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***Proceedings of the 6th
International Conference
on Health Issues in
Arab Communities***

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EDITOR'S CORNER

ACCESS Health Journal: Investigating, Educating and Improving Health

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When immigrants settle in an adoptive land, they experience socio-economic transformation that directly impacts their health, often in a negative manner. It is the responsibility of public health and medical authorities to evaluate and attempt to offset these detrimental effects on the health of the community. This has been one of the missions of ACCESS since its inception in 1976. This undertaking by ACCESS has been complicated by the fact that Arabs in the United States are not considered a minority. It is not possible through systematic analysis of data collected by federal and state agencies to understand the health status and health needs of Arab communities in the United States. Despite this limitation, ACCESS has been striving to fill this gap in knowledge through the stimulation of research, the documentation of outcomes, and the facilitation of collaboration and dialogue among scientists interested in the health of Arab communities.

ACCESS' approach has been implemented via close coordination of the activities of three distinct entities: ACCESS Community Health and Research Center, the International Conference on Health Issues in Arab Communities, and ACCESS Health Journal. Each of these entities has contributed individually to the understanding of the status and health needs of Arab communities. Each of these entities has also complemented the efforts of the other two. The outcome has been a steady improvement in our understanding of existing health conditions and health needs in Arab communities, promotion of thriving research directed at improving health within Arab communities, and collaborative efforts to link clinicians and scientists involved in the health of immigrant communities with their counterparts throughout the Arab world.

At the ACCESS Community Health and Research Center, innovative research and clinical programs have been administered in Southeast Michigan in two clinical centers operated by ACCESS in Dearborn and Sterling Heights, Michigan. The clinical services have been instrumental in providing badly

Continued on next page

ACCESS Health Journal: **Investigating, Educating and Improving Health**

(continued from page 1)

needed medical and mental health services to low income families (mostly immigrants). The research programs have resulted in the acquisition of numerous grants to help improve the health of Arab Americans, understand their needs, and integrate preventive and improved health style strategies into their daily lives. These concerted efforts have ensured the growth of evidence-based public health research in the Arab American community, and those efforts have revealed valuable information regarding Arab health.

To bring forth meaningful changes in the area of public health in Arab communities, ACCESS has hosted a series of international conferences focused on health issues in Arab communities since 1999. These conferences have brought together international and local thought leaders and experts from the United States, the Arab World, Europe, Africa, and Australia who shared data and knowledge in various areas of healthcare, including social determinants of health, quality of health care, chronic diseases, mental health conditions, genetics, and social and environmental factors affecting Arab health. The conferences have tackled important global research topics, encouraged dialogue among regional health leaders, and paved the foundation for international partnerships. These efforts set the stage for medical and public health experts to establish international and regional cooperation and stronger institutions to build a medical and public health sector that can overcome deep-seated regional challenges.

The third component of ACCESS's strategy to improve the health of Arab communities is the promotion of health education and communication. A large number of educational activities organized and coordinated by ACCESS are held regularly to benefit health professionals and lay people alike. Perhaps one of the most important educational tools that have been implemented is the *ACCESS Health Journal*, an electronic peer-reviewed publication that is easily distributed to our communities on a global scale. This journal is a vehicle to document the proceedings of the ACCESS international conferences. It is also a forum for professionals to disseminate knowledge to Arab communities about health style modifications and social determinants of health. In addition, it is a platform for documentation of the positive outcomes of

intervention efforts, and the striking improvement in compliance with preventative health care strategies that Arab communities deserve.

We are proud to publish this issue of *ACCESS Health Journal*. This is not only a valuable documentation of the innumerable evidence-based studies on the health status of Arab communities, but also serves as a testament to our commitment to the medical and mental health of our constituents. By clearly identifying health challenges in Arab communities, and detailing how we are confronting them and what the outcomes of our interventions are, this journal is setting the stage for a future free of preventable diseases in Arab communities. We strive to chronicle scientific and clinical progress and demonstrate that commitment to health will yield favorable outcomes.



This particular issue serves as the Proceedings of the 6th International Conference on Health Issues in Arab Communities held at the Dearborn Inn during the month of October, 2012. All of the articles and abstracts have been peer reviewed and edited in accordance with the format of this journal. The issue is structured to mimic the format of the conference. The articles have been divided into various sections representing the general themes of the conference. In addition to full-text articles, we have included abstracts of sessions that we felt needed to be highlighted and shared with all our audience. We have also invited several international experts to submit editorials that reflect the state of knowledge regarding themes that are relevant to a deeper understanding of health and well-being within Arab communities. We trust you will find these articles enlightening, and hope this journal will stimulate further research and involvement in the health of Arab communities throughout the world.

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The Patient-Centered Medical Home: The Promise, the Evidence and the Michigan Demonstration Project

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Key words: *Patient-centered care, medical home*

The patient-centered medical home (PCMH) is both a concept and a medical care setting. Conceptually, it is fundamentally a set of principles related to evidence-based care, team care, improved access, care coordination, and payment aligned with value rather than volume.

- The PCMH is under intense scrutiny in the US, viewed by health planners as a potential way to reinvigorate interest in the primary care profession to address the shrinking workforce.
- The PCMH is viewed by primary care physicians as an opportunity—and a challenge—that expects them to transform their operations (and their mind-set) while also running a busy practice that sees many patients every day.
- The PCMH is viewed by patients and consumers as an opportunity to participate in shared decision-making about their health and healthcare with their physician and practice team.
- The PCMH is viewed by public health professionals as a means to improve population health by coordinating the currently fragmented medical care delivered to individuals and families.
- The PCMH is viewed by purchasers, policymakers, and increasing numbers of payers as a promising way to increase efficiency improve quality, and lower health care costs.

Many are watching the numerous demonstrations and pilot projects currently underway across the country that are testing the promise of the PCMH model, hoping to see evidence of better health outcomes, increased satisfaction of both patients and their primary care physicians and staff, and—especially—reduction of unsustainably high health care costs. While not yet considered definitive, such evidence is mounting.

International Health Care Comparisons

Before reviewing the evidence for the PCMH, it may be useful to understand the context in which the model has evolved in the United States.

Unlike most other countries, health systems in the US have been typically focused on care delivered by sub-specialists rather than by primary care providers. Primary care in the US is widely viewed as in dire need of improvement.

Overall, healthcare in the United States in comparison to other countries can be captured simply: higher costs without better outcomes. According to the Commonwealth Fund, health care spending in the US in 2008 towered over the comparison countries, both in per capita (\$7,538) spending and as a percentage of gross domestic products (16%). In contrast, the median per capita cost in ten comparison industrialized countries was \$2,995

and the percentage of gross domestic product was 8.7%.¹ Numerous studies suggest that major reasons for higher spending include substantially higher prices, more fragmented care delivery that leads to duplication of resources, and extensive use of poorly coordinated specialists.

With regard to quality of care, the US had among the highest rates of hospital admissions for five chronic conditions (asthma, congestive heart failure, diabetes, chronic obstructive pulmonary disease, and hypertension) and the greatest number of lower-extremity amputations due to diabetes. Despite spending more on healthcare than any other country, the United States lags behind on a number of indicators of health system performance.^{2,3} Given the multiple contributors to health outcomes, it remains a challenge to assess the contribution of health care to population health. One approach that provides a useful approximation is the concept of amenable mortality, i.e., deaths that should not occur in the presence of timely and effective health care.⁴ The key issue is the prevention of death. For example, although the acquisition of tuberculosis is largely driven by socioeconomic conditions, timely treatment is effective in preventing death. The number of deaths from diabetes also provides a yardstick of access—or the lack of it—to effective care.

The concept of amenable mortality has been applied widely as a way to assess the quality of care across countries and over time. A current study using this concept⁵ indicates that, between 1999 and 2007, the US increasingly lagged behind in comparison to France, Germany, and the United Kingdom. Americans under age 65 during this period had elevated rates of amenable mortality compared to their peers in Europe. For American men over age 65, amenable mortality rates during this period fell by 18.5 percent in the United States compared to a 37 percent decline in the United Kingdom. Among women age 65+, the US rates fell by 18 percent while those in the United Kingdom fell by 32 percent.

With chronic diseases on the rise as the post-World War II “baby boomers” in the US reach retirement age, there is strong interest in the PCMH model as an opportunity to assure more effective treatment and coordination of care to improve health status and prevent the unnecessary use of scarce and expensive resources.

History of the Patient-Centered Medical Home

The term “medical home” was first used by the American Academy of Pediatrics in 1967 to describe the concept of a single centralized source of care and medical record for children with special health care needs.⁶ In 2007, a Joint Agreement was signed by the leading national primary care associations affirming a set of seven principles of the “patient-centered medical home.”⁷

The current concept of PCMH is based on many years of efforts to redesign primary care to provide the highest possible quality of care. The cornerstone of the PCMH is the Chronic Care model, a model for organizing chronic illness care associated with improved health outcomes.⁸ Most studies of the Chronic Care model have focused on single diseases or conditions. The PCMH builds on this model but is intended to address the full range of patient-focused health care needs.

Even though definitive evidence is lacking about the impact of the PCMH on quality of care and cost, the PCMH model has been endorsed by most national health insurers, most Fortune 500 companies, consumer organizations, labor unions, and most relevant medical specialty associations. Nearly every American state is currently involved in implementing PCMH to some degree, from small pilot projects to passage of state laws or regulations incentivizing practices to create a PCMH. Forty-one states currently have adopted policies or initiated programs intended to advance the medical home model of primary care that provides whole-person, accessible, comprehensive, ongoing and coordinated patient-centered care.⁹

1 Squires, D. (2011, July). *The US health system in perspective: A comparison of twelve industrialized nations*. Commonwealth Fund Publication 1532, Vol. 16.

2 Fuchs, V. (2010). Government payment for health care: Causes and consequences. *N. Engl. J. Med.*, 363, 2181-2183.

3 Muennig, P. A. et al. (2011). What changes in survival rates tell us about US healthcare. *Health Aff.*, 29(11), 2105-2113.

4 Nolte, E., & McKee, M. (2004). *Does healthcare save lives? Avoidable mortality revisited*. London: Nuffield Trust.

5 Nolte, E., & McKee, M. (2012). In amenable mortality—Deaths avoidable through health care—Progress in the US lags that of three European countries. *Health Aff.*, 31(9), 2114-2122.

6 Sia, C., Tonniges, J. H. et al. (2004). History of the medical home concept. *Pediatrics*, 113(5 Suppl.), 1473-1478.

7 AAFP, AAP, ACP, & AOA. (n.d.). *Joint principles of the patient centered medical home*. <http://www.pcpcc.net/content/joint-principles-patient-centered-medical-home>

8 Wagner, E. H., Glasgow, R. E. et al. (2001). Quality improvement in chronic illness care: A collaborative approach. *Joint Commission Journal of Quality Improvement*, 27(2), 63-80.

