**	**Uncertain (1)**	**No(0)**
Negative	**Yes (3)**	**Possibly (2)**	**Uncertain (1)**	**No(0)**

Narrative_____

54. Would telling anyone about your condition affect your social status?

Positive	**Yes (3)**	**Possibly (2)**	**Uncertain (1)**	**No(0)**
Negative	**Yes (3)**	**Possibly (2)**	**Uncertain (1)**	**No(0)**

Narrative_____

55. Would your illness affect your job?

Positive	**Yes (3)**	**Possibly (2)**	**Uncertain (1)**	**No(0)**
Negative	**Yes (3)**	**Possibly (2)**	**Uncertain (1)**	**No(0)**

Narrative_____

56. Would you think less of yourself because of this problem? Will it reduce your pride or self-respect?

Yes (3)	**Possibly (2)**	**Uncertain (1)**	**No(0)**

Narrative_____

57. If people know about your illness, will that affect your family, relatives and friends either in a good way or a bad way?

Positive	**Yes (3)**	**Possibly (2)**	**Uncertain (1)**	**No(0)**
Negative	**Yes (3)**	**Possibly (2)**	**Uncertain (1)**	**No(0)**

Narrative_____

58. If people know about your illness do you think will have more or less contact with your family?

More contact	**Yes (3)**	**Possibly (2)**	**Uncertain (1)**	**No(0)**
Less contact	**Yes (3)**	**Possibly (2)**	**Uncertain (1)**	**No(0)**

Narrative_____

Media related

59. What are the main sources of your knowledge about HIV?

Information sources	
10. TV	
11. Movies	
12. MOH	
13. VCT	
14. Newspapers	
15. Radio	
16. Health worker	
17. Religious leader	
18. Other, specify	

60. Of the various media you mentioned and others, how frequent do watch, read, or listen to them?

TV	**Daily**	**Weekly**	**Occasionally**	**Rarely**	**Never**
Radio	**Daily**	**Weekly**	**Occasionally**	**Rarely**	**Never**
Newspapers	**Daily**	**Weekly**	**Occasionally**	**Rarely**	**Never**
Movies	**Daily**	**Weekly**	**Occasionally**	**Rarely**	**Never**

61. Do you think that there is any programme or article that talks directly or indirectly about HIV? Can you specify one or some of them?

More contact	**Yes (3)**	**Possibly (2)**	**Uncertain (1)**	**No(0)**
Specified programs				

Narrative_____

62. What you think if their impact?

Positive	**Yes (3)**	**Possibly (2)**	**Uncertain (1)**	**No(0)**
Negative	**Yes (3)**	**Possibly (2)**	**Uncertain (1)**	**No(0)**

Narrative_____

63. Do you think media in its various forms should address HIV?

More (3)	Same (2)	Less (1)	No(0)

Narrative_____

64. In your opinion, is there any HIV/AIDS related focus that media should focus at?

Narrative_____

Closure

65. What do you think should be done about HIV/AIDS in Jordan and the region in general?

Narrative_____

66. What was it like to talk to us?

Narrative_____

Finally I would like to thank you for your time and cooperation.

Interviewer comments: _____

_____

Interview end time | | |

9.3 Curriculum Vitae

Personal Information

Name	Abdulsalam Alkaiyat
Nationality	Palestinian
Place and date of birth	Nablus (Palestine); September 9, 1981
Email	abdulsalam.alkaiyat@unibas.ch

Education

2010-2013	PhD in Epidemiology, Swiss Tropical and Public Health Institute, Basel University, Basel–Switzerland.
2007-2009	Master in Epidemiology, Swiss Tropical Institute, Basel University, Basel–Switzerland
2005-2006	Training in Molecular Pharmacy, Basel University and Novartis Institute For Biomedical Research, Basel-Switzerland.
2000-2005	Bachelor of Pharmaceutical Sciences, Al-Najah University, Nablus-Palestine
1999	Tawjihi Diploma, Scientific Stream, Nablus-Palestine

Work experience

2009	Local consultant, Swiss International Health Centre, Basel-Switzerland
2006-2007	Research assistant, Faculty of Medicine, University of Jordan, Amman -Jordan
2005-2006	Diploma student, Novartis Institute for Biomedical Research, Basel-Switzerland
2003-2005	Pharmacist, Al-Kamal Community Pharmacy, Nablus-Palestine
1999-2001	Manager, AllNet Internet Cafe, Downtown Nablus-Palestine

Publications

Alkaiyat A, Schaetti C, Liswi M, Weiss MG. (2014) Condom use and HIV testing among MSM in Jordan. *Journal of the International AIDS Society* 17: 18573.

Alkaiyat A and Weiss MG. (2013) HIV in the Middle East and North Africa: Priority, control and culture. *International Journal of Public Health* 58 (6): 927-37.

Alkaiyat A, Liswi M, Batieha A, Weiss MG. (2014) HIV/AIDS-related stigma among people with HIV/AIDS in Jordan. (under review)

Alkaiyat A, Liswi M, Batieha A, Weiss MG. (2012) Diagnosis, help seeking, treatment uptake and adherence to antiretroviral therapy for HIV/AIDS in Jordan. (under review)

Sweileh W, Alkaiyat A, Jaradat N. (2004) Typical and Atypical Antipsychotic Drug Utilization in a Psychiatric Clinic in Palestine. *An Najah University Journal for research in Natural Sciences* 01/2004: 18

Memberships

Global Network of Researchers on HIV/AIDS in the MENA Region

Arab Human Rights Organisation, Jordan and Egypt

Palestinian Haemophilia Association, Ramallah-Palestine

Arab Thought Forum, Amman-Jordan

Union of Pharmacists, Nablus-Palestine

Palestinian Red Cross, Nablus-Palestine

Seeds of Peace, New York-USA