9 <http://nashp.org/med-home-map>

Primary Care Workforce

Another important aspect of US healthcare is the shrinking primary care workforce. There are many reasons cited to explain this, but the most important likely are:

- A large percentage of current primary care physicians are nearing retirement age. Only about 8 percent of medical school graduates are choosing to become primary care physicians.
- Primary care physicians have significantly lower incomes than sub-specialists.
- Healthcare cost controls have reduced reimbursement rates even further for primary care physicians, requiring them to see more and more patients per day in order to sustain their practice, leading to a poorer quality of work life and “burn-out.”

All of the above explanations result in reduced access to primary care services for growing numbers of US citizens, particularly those living in rural areas and inner cities. The new US healthcare reform law (i.e., Patient Protection and Affordable Care Act) offers some relief in the form of additional payments for primary care services and incentives to medical students to choose a primary care residency. However, the law is controversial and the upcoming US election could impact how—or even whether—this law is implemented.

Definition of the Patient-Centered Medical Home

Numerous definitions and variable features of the PCMH exist. Building on the work of many, and attempting to standardize aspects of the model, the US Agency for Healthcare Research and Quality (AHRQ)¹⁰ declares that the PCMH is a model of organization of primary care that delivers five core functions of primary care, defined as follows:

- *Comprehensive care* means that the PCMH is designed to meet the majority of a patient’s physical and mental health care needs including health promotion and preventive care as well as acute and chronic care needs. This is provided through a team-based approach to care, involving multi-disciplinary health professionals: i.e., nurses, dietitians, behavioral health professionals, pharmacists, health educators, etc., in addition to primary care clinicians: i.e., physicians, physician assistants, and nurse practitioners.
- *Patient-centeredness* means that primary care is oriented towards the whole person, and involves partnering with the patient and family for shared decision-making, delivered in ways that reflect an understanding of and respect for the patient/family’s culture, unique needs, preferences, and values.
- *Coordinated care* means that patient care is coordinated across all parts of the healthcare delivery system including community care, hospital care, specialist care, long-term care, and home health care, with a strong emphasis on assuring timely and safe transitions to different care settings.
- *Accessible services* means that there are shorter waiting times for urgent needs, appointment scheduling options before and/or after normal office hours and/or weekend access, and around-the-clock telephone access to a member of the care team.
- *Quality and safety* means there is a commitment to evidence-based medicine, quality improvement, and population health management.

The AHRQ also recognizes three Foundational Supports required to build and sustain the PCMH, including:

- The central role of *health information technology* (i.e., electronic health records; all-patient, all-payer registries; portals for patients to access their PCMH and their medical data) for successfully operationalizing and implementing key functions of the medical home
- The requirement for significant *additional workforce development* (i.e., primary care physicians, nurse/social worker care managers, dentists, behavioral health specialists, health coaches, community health workers)
- The urgent need for *fundamental payment reform* to correct the longstanding misalignment of incentives for primary care services and for covering the costs of implementing the PCMH model

10 AHRQ Publication No. 12-0020-EF, February 2012.

PCMH Certification Options

How do employers or payers or consumers know which primary care practices are patient-centered medical homes? The answer is that these practices choose to become certified (or designated or recognized) by well-regarded national or state or private accreditation programs. According to a recent analysis by the Urban Institute of seven national certification programs and several state programs,¹¹ the features of the PCMH that determine certification (and the weighting of those features) are quite variable across these programs. PCMH features or functions are listed below, with the order of the list reflecting the most-frequent to the least-frequent requirements that appear in these certification programs):¹²

1. Coordination of care
2. Electronic health IT
3. Quality measurement
4. Patient engagement
5. Self-management education
6. Written policies
7. Population management
8. Access to care
9. Quality improvement
10. Care plan
11. Evidence-based care
12. Culturally-competent communications
13. Medical records
14. Comprehensiveness of care
15. Multi-disciplinary team-based care
16. Community resources
17. Continuity of care
18. Compact between practice and patient re PCMH

One consequence of such variability in the features of the PCMH is to complicate evaluation of this model. The Commonwealth Fund established the Patient-Centered Medical Home Evaluators' Collaborative in 2009, charging 75+ researchers with reaching consensus on a standard core set of outcome measures and instruments.¹³ The Center for Medicare and Medicaid Services (CMS) is currently supporting a variety of studies of the PCMH model, in spite of the challenges of variable definitions, interventions, and evaluation designs. One of those studies is underway in Michigan and will be described in detail later.

Evidence in the Literature about PCMH

Grumbach and Grundy¹⁴ reviewed available prospective, controlled studies of PCMH interventions and concluded that investing in PCMH in primary care settings appears to result in improved quality of care and patient experiences and reductions in primary care-sensitive emergency department utilization and hospitalizations. They further concluded that evidence was beginning to accumulate that investments in primary care can bend the cost curve, with several major evaluations showing that PCMH initiatives have produced a net savings in total health care expenditures for the patients served by these initiatives.

An article published in *Health Affairs* in May 2010¹⁵ reviewed seven successful PCMH models and identified four features common to all these models: (1) the use of dedicated care managers, (2) expanded access to health practitioners, (3) data-driven analytic tools, and (4) the use of incentives to drive care transformation.

11 National Center for Quality Assurance (NCQA) Standards, 2008 and 2011; Joint Commission PCMH Designation; Utilization Review Accreditation Commission; (URAC) Patient-Centered Health Care Home; TransformMED Medical Home Implementation Quotient; Center for Medical Home Improvement Medical Home Index; Minnesota Health Care Home Certification Program; Oklahoma SoonerCare (Medicaid) PCMH Program; Blue Cross/Blue Shield of Michigan PCMH Designation Program.

12 Urban Institute Health Policy Center. (2012, March). *PCMH recognition tools: A comparison of ten surveys' content and operational details*.

13 Rosenthal, M. B., Abrams, M. K. et al. (2012, May). *Recommended core measures for evaluating the patient-centered medical home: Cost, utilization, and clinical quality*. Commonwealth Fund Publication 1601, Vol. 12.

14 Grumbach, K., & Grundy, P. (2010, November). *Outcomes of implementing patient centered medical home interventions*. http://www.pcpcc.net/files/evidence_outcomes_in_pcmh.pdf

15 Fields, D., Leshen, E. et al. (2010, May). Driving quality gains and cost savings through adoption of medical homes. *Health Affairs*, 29(5), 819-826.

More definitively, however, the Agency for Healthcare Research and Quality commissioned an electronic and manual literature search that identified 5,086 articles studying the PCMH.¹⁶ Their 2012 screening process and subsequent rating process identified 58 unique studies that met all inclusion criteria to permit an assessment of the strength of evidence on the effects of the PCMH on patient and staff experiences, process of care, clinical outcomes, and economic outcomes. They noted that rating the strength of evidence for these studies was quite challenging because of the range of study designs, populations, variable interventions under the label of PCMH, and study outcomes. Their findings:

- Evidence is moderately-strong that the medical home improves the patient experience with care and receipt of preventive care services.
- Evidence is less robust but suggests that the medical home improves the staff experience.
- Evidence is low for an association between PCMH and lower health care utilization (a combination of inpatient and emergency department use).
- Current evidence is insufficient to determine the effect on clinical and most economic outcomes.
- Current studies are likely underpowered to assess the cost outcome.

Michigan's PCMH Demonstration Project

As noted earlier, the state of Michigan is involved in a major Medicare- and Medicaid-supported demonstration project, the Multi-Payer Advanced Primary Care Practice (MAPCP). Michigan is one of eight states participating in this three-year multi-payer PCMH demonstration. Michigan's Primary Care Transformation (MiPCT) Demonstration project is the largest PCMH demonstration in the nation.

Primary care practices participating in the MiPCT project were required to:

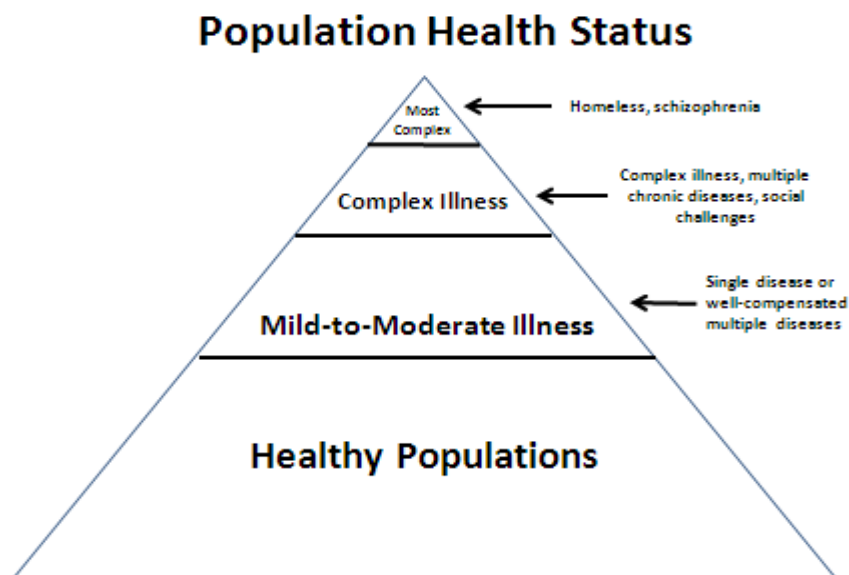
- Be part of an existing Michigan physician organization (PO) or physician hospital organization (PHO)
- By July 1, 2010, have received PCMH recognition either through BCBSM's PGIP-PCMH program or from NCQA's Level 2 or 3 designation program
- Maintain their PCMH recognition or designation throughout all three years of the demonstration
- Sign a participation contract with the Michigan Department of Community Health and meet specified MiPCT requirements

MiPCT Demonstration Project participants currently include 400 primary care practices located throughout the state, involving 1,700+ physicians, 36 physician organizations, and four major payers. The project expects to serve approximately 1 million Michigan residents per year—patients attributed to Medicare, Medicaid Managed Care, Blue Cross Blue Shield of Michigan, and Blue Care Network.

The Intervention

As noted in the Figure 1, the MiPCT approach to population management encompasses patients at all stages of health. The goal of the Michigan Transformation Project is to improve overall population health via risk reduction for healthy individuals, self-management support to prevent patients with moderate chronic disease levels from progressing to the complex category, care management and coordination of care across health settings for patients with complex chronic diseases and/or complex social needs, and coordinated end-of-life care.

¹⁶ The patient-centered medical home: Closing the quality gap—Revisiting the state of the science—Executive summary. (2012, July). *Evidence Report/Technology Assessment*, No. 208. AHRQ Publication No. 12-E008-1.

Figure 1. Status of Patients at All Stages of Health

Recognizing that no two practices are alike, MiPCT allows flexibility in meeting the project goals. In order to participate, practices are expected to create an individualized plan to demonstrate a focus on four specific MiPCT functions and also achieve required PCMH infrastructure; these are defined and discussed on the following pages. One of the most important interventions of the MiPCT is the hiring and training of moderate care and complex care managers and embedding them within each practice's primary care team to take responsibility for care management, care coordination, and self-management education and support for the practice's panel of patients.

It is fortunate that the majority of patients seen in primary care settings (i.e., estimated at 55%) are considered to be in the healthy category, requiring only occasional acute care visits, encouragement for healthy lifestyles, and age-appropriate preventive screening for risk factors and early detection of disease—all relatively inexpensive interventions. The goal of population health in MiPCT is to keep the healthy from progressing to chronic illnesses and to keep those with mild to moderate illnesses (estimated at 35%) from developing additional chronic conditions and/or associated complications that require more complex and more expensive care management. The majority of healthcare spending in the US as well as in Michigan is on the estimated 3-8% of patients with complex or very complex medical and/or social situations. Control of healthcare costs requires early identification of patients at risk and giving them appropriate assistance in the primary care setting and the community to prevent ambulatory care-sensitive hospitalizations and preventable emergency department visits.

The overarching goal of the Michigan PCMH demonstration is to achieve the "Triple Aim": improved health status, improved satisfaction of patients and providers, and reduced healthcare costs.¹⁷

Michigan's Transformation Project is built on the extensive PCMH work created and underwritten over the past six years by Blue Cross Blue Shield of Michigan (BCBSM), the state's largest insurer. A citation below¹⁸ is included to illustrate the extensive guidance provided by BCBSM to physician organizations (POs) or physician-hospital organizations (PHOs) and their PCMH-designated primary care practices.

The MiPCT Demonstration aims to: align financial incentives for physicians across payers; improve the management of chronic care conditions through evidence-based decision-prompts in electronic record systems and the addition of well-trained care managers into every practice; encourage each member of the healthcare team to work at the top of his/her license; achieve at least budget neutrality (if not cost-savings) for all participating payers; address end-of-life issues through training of primary care physicians and consistent interventions related to advanced directives and palliative care; and

17 Berwick, D. et al. (2008, May-June). *Health Affairs*, 27(3), 759-769.

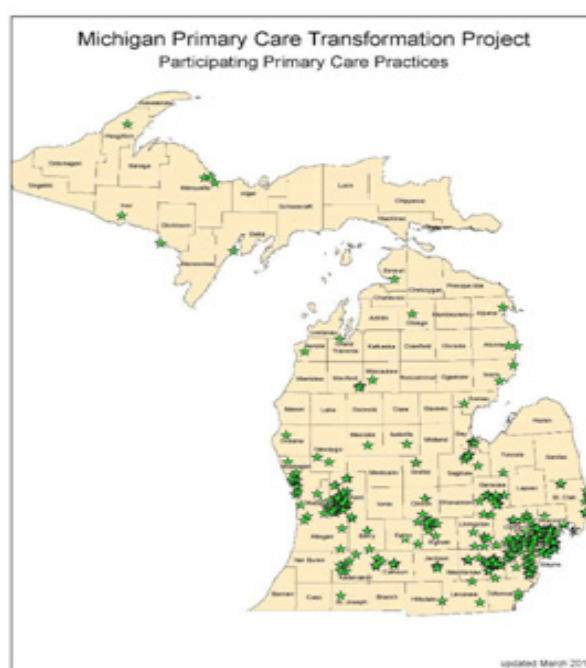
18 BCBSM, <https://www.bcbsm.com/pdf/PCMH-and-PCMH-N-Interpretive-Guidelines-2012-2013-Final.pdf>

ensure that all participating POs and PHOs that support their participating practices have common training, expectations and reporting mechanisms.¹⁹ POs and PHOs are responsible to assist with implementation of the MiPCT Project and to support their affiliated practices in development of PCMH capabilities.

Continued participation by Medicare as a payer in the demonstration is dependent on their actuaries' projections of revenue-neutrality by the end of the three-year demonstration. In other words, the amount that Medicare is spending on MiPCT interventions in Michigan over the next three years (estimated to be \geq \$100 million) must be no more than the amount saved for participating Medicare beneficiaries. Other participating payers have similar expectations.

Figure 2 is a map of Michigan's 83 counties showing the location of the approximately 400 primary care practices participating in the MiPCT Demonstration Project. Both heavily urban communities in lower Michigan as well as rural areas in northern Michigan have practices participating in this demonstration.

Figure 2. Primary Care Practices Participating in the MiPCT Demonstration Project



MiPCT Funding Model

In addition to each practice's usual fee-for-service payments for services rendered, participating practices are eligible for per member per month (PMPM) payments to support and reward their PCMH transformation efforts. Participating payers include Medicare FFS, Medicaid Managed Care, Blue Cross Blue Shield of Michigan, and Blue Care Network paying the following fee structure (or the equivalent) for their attributed members:

- Care coordination: \$3.00 PMPM (or \$4.50 for Medicare) to hire care managers
- Practice transformation: \$1.50 PMPM (or \$2.00 PMPM for Medicare) to support infrastructure expenses
- Performance incentives: \$3.00 PMPM for all payers, distributed in variable amounts based on PO/Practice performance

19 As of 2012, there were 40 physician organizations (or physician-hospital organizations) in Michigan. Most Michigan primary care practices and many specialty practices (N = 15,500 primary care and specialty physicians serving millions of Michigan residents) are members of POs or PHOs. These POs help to negotiate contracts with payers on behalf of their member practices, and they also facilitate transformation within their practices. BCBSM, through its Physician Group Incentive Program (PGIP), uses a wide variety of initiatives to reward POs for improved performance of their practices. Patients throughout the state, regardless of payer, benefit from the improved care processes developed through PGIP's PO/Practice/Provider community. Developing systems of care that are used for all patients regardless of payer helps assure that providers don't have to alter care processes based on whether patients have insurance, or which insurance they have. This is an important factor in ensuring that the best practices and care processes are reliably provided to all patients, all of the time.

The total paid to POs and practices for non-Medicare patients is \$7.50 PMPM. Medicare is paying an additional \$2.00 PMPM (a total of \$9.50 PMPM) to cover additional services because of the greater prevalence of chronic diseases in their aging populations. In addition, all payers are paying \$0.26 PMPM to cover the central administrative expenses for the demonstration project.

Figure 3 is a graphic that conveys the ten PCMH domains or functions heavily involved in the MiPCT Demonstration Project, including the four (highlighted) focus areas targeted for special attention.

Figure 3. PCMH Domains Involved in the MiPCT Demonstration Project

Domains of Michigan Primary Care Transformation Project



The leadership of MiPCT believes that a concerted focus on four of the ten broad PCMH domains or functional areas (highlighted above) will enable the project to achieve its Triple Aim goals.²⁰ The MiPCT is placing a specific focus on: (1) individual care management, (2) self-management education, (3) care coordination, and (4) linkages to community resources. Further development of these four domains during the demonstration will build upon the strong PGIP-PCMH foundation already developed in many of the participating Michigan practices. Noting that there are significant differences in these definitions across the US, the Michigan demonstration has defined these four domains as follows:

- *Care management* is the application of systems, science, incentives and information to improve the efficiency and impact of primary care practice operations; assistance to patients and their families to engage in partnership with the practice to manage their health more effectively; and use of the team concepts of Wagner's chronic care model. Team members use electronic patient registries to monitor the care needs of subgroups within the practice (e.g., the control status of all individuals with a diagnosis of Type II diabetes; individuals with poorly controlled asthma without a recent follow-up visit; children age 6 or younger not up to date on immunizations; adults age 50+ not up to date on colorectal screening).

20 Malouin, J. et al. Michigan Primary Care Transformation Project: Information for Michigan POs/PHOs and payers. <http://mipctdemo.files.wordpress.com/2011/09/mipct-summary-document-sept-8-2011.pdf>

- *Self-management support* is support and encouragement provided to those with chronic conditions to help them understand their own central role in managing their health, making informed decisions, and engaging in healthy behaviors. Providers use motivational interviewing skills to help patients or families identify realistic goals and develop a care plan, helping to build knowledge, skills and confidence in patients (and/or families) about their ability to manage their health.
- *Care coordination* is the service provided by a practice-embedded care manager (typically a nurse or social worker) who assists patients to navigate the complex healthcare system, and assures successful transitions between hospital and home, hospital to rehabilitation or long-term care, or transitions to and from medical specialists. The goal is to improve coordination of care delivered by providers external to the practice, while providing cost effective, non-duplicative services. Reconciliation of medications post-hospitalization is a serious patient safety issue and an important expectation of care managers. Care managers also are directly involved in helping patients learn how to self-manage their health and/or disease.
- *Linkage to community resources* requires building knowledge and skills among the practice team about available programs and services and other resources in the patient's community. Such resources include evidence-based disease education programs, peer support groups, healthy lifestyle opportunities, and services directed at the social determinants of health (e.g., services to address unsafe housing, food insecurity, lack of health insurance, joblessness, low literacy, legal needs, and more). Practice teams are expected to develop effective communication and motivational skills to enable them to make effective referrals for their patients with such life challenges to community resources that can assist them.²¹

MiPCT Clinical Interventions

The clinical interventions in the MiPCT project are intended to focus on the patient's needs wherever he or she is on the health/disease continuum, and assure that evidence-based care is provided.

As noted earlier, the addition of two types of care managers (moderate care managers and complex care managers) into participating practices is considered to be one of the most promising means to achieve the quality and cost reduction goals of this demonstration project.

- *Moderate care managers* are expected to provide care management and care coordination for adult and pediatric patients with mild to moderate illness, under minimal supervision. This individual assists patients who are at risk for developing chronic conditions to minimize these risks and provides self-management support and patient education to those with chronic disease(s). The monitor will assess, plan, implement, monitor, and evaluate delivery of individualized patient care with the goal of optimizing the patient's health status. This individual will manage a caseload of approximately 500 patients, of which 90-100 are actively supported at any one time.
- *Complex care managers* are expected to provide care management and care coordination for adult and pediatric patients with complex illness in the primary care setting under minimal supervision. This individual identifies the targeted high risk population within practice site(s) by primary care physician referral, risk stratification, or patient lists, including patients with repeated social and/or health crises. This care manager will collaborate with specialists, provide targeted interventions to avoid hospitalization and emergency room visits, coordinate care across settings, and help patient/families understand health care options. The Complex Care Manager is expected to manage a caseload of approximately 150 complex patients, of which 30 to 50 patients are actively followed by the care manager at any point in time.

21 The Michigan Department of Community Health (MDCH) is working to identify funding to enable the statewide hiring of lay community health workers (CHWs) trained to assist high-risk clients to connect to services addressing the social determinants of health (SDOH), e.g., safe housing, home heating, healthy food, legal assistance, dental care, dependable transportation, stable employment, access to a medical home, domestic violence prevention, etc. This model is based on the theory that until one's significant social, psychological, economic and/or educational life challenges are resolved there is little possibility of engaging the individual in attending to self-management of his/her health condition(s). This model is based on the evidence-based Pathways/Community Hub project reviewed at length by the AHRQ as an effective method to resolve SDOH. Recently, the Michigan Public Health Institute received a 3-year CMS grant to implement this model in three of Michigan's 83 counties. MDCH is working closely with MPH on this project, and the MiPCT leadership will be closely observing its start-up and outcomes.

Data Collection and Evaluation

Under the MiPCT, a multi-payer claims data repository is under development that will merge claims and eligibility data from multiple payers to produce risk-adjusted reports to POs and Practices, dashboard performance reports, high-risk patient lists to facilitate care management, and a web-based claims data portal. This data repository, known as the Michigan Data Collaborative (MDC), currently provides POs and their practices with patient attribution lists for all participating payers and, in 2013, expects to be able to link clinical data with claims data to enable POs and practices to monitor both their clinical care and utilization of services by their patients. The MDC also is calculating performance incentives owed to participating POs and practices.

The Michigan Public Health Institute (MPHI) is designing and implementing the state's evaluation of the MiPCT project. MPHI has developed a logic model, has implemented a survey of participating practices to determine the degree of awareness about the MiPCT, and is implementing a patient survey to develop initial data about patient satisfaction with their PCMH. MPHI also will make use of the databases developed by the MDC to assess cost and quality of care.

CMS/Medicare has also contracted with several national organizations to develop and implement a national evaluation of the eight states participating in their MAPCP demonstration project.

Conclusion

Michigan believes it is well positioned to meet the challenge of improving population health through transforming the delivery of primary care. Michigan and the other states participating in the CMS demonstration are on track to demonstrate to the nation that providing coordinated, enhanced primary care for patients during all stages of life and across the health continuum will ultimately reduce the burden of chronic disease, engage patients in a manner that both improves their ability to manage their own health and their experience of care, and stabilizes or reduces healthcare costs.

A First Look at Chronic Diseases and Lifestyle Behaviors Among Arab and Chaldean Americans in Southeast Michigan

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Key words: *Chronic disease, health behaviors, diabetes, obesity, Arab Americans*

Abstract

A university-community partnership was formed for the purposes of conducting a statewide health needs assessment of Arab and Chaldean Americans. As a beginning project, Michigan State University and the Arab Community Center for Economic and Social Services (ACCESS) jointly conducted a pilot study in Southeast Michigan. The study sampled 89 Arab and Chaldean Americans. We examined the relationship of personal health behaviors and level of acculturation on diabetes prevalence and its related risk factors. Arab and Chaldean community health workers conducted in-person interviews with adults using a modified Behavioral Risk Factor Surveillance System (BRFSS) instrument. Data were analyzed with SPSS statistical software. Fisher's Exact Test was used due to the small expected cell counts (< 5). Significant correlations ($p < 0.001$) were found between individuals reporting diagnosis of diabetes and mean body mass index (BMI), age, English fluency, and educational attainment. This study was a first step. A larger-scale health needs assessment should be conducted to ascertain the validity and reliability of the methods used and the application of our findings to Arab and Chaldean Americans living across the United States.

Introduction

Chronic diseases continue to be leading causes of mortality and morbidity for the past century across demographics. The same appears to be true for Arab Americans living in Michigan, according to Michigan Department of Community Health (MDCH) data from a 2008 profile of Michigan's minority population. The profile lists heart disease, cancer, diabetes, stroke, and unintentional accidents among the leading causes of mortality, with heart disease and cancer accounting for 54% of the deaths among Arab Americans living in Michigan (MDCH, 2008). A preponderance of the available research on Arab Americans has taken place in Michigan, with a large portion of these studies taking place in Dearborn and sections of Detroit. In our pilot study we aimed to assess the health and wellness of varied Arab and Chaldean American communities throughout the quad-county area of southeastern Michigan, which includes Wayne County, Macomb County, Oakland County, and Washtenaw County. Within this paper we will look specifically at the behavioral factors practiced by our study participants and how they related to the diagnosis of diabetes, a chronic disease shown to affect Arab Americans disproportionately. While significant associations were found, further research with a larger number of Arab and Chaldean Americans will have to be completed to validate our findings.

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Objectives

Our objectives were:

- To assess the various lifestyle and cultural factors associated with increased BMI and chronic disease among Arab and Chaldean Americans living in the southeastern (Wayne, Macomb, Oakland, and Washtenaw counties) area of Michigan
- To compare pilot findings among the Arab and Chaldean community living in southeastern Michigan with lifestyle and cultural factors associated with increased BMI and chronic disease among the general Michigan and national population

Methods

A long-term objective of the ACCESS-MSU partnership is to conduct a statewide survey of the health of Arab/Chaldean Americans in Michigan. To achieve this objective, ACCESS and MSU conducted a pilot study to test the feasibility and acceptability of a survey instrument, a sampling strategy, and interviewing procedures with a small non-probability sample of Arab/Chaldean Americans in Michigan. Researchers from ACCESS and MSU developed a modified version of the Behavioral Risk Factor Surveillance System (BRFSS). Established in 1984 by the Centers for Disease Control and Prevention, the BRFSS is a state-based system of health surveys that gathers surveillance data on health risk behaviors, preventive health practices, and health care access, with a strong focus on chronic disease. To make the BRFSS suitable for a study of the Arab/Chaldean American population, the ACCESS-MSU team added questions related to ethnic identity, immigrant/nativity status, language and literacy, dietary acculturation, access to healthcare, substance use, and income. The modified survey instrument was then translated into Arabic. This study was approved by the Michigan State University Institutional Review Board for human subjects.

Although the BRFSS has been used primarily as a telephone survey instrument, our research partners at ACCESS believed that, in the post-9/11 context, many Arab/Chaldean Americans would be reluctant to speak with strangers over the telephone about their health status. Consequently, we hired members of the ACCESS staff, many of whom are themselves members of Arab/Chaldean communities in Southeast Michigan, to conduct face-to-face interviews. The interviewers were trained in research ethics and the techniques of face-to-face survey administration. Following interviews, interviewers conducted regular debriefing meetings with the research team to identify and correct problems with the survey instrument, recruitment procedures, or survey administration. Interviewers recruited participants for the study in one of two ways: either by identifying recruits through their own social networks within local Arab and Chaldean communities, or by reaching out to additional local Arab/Chaldean communities through mosques and community centers to obtain a sample that reflected the full diversity of Arab/Chaldean communities in Southeast Michigan. Through these methods, a convenience sample of 89 Arab/Chaldean Americans was obtained.

Debriefing meetings with interviewers uncovered no major problems with the face-to-face interviewing procedures or the modified BRFSS survey instrument. Out of the 90 individuals who were asked to complete the survey, only one refused, reflecting the high degree of trust participants placed in the interviewers. Additional evidence of this trust can be found in the willingness of participants to respond to sensitive questions about alcohol/tobacco/substance use, mental illness, and child/adult abuse. Data were analyzed with SPSS statistical software and Fisher's Exact Test was applied throughout due to small expected cell counts (< 5).

Results

Sample

A total of 32 men (36%) and 57 women (64%) participated in the in-person interviews. Their ages ranged from 18 to 81. Of the five medical conditions, 18.2% participants reported living with asthma and 12.4% reported living with diabetes. Nearly 25 percent of participants reported they were obese and 34% reported they were overweight. Only 41% of the participants reported being neither overweight nor obese.

Demographic and Behavioral Factors Related to Diabetes

Individuals with diabetes had, on average, a BMI nearly seven points higher than those without diabetes (Table 1; $t(69) = -3.56, p < .001$).

Table 1. BMI and Diabetes

<i>Diabetes</i>	<i>Mean BMI</i>	
Yes	33.24	$t(69) = -3.56, p < .001$
No	26.31	

Individuals older than 35, able to read and write English fluently, born outside of the US, with an education of high school completion or less, and with an annual income below \$25,000 were more likely to have diabetes (Table 2).

Table 2. Demographic and Behavioral Correlates of Diabetes

<i>Factor</i>	<i>DIABETES</i>		<i>Fisher's Exact Test</i>
	<i>No</i>	<i>Yes</i>	
Age			$p < .001$
18-34	45 (60%)	0 (0%)	
35-100	30 (40%)	11 (100%)	
Language in home			$p = .197$
Ar/Ch	59 (81%)	11 (100%)	
English	14 (19%)	0 (0%)	
Arabic literacy			$p = 1.00$
Fluent	30 (42%)	4 (36%)	
Not fluent	42 (58%)	7 (64%)	
English literacy			$p < .001$
Fluent	29 (39%)	11 (100%)	
Not fluent	46 (61%)	0 (0%)	
Exercise			$p = .197$
Yes	39 (52%)	3 (27%)	
No	36 (48%)	8 (73%)	
Hours of TV			$p = 1.00$
Fewer than 2	24 (32%)	3 (27%)	
2 or more	52 (68%)	8 (73%)	
Servings of fruit/vegetables			$p = .058$
0-2	38 (50%)	2 (18%)	
3 or more	38 (50%)	9 (82%)	
Servings of red meat			$p = 1.00$
2 or fewer	29 (38%)	4 (36%)	
3 or more	47 (62%)	7 (64%)	
Place of birth			$p = .033$
In US	23 (30%)	0 (0%)	
Outside US	53 (70%)	11 (100%)	
Education			$p < .001$
HS or less	24 (32%)	11 (100%)	
Some college or more	52 (68%)	0 (0%)	
Income			$p = .027$
< 25K	32 (44%)	7 (88%)	
25K or more	40 (56%)	1 (12%)	

Discussion

In this pilot study of Arab and Chaldean Americans we examined age, BMI, and certain behavioral practices (see Table 2) as they related to reported chronic disease, specifically diabetes. When the sample was adjusted for age and divided into two age groups, all of the diabetics fell in the 35 to 100 years old group and no diabetics were younger than 34, strongly suggesting that the problem is Type II diabetes. In addition, the diabetics had on average a nearly 7 (precisely 6.93) point higher body mass index (BMI) than the non-diabetics, indicating that weight and/or obesity may be strong indicators of possible etiology in this sample.

The prevalence of reported diabetics in the pilot study was 12.4%, accounting for 11 of 89 participants. Larger studies have been conducted on diabetes in Arab Americans. For example, Dallo and Borrell (2006) used the National Health Interview Survey (NHIS) with a sample of 425 Arab Americans and found a prevalence of diabetes of 4.8% with no significant difference in the prevalence of Arab Americans and non-Hispanic whites. However, a study in Dearborn, MI with a sample size of 542 Arab-American participants in which glucose tolerance testing was used, rather than just reported diabetes, found an overall prevalence of diabetes adjusted for age of 15.5% in women and 20.1% in men (Jaber et al., 2003).

In this pilot study, an examination of the behavioral factors that distinguished diabetics from non-diabetics found that the diabetics all fell in the group that reported to be fluent in English. Arabic literacy (reported fluency or not) was not significantly different between diabetics and non-diabetics.

In terms of activity levels, measured by reported exercise and reported hours of TV watched, neither parameter demonstrated any differences between diabetics and non-diabetics. In reference to the dietary factors examined, daily consumption measured by servings of fruits and vegetables and servings of red meat also showed no differences between diabetics and non-diabetics. Either the small sample size or the possibility that some other dietary factors not measured may be responsible for the differences in BMI between diabetics and non-diabetics.

Other factors (place of birth, education, and income) were significantly different between diabetics and non-diabetics. In this sample, all of the diabetics were foreign-born, all of the diabetics had educations of high school or less, and there was a larger percent of the diabetics (88%) that had incomes of less than \$25,000. The fact that lower income, foreign-born immigrants appear to be in a higher-risk group for a chronic disease like diabetes identifies a potentially vulnerable and susceptible high risk sub-group of Arab Americans. These findings warrant further future investigation and research in a larger probability sample.

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Health Disparities Between Arab and Chaldean Americans in Southeast Michigan and Michigan Residents: Differences in Access to Health Providers and Insurance

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Abstract

Southeastern Michigan and, in particular, the Detroit Metro Area, has one of, if not the highest, concentrations of Arab Americans and Chaldeans living outside of the Middle East. While there is a great deal of interest in these populations, relatively little is known about their health status. Building on past studies, a partnership between Michigan State University and the Arab Community Center for Economic and Social Services (ACCESS) conducted a pilot survey of 89 Arab and Chaldean residents as the first step in a longer term initiative to provide a more comprehensive health assessment of this population. In this paper, we report partial results of this study, comparing the statistical findings of health status in this population to the statistical findings for similar questions asked in a 2010 statewide survey. Our findings indicate that Arab and Chaldean Americans are not as likely to report being in very good health, are less likely to have health coverage, but are more likely to have a regular doctor than members of the general population. While these findings may be an artifact of the convenience sample chosen for this survey, they do indicate the need to further investigate the general health and access to health services among Arab and Chaldean Americans.

Introduction

Health disparities are differences in health outcomes between groups that reflect social inequalities. Indicators of health outcomes include self-report of overall health status as well as conditions such as cardiovascular disease, cancer, and asthma. Social inequalities that impact health outcomes include education, race/ethnicity, access to health care providers and insurance coverage (Frieden, 2011).

Many of the studies and reports on health disparities and inequalities examine the African-American and Hispanic populations. Unfortunately, the US census and other national databases such as the Behavioral Risk Factor

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Surveillance System (BRFSS) include Arab-Americans as “white,” or “white non-Hispanic,” that is, a person having origins from Europe, the Middle East or North Africa. This means that only a relatively few studies examine the health status, access to health care and health disparities of Arab-Americans. Like Hispanic-Americans, Arab-Americans are very diverse. They come from a wide range of nations from Morocco to Iran, including the Gulf region. Arab-American religions include Islam, both Shi’a, Sunni, and even some Sufi, Druze, Baha’i, and Christian, including Roman Catholic, Eastern Orthodox, Protestant, and Eastern-rite churches—Chaldean, Coptic, Maronite, Melkite, Syrian, and other denominations.

The majority of research on Arab Americans has focused on the Dearborn/Metropolitan Detroit population, with a few exceptions in California and New York. In the late 1980s and early 1990s, social service organizations in the Metropolitan Detroit area began conducting their own research on Arab American health, employing their own research directors and researchers, helping to raise the visibility of Arab Americans in the literature. This includes the series of papers presented at the International Health Conferences sponsored by the Arab Community Center for Economic and Social Services (ACCESS; Sakr & Hammad, 2005). After 9/11 and the Iraq war, research again focused on Arab-American health, particularly on the impact of 9/11 on the health of refugees in terms of stress, post-traumatic stress disorder (PTSD), and psychological well-being.

One systematic review of the literature examined 34 papers published between 1980 and 2008 (Abdulrahman, El Sayed, & Galea, 2009). Their conclusions were that the majority of research surveyed had been conducted in Michigan (26 of the 34 papers reviewed) and revealed a lack of consensus and conflicting data concerning the health patterns and risk factors among Arab Americans. In addition, they indicated that the Arab American community differed from the general population in several ways. The large numbers of recent immigrants may experience stress linked to acculturation, discrimination and marginalization that may be important in the etiology of disease. Overall, a majority of the research studied immigrants and the foreign-born rather than their children who were born in the US. Clearly more research is needed on the health of Arab Americans.

A profile of Michigan’s minority population produced by the Michigan Department of Community Health (MDCH, 2008) indicated that the leading causes of mortality for Arab Americans in Michigan are heart disease, cancer, diabetes, stroke, and unintentional accidents. Heart disease and cancer accounted for over half (54.2%) of deaths in Arab Americans in Michigan (MDCH 2008). There appears to be a consensus that Arab Americans suffer from health disparities (Forzley, 2005).

Using the National Health Interview Survey (NHIS) for 2002-03, which included a sample of 425 Arab Americans, Dallo and Borrell (2006) reported a diabetes prevalence of 4.8 percent for Arab Americans as compared with 6.9 percent for non-Hispanic whites, which they concluded was non-significant. However, an earlier random sample study with a slightly larger group of 542 Arab-American participants conducted in Dearborn, MI (that included actual testing for glucose tolerance) found an overall prevalence of diabetes adjusted for age of 15.5 percent in women and 20.1 percent in men (Jaber et al., 2003). They also reported a lower level of self care by diabetic patients.

Johnson et al. (2005) surveyed 600 Arab American households in metro Detroit, the largest immigrant reception zone for Arab Americans in North America. They found that, although the prevalence of asthma among African Americans and Hispanics is generally higher than the prevalence in the general population, the prevalence among Arab Americans was lower than the national, statewide, and metro Detroit population averages. While the highest reported trigger of asthma attacks by at-risk individuals was air pollution at 79 percent, the length of residence in the neighborhood was not significantly associated with asthma prevalence or severity, as would be expected if increased exposure to high pollution levels in metro Detroit were responsible for the positive association between asthma severity and residence. However, asthma prevalence was highest among moderately acculturated immigrants compared with new immigrants and those who were well acculturated, suggesting that among Arab Americans in the Detroit area, asthma risk factors associated with new immigrant status are replaced by “Western” risk factors as the population becomes more acculturated.

Cortesville (2010) found that previously published studies of Arab American households in Southeast Michigan undergoing a fasting blood glucose test reported a total diabetes prevalence (both diagnosed and undiagnosed) of 18.3 percent compared to a total diabetes prevalence of 11.0 percent for whites. Cortesville suggested that the disparity seen in the total diabetes prevalence might be explained by the proportion of total diabetes that was undiagnosed. Arab Americans and Chaldeans who have diabetes are thought to be undiagnosed between 45 to 50 percent of the time, compared to whites who are undiagnosed 38 percent of the time. The fact that the Arab-American community in Dearborn includes more low-income and recent immigrants may also contribute to this disparity in the reported prevalence of diabetes and warrants further research into the causes of the differences.

As with other minorities, there are concerns about access to health care. The state of Michigan has identified Arab and Chaldean Americans as one of five population groups that it will focus on to eliminate health disparities. While Arab Americans nationally have higher education rates and incomes than other Americans (Arab American Institute, 2012), the *2009 Minority Health Disparities Report* (MDCH, 2010, p. 36) found that in Michigan, 20.5 percent of non-elderly Arab-Americans were uninsured, which was approximately the same as percentage as non-elderly African Americans (19.0%) and non-elderly Hispanic-Latinos (21.1%).

The purpose of this study is to analyze the relationship between the social determinants of health and health outcomes among a convenience sample of Arab and Chaldean Americans residing in southeast Michigan and compare it to a statewide general population survey. We will first compare self-reported overall health status, diabetes and asthma. We will then examine access to health care in terms of having a personal doctor or health care professional and having health insurance.

Method

In order to identify health disparities and differences in access to health care providers and insurance, this study compares two sets of survey data. The first is a survey of Arab/Chaldean Americans living in Southeast Michigan (Dearborn and metro Detroit). The second is a statewide survey of Michigan residents.

Researchers from the Arab Community Center for Economic and Social Services (ACCESS) and Michigan State University (MSU) developed a modified version of the Behavioral Risk Factor Survey (BRFS). To make the BRFS more suitable for a study of the Arab and Chaldean American population, we added questions related to ethnic identity, immigrant/nativity status, language and literacy, dietary acculturation, access to healthcare, substance use, and income. The modified survey instrument was translated into Arabic.

Although the BRFS has been used primarily as a telephone survey instrument, in the post-9/11 context the research team decided, based on previous attempts at research in the community, that many Arab/Chaldean Americans would be reluctant to speak with strangers over the telephone about their health status. Consequently, we hired Arab/Chaldean community members to conduct face-to-face interviews. The interviewers were trained in research ethics and face-to-face survey administration. The research team conducted regular debriefing meetings with the interviewers to identify and correct problems with the survey instrument, recruitment procedures, or survey administration. Interviews were conducted between March 8, 2011 and April 19, 2011. A total of 89 interviews were completed with Arab and Chaldean adult men and women in Southeast Michigan. This study was reviewed and approved by the Michigan State University Institutional Review Board.

The 57th State of the State Survey (SOSS, 2010) was conducted by Michigan State University's Institute for Public Policy and Social Research (IPPSR) from October 25, 2010 through December 30, 2010. The quarterly survey is administered via telephone by the IPPSR Office for Survey Research. Respondents' households were selected using list-assisted random digit dial sampling procedures. This round of the survey reached 1,003 Michigan adults age 18 and over. The margin of sampling error was ± 3.1 percent and the completion rate was 42 percent. To assure representation of major regions within Michigan, the sample was stratified into six regions, each consisting of a set of contiguous counties, plus the City of Detroit. The grouping of counties corresponds to that used by MSU Extension prior to July 2005, with Detroit separated out from the Southeast region.

Data analysis utilized χ^2 and log linear G^2 statistical tests for two way and three way contingency tables respectively (see Vassarstats, 2012).

Results

Health Status

A common measure of health outcomes is self-reported health status on a five point scale from excellent to poor. Table 1 compares Arab-Americans in the ACCESS survey with respondents in the statewide survey. While those reporting excellent (13.5% vs. 16.4%) and fair to poor (19.1% vs. 16.1%) health appear similar, the major differences are between those reporting very good (24.7% vs. 41.3%) and good (42.7% vs. 26.2%) health, $\chi^2(3, N=89) = 14.6, p = .002$. Overall, this suggests that Arab-Americans in the ACCESS survey are not as likely as members of the general population to report being in very good health.

Table 1. Self-Reported Health Status, % (N)

	<i>ACCESS Survey</i>	<i>Statewide Survey</i>
Excellent	13.5% (12)	16.4% (164)
Very good	24.7% (22)	41.3% (413)
Good	42.7% (38)	26.2% (262)
Fair and poor	19.1% (17)	16.1% (160)

chi-square = 14.6; degrees of freedom = 3; probability = 0.002

Two other indicators of health status are self-reported diabetes and asthma. The chi-square analysis revealed no significant differences for diabetes (Table 2) between the Arab-Americans and statewide respondents ($p = 0.389$), and a non-significant difference for asthma ($p = 0.058$; Table 3).

Table 2. Self-Reported Diabetes, % (N)

	<i>ACCESS Survey</i>	<i>Statewide Survey</i>
Yes	12.4% (11)	9.5% (95)
No	87.6% (78)	90.5% (902)

chi-square = 0.743; degrees of freedom = 1; probability = 0.389

Table 3. Self-Reported Asthma, % (N)

	<i>ACCESS Survey</i>	<i>Statewide Survey</i>
Yes	18.2% (16)	11.4% (113)
No	81.8% (72)	88.6% (882)

chi-square = 3.59; degrees of freedom = 1; probability = 0.058

Access to Health Care

Somewhat surprisingly, the ACCESS survey respondents were more likely to have a personal doctor or health care provider than statewide survey respondents (87.5% vs. 77.0%), $\chi^2(1, N=89) = 5.74, p = .017$ (Table 4). This, however, may partially be the result of the convenience sample emanating from ACCESS with its community health center and services.

Table 4. Have Personal Doctor or Health Care Professional, % (N)

	<i>ACCESS Survey</i>	<i>Statewide Survey</i>
Yes	87.5% (70)	77.0% (769)
No	11.3% (9)	23.0 (230)

chi-square = 5.74; degrees of freedom = 1; probability = 0.017

By far the greatest gap between the Arab-American respondents and the statewide survey respondents was the percentage who reported having health care coverage/insurance (Table 5). Only 67.4 percent of the Arab-American respondents reporting health insurance compared with 88.6 percent of the statewide respondents ($p < 0.001$). This is also well below the 2009 *Michigan Minorities Disparities Report* estimate (MDCH, 2009), which reported that 79.5 percent of Arab-Americans had some form of health coverage. Again, the low percentage insured for the ACCESS survey may reflect respondents using the ACCESS community health center as their regular source of care because they had no insurance.

Table 5. Have Health Care Coverage/Insurance, % (N)

	<i>ACCESS Survey</i>	<i>Statewide Survey</i>
Yes	67.4% (60)	88.6% (880)
No	32.6% (29)	11.4% (114)

chi-square = 31.8; degrees of freedom = 1; probability = 0.000

When having insurance is controlled for age, the differences between the ACCESS and statewide survey become curvilinear (Table 6), with the greatest disparities occurring for the 30-49 and 50-65 age groups (50.0% vs. 87.8% and 69.2% vs. 94.2%). The small differences for those over 65 (87.5% vs. 92.1%) undoubtedly reflect access to Medicare, and, for those under 30 (73.8% vs. 75.5%), they most likely result from coverage under a parent's plan or being on Medicaid. The differences between the ACCESS and statewide surveys persist for gender (Table 7) as well for both males (71.9% vs. 84.8%) and females (64.9% vs. 91.7%).

Table 6. Have Insurance by Age, %YES (N)

	<i>ACCESS Survey</i>	<i>Statewide Survey</i>
LT 30	73.8% (42)	75.5% (203)
30-49	50.0% (26)	87.8% (211)
50-65	69.2% (13)	94.2% (206)
65+	87.5% (8)	93.1% (168)

A = Yes, no insurance; B = Age categories; C = ACCESS/SOSS

Source	G2	Df	P
ABC	87.68	10	< .0001
AB	38.32	3	< .0001
AC	20.6	1	< .0001
BC	23.72	3	< .0001
AB(C)	43.36	6	< .0001
AC(B)	25.64	4	< .0001
BC(A)	28.76	6	< .0001

Table 7. Have Insurance by Gender, %YES (N)

	<i>Pilot Survey</i>	<i>State of State Survey</i>
Male	71.9% (32)	84.8% (467)
Female	64.9% (57)	91.7% (528)

A= Yes, No Insurance; B= Gender male/ female; C = ACCESS/SOSS

Source	G2	Df	P
ABC	40.46	4	< .0001
AB	6.04	1	0.014
AC	24.5	1	< .0001
BC	4.04	1	0.0444
AB(C)	11.92	2	0.0026
AC(B)	30.38	2	< .0001
BC(A)	9.92	2	0.007

Education has a marked impact on having health insurance. In general, the higher the education, the more likely people are to have health insurance, which is reflected in the statewide survey (Table 8). However, the result from the ACCESS survey is curvilinear, with respondents with less than a high school education and college graduates (75.0% and 84.6% respectively) more likely to have insurance than high school graduates or those with some college (30.8% and 61.5% respectively). Except for those with less than a high school education, the ACCESS respondents were much less likely to have health insurance than those with comparable educational levels in the statewide survey. Perhaps the high proportion of ACCESS respondents with less than a high school education but with health insurance (75.0%) reflects the ability of the Arab-American community to enroll them in Medicaid or a disproportion of married women who are covered through their husband's insurance.

Table 8. Have Insurance by Education, % YES

	ACCESS Survey	Statewide Survey
LT HS	75.0% (24)	66.6% (39)
HSG	30.8% (13)	81.3% (229)
Some College Tech	61.5% (26)	85.0% (311)
College Grad	84.6% (26)	96.6% (370)

A = Yes, no insurance; B = Education; C = ACCESS/SOSS

Source	G2	Df	P
ABC	139.24	10	< .0001
AB	63.9	3	< .0001
AC	22.36	1	< .0001
BC	47.3	3	< .0001
AB(C)	69.58	6	< .0001
AC(B)	28.04	4	< .0001
BC(A)	52.98	6	< .0001

Discussion/Conclusion

This study analyzed the relationship between social determinants of health and health outcomes among a convenience sample of Arab and Chaldean Americans residing in Southeast Michigan and compared it to a statewide general population survey. Our analyses found that Arab and Chaldean Americans were *less* likely to report being in very good health than the general population. There were no significant differences between Arab and Chaldean Americans and the general population in the prevalence of diabetes or asthma.

In terms of access to health care, Arab and Chaldean Americans were more likely to have access to a personal doctor or health care professional than members of the general population, but were less likely to have health insurance. This finding may be an artifact of the sample, which was largely drawn from clients of ACCESS. The greatest disparities between the two populations in health insurance coverage were for individuals between the ages of 30 and 65. It may be that younger Arab and Chaldean Americans are covered through their parents' health insurance plans or state health insurance plans for children and older Arab and Chaldean Americans are enrolled in Medicare. Education was a significant predictor of health insurance coverage. Although Arab and Chaldean Americans with less than a high school education were *more* likely to have health insurance, those who had graduated from high school or had at least some college were *less* likely than members of the general population to have some form of health insurance.

All of this leads to a call for future research. This study has identified some issues with real policy and research relevance, but the findings are preliminary. Based on a convenience sample of 89 individuals, it is impossible to say anything that is generalizable to the population of Arab and Chaldean American in Michigan or the US. We have developed proposals for more comprehensive research that would provide generalizable data to test these initial findings. If these findings are upheld in a larger study, it would indeed have serious policy implications for directing health research dollars. For the

moment, we can certainly say that the social determinants of health in the Arab and Chaldean populations of Michigan do not appear to fit easily into the usual categories of immigrant and refugee health research, nor into the stereotypes of the Arab and Chaldean American population. The Arab and Chaldean population in the US is growing and deserving of attention. This should serve as a call for directing more resources toward that effort.

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Immigration, Acculturation, and Health Among a Sample of Arab and Chaldean Americans in Southeast Michigan

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Key words: *Immigration, acculturation, health behavior, diabetes, obesity, Arab Americans*

Abstract

With a large Arab-American population in Michigan, including many foreign born and new immigrants, the process of acculturation and its impacts upon health can potentially provide insights for future prevention. In a collaboration between the Arab Community Center for Economic and Social Services (ACCESS) and Michigan State University, we completed a pilot-study total of 89 interviews with Arab and Chaldean adult men and women in the Dearborn area and extracted the 66 that were immigrants (born in a country outside the US). We found that in this sub-sample, different measures of acculturation were related to different health outcomes and behaviors, some indicating that Arab Americans may be unique among foreign-born populations in the US and may warrant further study. With a bio-cultural perspective, we examined both social factors (language), and constructed variables, including dietary factors such as high consumption of fruits and vegetables, high meat consumption, and behavioral risks (smoking and obesity/BMI). Our results indicate that (1) higher levels of acculturation (measured by either English language acquisition or greater time in the US) were generally associated with better health behaviors and health outcomes; (2) our data indicate differences between men and women in acculturation health outcomes; and (3) our analysis shows health outcomes vary by different measures of acculturation, indicating the importance of using multiple measures of acculturation in Arab health research. The strong relationship found between healthier food consumption, exercise, diabetes, and obesity with our acculturation measures warrants future research on a larger and more representative sample.

Introduction

Acculturation has been defined in many ways. By as early as 1938 social scientists, including anthropologists and sociologists, had become interested in acculturation. Acculturation was defined as that which “comprehends those phenomenon which result when groups of individuals having different cultures come into continuous first-hand contact, with subsequent changes in the cultural patterns of either or both groups” (Redfield, Linton, & Herskowitz, 1938, p. 149). Today it is common practice to add the concept of cultural adaptation to the process of acculturation. In ethnic studies, assimilation (an incorporation into the host society accompanied by a complete loss of separate identity) has long been distinguished from acculturation (see Crispino, 1980). In addition to cultural acculturation, biological adaptation occurs in groups of individuals over multiple generations as they adapt to a new environment. The combination of acculturation (changing cultural habits, behaviors, and beliefs in particular) and biological adaptation can be referred to as bio-cultural adaptation. Cultural adaptation can influence biology. Dietary acculturation, for example, can impact body mass index (BMI) and that can have many health consequences.

In this collaboration between a sociologist and an anthropologist, we bring together the areas of sociology and anthropology, using bio-cultural and multidisciplinary perspectives. An example of a bio-cultural perspective in anthropology in an immigrant population acculturating to a new culture is the work of Craig Janes (1990), focusing

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on migration, social change, and health in a Samoan community in California. This study emphasized stress and health in the immigrant population, as seen in similar studies in other populations in the work of Paul Baker (see Baker et al., 1986) and William Dressler (see Dressler et al., 1996). Bryan Turner reminded us of the “plethora of writers: Berger, Bourdieu, Deleuze, Douglas, Elias, Foucault, and O’Neill” (Turner, 1992, p. 1) who shaped the thinking on the sociology of the body. Many of these same thinkers have also influenced studies of the body in anthropology, giving us a shared theoretical ground for our collaboration. This pilot study is a relatively small sample of individuals for a sociological study, and a somewhat large study for an anthropological study, bridging the gap between disciplines in another way. We were very interested in gender differences in acculturation and health and brought this perspective to our analysis in this sample of immigrants (see Nawyn, 2010).

Previous studies of immigrant acculturation to life in the United States focused on various aspects of acculturation such as language acquisition, dietary change, modifications in religiosity, and other behavioral changes. Specifically, in Arab-American studies, acculturation has been examined in a number of ways. The role of religiosity in Muslim Arabs was examined by Elkholy (1969), who concluded that while Muslims may have more trouble acculturating, they preserve more of their identity than do Christian Arabs due to the uniqueness of their Islamic faith. In contrast, Hooglund (1985) provided the story of the first mosque in the US in North Dakota, where the entire tiny Muslim community was totally assimilated into mainstream American religion (Christianity) and culture. In regard to health and acculturation, Jadalla and Lee (2012), in a study of 297 adult Arab Americans in California, examined reported mental and physical health and smoking. Acculturation, which they defined as an “attraction to American culture,” was found to have different patterns of associations between acculturation and physical and mental health. Jaber et al. (2003) found that a lack of acculturation (using factors such as attendance at American or Arabic schools, not being able to read Arabic, less activity in Arab organizations, and eating Arabic food, etc.) in 520 Arab Americans age 20-75 in southeastern Michigan was associated with diabetes. Hassoun (1995), in a study of acculturation, dietary change, and hypertension, surveying 300 Arab American adults, found that high fat intake, in particular, corresponded with hypertension.

In this pilot study of Arab Americans in Michigan, our objective was to find factors associated with acculturation (measured by either English language acculturation or time in the US) that could have significance to health and could be applied to the analysis of a much larger statewide survey. As a bio-cultural study, cross-tabulations and construction of both linguistic and dietary factors were researched that could have health significance in Arab-American populations.

Method

Researchers from ACCESS and MSU developed a modified version of the Behavioral Risk Factor Survey (BRFS). To make the BRFS more suitable for a study of the Arab/Chaldean American population, we added questions related to ethnic identity, immigrant/nativity status, language and literacy, dietary acculturation, access to healthcare, substance use, and income. The modified survey instrument was translated into Arabic.

Although the BRFS has been used primarily as a telephone survey instrument, our research partners at ACCESS convinced us that, in the post-9/11 context, many Arab/Chaldean Americans would be reluctant to speak with strangers over the telephone about their health status. Consequently, we hired Arab/Chaldean community members to conduct face-to-face interviews. The interviewers were trained in research ethics and face-to-face survey administration. Interviewers conducted regular debriefing meetings with the research team to identify and correct problems with the survey instrument, recruitment procedures, or survey administration.

We completed a total of 89 interviews with Arab and Chaldean adult men and women in the Dearborn area. Of this total, 66 were immigrants (born in a country outside the US). We limited our analyses to this sub-group. For our independent variables, we used gender, English language ability, and length of time in the US. We constructed a new variable measuring English ability (consolidating people who reported speaking English well or fluently), and added a new variable to the BRFS measuring time since entering the US (within the last 5 years, 10 years, 20 years, 30 years, and 40 or more years). For our dependent variables, we constructed measures of high red meat consumption (3 or more times per week), high fruit and vegetable consumption (3 or more times per day), a smoking variable (which combined narghile use with other types of smoking), and an obesity variable that calculated the BMI of individuals, using $BMI \geq 30$ as the definition of obese. We also examined English/Arabic bilingualism, but this variable was highly collinear with speaking English well or fluently, so we used the latter in all subsequent analysis. Our goal for this component of the larger study was to examine how acculturation (measured as the ability to speak English well or fluently and the length of time since the immigrant entered the US) was related to health behaviors (red meat consumption, fruit and vegetable consumption, smoking, and exercise) and health outcomes (diagnosis of diabetes, asthma, and being obese).

Results

Our data analyses produced surprising findings, some of which suggest that Arab immigrants may be unique among foreign-born populations in the US and warrant further study. First, higher levels of acculturation (measured by either English language acquisition or greater time in the US) were generally associated with better health behaviors and health outcomes, contradicting most studies indicating that immigrants' health deteriorates with greater acculturation. Second, our data indicate some important differences between men and women, in which some types of acculturation are related to health outcomes for women but not men, and vice versa. Third, our analysis shows health outcomes vary by different measures of acculturation, indicating the importance of using multiple measures of acculturation in Arab health research.

Table 1 depicts the univariate distributions of our key variables. Our sample of immigrant Arabs was disproportionately women (68.2%). The majority (65.2%) reported being able to speak English well or fluently. A large proportion of our sample had arrived between 10 and 20 years ago (40.9%), with about a third (33.3%) arriving 10 years ago or less. For our dependent variables, we found a large percentage of people reporting high red meat consumption (60.6%), but almost equally high fruit and vegetable consumption (53.0%). Including both cigarette and narghile smoking, our sample has high smoking prevalence (47.0% reported smoking at least some days), and relatively high rates of obesity (31.8%, comparable to the general US-born population). The prevalence of diabetes (16.7%) and asthma (13.9%) were comparable or slightly higher than what is found in the general US population.

Table 1. Distribution of Nominal and Ordinal Variables

	%
Gender	
Men	31.8
Women	68.2
Ability to speak English well	65.2
Time since arrival in US	
Within the last 5 years (2006)	13.6
Within the last 10 years (2001)	19.7
Within the last 20 years (1991)	40.9
Within the last 30 years (1981)	18.2
Within the last 40 years (1971)	7.6
High red meat consumption	60.6
High fruit and vegetable consumption	53.0
Smokes	47.0
Exercised in last 30 days	42.4
Diagnosed with diabetes	16.7
Diagnosed with asthma	13.9
Obese	31.8

For our multivariate analysis, we first examined gender differences across the dependent variables, measuring health behaviors (high consumption of red meat, high consumption of fruits and vegetables, smoking, and exercising) and health outcomes (diabetes diagnosis, asthma diagnosis, and obesity). To test the relationships between acculturation (measured as English language acquisition and time since arrival) on health behaviors and outcomes, we performed cross-tabulations, reporting two-tailed chi-square analysis of significance. These findings are depicted in Table 2.

Table 2. Cross-Tabulations of Gender, Language Fluency, and Time Since Arrival with Health Behaviors and Outcomes

	<i>High Red Meat Consumption</i>	<i>High Fruit and Vegetable Consumption</i>	<i>Smokes</i>	<i>Exercised in Last 30 Days</i>	<i>Diagnosed with Diabetes</i>	<i>Diagnosed with Asthma</i>	<i>Obese</i>
Gender							
Male	52.4	38.1	61.9	57.1	9.5	14.3	47.6
Female	64.4	60.0^	40.0^	35.6^	20.0	13.6	24.4^
Speaks English well							
No	69.6	60.9	43.5	17.4	39.1	13.0	43.5
Yes	55.8	48.8	48.8	55.8**	4.7***	14.3	25.6
Years since arrival							
< 20s	77.3	31.8	54.6	40.9	13.6	4.6	36.4
≥ 20	52.3*	63.6*	43.2	43.2	18.2	18.6	29.6

^ p < .10; * p < .05; ** p < .01; *** p < .001

We found large differences between men and women with regard to fruit and vegetable consumption, smoking, exercise, and obesity. With the exception of exercise, women reported more healthy behaviors and had a lower prevalence of obesity. None of these findings were statistically significant beyond a .10 level, but they at least suggest that Arab immigrant women might have better health behaviors and outcomes than men.

Looking at acculturation, we found that different measures of acculturation were related to different health outcomes and behaviors. The ability to speak English well was positively associated with having exercised during the last 30 days and negatively associated with diabetes. Being in the US for 20 years or more was negatively associated with high red meat consumption and positively associated with high fruit and vegetable consumption. Contrary to what past research on immigrant acculturation has found, our sample exhibited healthier consumption patterns and lower likelihood of diabetes with greater acculturation.

In order to see if there were gender differences within these relationships, we ran another set of cross-tabulations separately by gender. These results are displayed in Table 3, with only the dependent variables that had significant results (fruit and vegetable consumption, exercise, diabetes, asthma, and obesity). By conducting the cross-tabulations separately by gender, we lose enough statistical power that some of the previously significant relationships become non-significant (such as red meat consumption). However, for many of the analyses we can see that the significant differences shown in Table 2 are driven by a particular gender. For fruit and vegetable consumption, both men and women who have been in the US 20 years or more are more likely to have fruit and vegetable consumption than men and women who have more recently arrived. And both men and women who speak English well are more likely to exercise than their non-English fluent counterparts. But women who are English fluent are much less likely than English fluent men to be diagnosed with diabetes, and are less likely to be obese. Therefore, it appears that the relationship between English fluency and a lower likelihood of having diabetes and being obese are relevant specifically to women, not men.

**Table 3. Cross-Tabulations Separately by Gender
(Statistically Significant Outcomes Only)**

	<i>High Fruit and Vegetable Consumption</i>		<i>Exercised in Last 30 Days</i>		<i>Diagnosed with Diabetes</i>		<i>Diagnosed with Asthma</i>		<i>Obesity</i>	
	<i>Men</i>	<i>Women</i>	<i>Men</i>	<i>Women</i>	<i>Men</i>	<i>Women</i>	<i>Men</i>	<i>Women</i>	<i>Men</i>	<i>Women</i>
Speaks English well										
No	25.0	68.4	0.0	21.1	25.0	42.1	25.00	10.5	50.0	42.1
Yes	41.2	53.9	70.6*	46.2^	5.9	3.9**	11.76	16.0**	47.1	11.5*
Years since arrival										
< 20	0.0	38.9	13.6	33.3	0.0	16.7	25.00	0.00	100.0	22.2
≥ 20	47.1^	74.2*	18.2	37.0	11.8	22.2	11.76	23.1*	35.3*	25.9

^ p < .10; * p < .05; ** p < .01

Also, we found that women who have been in the US at least 20 years are more likely to be diagnosed with asthma, whereas men who have been in the US for at least 20 years are less likely to be diagnosed with asthma (although for men this relationship is non-significant). This is the only finding in which we see greater acculturation associated with less healthy outcomes in our sample. Additionally, we see that men who have been in the US longer are less likely to be obese, with no apparent relationship between time since arrival and obesity for women. These findings point to the importance of examining gender differences in health within Arab populations, as there are distinctly different outcomes for men and women.

Conclusions

Our findings, while preliminary, indicate that there may be different associations between acculturation and health behaviors and outcomes for Arab immigrants compared to other foreign-born groups in the US. Contrary to other studies of immigrant health, we found that the ability to speak English and greater time in the US were associated with better health behaviors and fewer health problems. These findings could be related to the biased nature of our sample, in that all of the respondents were recipients of health services from our community partner organization. Thus, they may be more likely than other immigrants to receive information about their health. Greater time in the US might have led to more exposure to ACCESS's health education, resulting in our respondents engaging in healthier behaviors and thus a lower likelihood of developing diabetes (and being obese for women). It is also possible that the relationship between speaking English and exercising and lower likelihood of diabetes is a result of higher education, and not the ability to speak English per se. Considering the strong relationship between healthier food consumption, exercise, diabetes, and obesity with our acculturation measures, future research on a larger and more representative sample is imperative to understand the nature of these relationships.

Our findings also indicate that there are distinct relationships between acculturation and some health behaviors and health outcomes for men compared to women. Consistent with other research that includes a gendered analysis, we found that acculturation was associated with health in different ways for men and women, with some relationships (such as the ability to speak English with obesity) apparent for women but not for men. Future study of Arab immigrant health must take into account gender differences in health lifestyle, exposure to health information, and other factors that might contribute to different outcomes for men and women.

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The Metabolic Syndrome Among a West Algerian Population: Which Impact of the IDF, NCEP-ATP III and AHA/NHLBI Criteria? Preliminary Results, ISOR Study (Algeria)

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Key words: *Metabolic syndrome—IDF, NCEP-ATP III and AHA/NHLBI criteria; central obesity; ISOR; West Algeria*

Abstract

Introduction. While it is very useful to identify patients at high cardiovascular risk, the metabolic syndrome is still a subject of controversy regarding its diagnostic criteria. In Algeria, the abnormalities that constitute this syndrome (diabetes, obesity, dyslipidemia, hypertension, etc.) are at high and raised levels. On the other hand, the absence of health standards specific to our population raises the further problem of the syndrome definition and inhibits the development of practical recommendations to develop prevention strategies.

Objectives. The aim of our study is to describe the abnormalities constituting the metabolic syndrome among the adult population living in Oran, and to assess the frequency of the syndrome according to IDF, NCEP-ATPIII and AHA/NHLBI criteria.

Method. A cross-sectional study was conducted in 2008 on a sample of 786 subjects aged 30 to 64 years (ratio M/F = 0.94). The subjects, randomly selected from the list of insured persons residing in the city of Oran, participated in a clinical, anthropometric and biological survey (fasting glucose, triglycerides, total cholesterol, HDL and LDL cholesterol).

Results. The metabolic syndrome was present in 13.7% of men and 23.4% of women as defined by the NCEP/ATPIII, 22.1% of men and 33% of women as defined by the IDF, and 14.2% of men and 27.1% of women as defined by the AHA/NHLBI. In all cases, women were characterized by high prevalence of central obesity (from 45.1 to 67.7%) and reduced HDL-cholesterol (60.6 to 62.3%). Men more often presented elevated glucose values and/or a disorder of glucose metabolism (14.7 to 24.7%), a disorder of blood pressure (40.0 to 41.8%), and hypertriglyceridemia (16.8 to 17.9%).

Discussion. In all cases, women are the group at high risk for metabolic syndrome, given the prevalence of central obesity and low levels of HDL cholesterol. The definition of metabolic syndrome criteria according to NCEP/ATPIII is the most severe given the frequency of its abnormalities among the population.

Introduction

While it is very useful to identify patients at high cardiovascular risk, the metabolic syndrome is still a subject of controversy regarding its diagnostic criteria. In Algeria, the abnormalities that constitute this syndrome (diabetes, obesity, dyslipidemia, hypertension, etc.) are at high and raised levels. On the other hand, the absence of health standards specific to our population raises the further problem of the syndrome definition and inhibits the development of practical recommendations to develop prevention strategies.

The term “metabolic syndrome” describes a clustering of cardiovascular disease (CVD) risk factors of metabolic origin [1, 2]. The World Health Organization (WHO) was the first to propose criteria for diagnosis of the metabolic syndrome [3], followed by the National Cholesterol Education Program (NCEP) Adult Treatment Panel III [1]. The most recent definitions, both in 2005, are from the International Diabetes Federation (IDF) [4, 5] and from the American Heart Association/National Heart, Lung, and Blood Institute (AHA/NHLBI) [6, 7]. Although these organizations proposed to measure the same components, they suggested different combinations and different cut-off points.

Objectives

The aim of our study is to describe the abnormalities constituting the metabolic syndrome among the adult population living in Oran, and to assess the prevalence of the syndrome according to IDF, NCEP-ATP III and AHA/NHLBI criteria.

Method

Population

A cross-sectional study was conducted in 2008 on a sample of 786 subjects aged 30 to 64 years (ratio M/F = 0.94). The subjects, randomly selected from the list of insured persons residing in the city of Oran, participated in a clinical, anthropometric and biological survey (fasting glucose, triglycerides, total cholesterol, HDL and LDL cholesterol). A set of questionnaires was completed, which included details of personal and medical history. All subjects gave their informed consent prior to investigation.

Subjects with pregnancy, fever, infection, complicated DT2, chronic disease (cancer, renal failure) and subjects under treatment (corticoids, immunosuppressive drugs) were excluded.

Laboratory Methods

Blood was collected after a 12-hour fast. Kits from Human Diagnostics (Wiesbaden, Germany) were used for lipid and glucose analyses. A multichannel analyzer (Humastar, Human, Wiesbaden, Germany) was used for colorimetric enzymatic determinations of cholesterol (kit: Monotest Cholesterol with cholesterol esterase, cholesterol oxidase and peroxidase (CHOD-PAP)), triglycerides (kit: Perido- chrom Triglyceride with glycerol phosphate oxidase and peroxidase (GPO-PAP)) and glucose (kit: Glucose, glucose oxidase and peroxidase (GOD-PAP)). LDL cholesterol (LDL-C) was calculated by the Friedewald equation for participants with triglyceride levels < 500 mg/dl. A homogenous assay for measuring HDL levels was used.

Statistical Analysis

The Statistical Package for Social Sciences software, version 11.5 (SPSS Inc., Chicago, Illinois, USA) was used for statistical analyses. Data were summarized by calculating mean and standard deviations for quantitative variables and percentages for categorical variables.

Results

The metabolic syndrome was present in 13.7% of men and 23.4% of women as defined by the NCEP/ATPIII (Table 1), 22.1% of men and 33% of women as defined by the IDF (Table 2), and 14.2% of men and 27.1% of women as defined by the AHA/NHLBI (Table 3). In all cases, women were characterized by high prevalence of central obesity (from 45.1 to 67.7%) and reduced HDL-cholesterol (from 60.6 to 62.3%). Men more often presented elevated glucose values and/or a disorder of glucose metabolism (14.7 to 24.7%), a disorder of blood pressure (40.0 to 41.8%), and hypertriglyceridemia (16.8 to 17.9%).

Table 1. Frequency of the Metabolic Syndrome Abnormalities and Frequency of the Syndrome Defined According to the NCEP-ATP III Definition

<i>NCEP/ATPIII Defined Metabolic Syndrome</i>	<i>Men N=380</i>	<i>Women N=406</i>	<i>Total N=786</i>	<i>P</i>
Waist circumference > 102/88cm	11.3% (43)	45,1% (183)	28,8% (226)	< 0.001
Fasting glucose \geq 1.10 g/l	14.7% (56)	12.6% (51)	13.6% (107)	NS
Blood pressure \geq 130/ \geq 85 mmHg	40.0% (152)	33.5%(136)	36,6% (288)	0.035
Triglycerides \geq 1.50 g/l	16.8% (64)	10.3% (42)	13.5% (106)	0.005
HDL-cholesterol < 0.40/0.50 g/l	26.8% (102)	60.6% (246)	44.3% (348)	< 0.001
NCEP-ATP III syndrome present	13.7% (52)	23.4% (95)	18.7% (147)	< 0.001

Table 2: Frequency of the Metabolic Syndrome Abnormalities and Frequency of the Syndrome Defined According to the IDF Definition

<i>IDF Defined Metabolic Syndrome</i>	<i>Men N=380</i>	<i>Women N=406</i>	<i>Total N=786</i>	<i>P</i>
Waist circumference \geq 94/80 cm	38.4% (146)	67.7% (275)	53.6% (421)	< 0.001
Fasting glucose \geq 1.00 g/l or previously diagnosed Type 2 diabetes	24.7% (94)	19.0% (77)	21.8% (171)	0.03
Raised blood pressure: SBP \geq 130 or DBP \geq 85 mmHg or treatment of previously diagnosed hypertension	41.8% (159)	35.5% (144)	38.5% (303)	0.04
Raised triglycerides \geq 1.5 g/l or a specific treatment for this lipid abnormality	17.9% (68)	12.3% (50)	15.0% (118)	< 0.02
Reduced HDL-cholesterol < 0.4/0.5 g/l (men/women) or a specific treatment for this lipid abnormality	28.4% (108)	62.3% (253)	45.9% (361)	< 0.001
IDF syndrome present	22.1% (84)	33.0% (134)	27.7% (218)	< 0.001

Table 3: Frequency of the Metabolic Syndrome Abnormalities and Frequency of the Syndrome Defined According to the AHA/ NHLBI Definition

<i>AHA/NHLBI Defined Metabolic Syndrome</i>	<i>Men N=380</i>	<i>Women N=406</i>	<i>Total N=786</i>	<i>p</i>
Waist circumference > 102/88 cm	11.3% (43)	45.1% (183)	28.8% (226)	< 0.001
Fasting glucose \geq 1.00 g/l or previously diagnosed type 2 diabetes	24.7% (94)	19.0% (77)	21.8% (171)	0.03
Raised blood pressure: SBP \geq 130 or DBP \geq 85 mmHg or drug treatment for hypertension	41.8% (159)	35.5% (144)	38.5% (303)	0.04
Raised triglycerides \geq 1.5 g/l or drug treatment for elevated triglycerides	17.9% (68)	12.3% (50)	15.0% (118)	< 0.02
Reduced HDL-cholesterol < 0.4/0.5 g/l (men/women) or drug treatment for reduced HDL cholesterol	28.4% (108)	62.3% (253)	45.9% (361)	< 0.001
AHA/NHLBI syndrome present	14.2% (54)	27.1% (110)	20.9% (164)	< 0.001

Discussion

While our data show a higher level of the MetS prevalence in the studied population compared to the French population [8], it seems to be less frequent than the Turkish [9]. The prevalence of MetS was higher among women (33% [IDF], 27% [AHA] and 24% [NCEP]) compared to men (22% [IDF], 14% [AHA] and 13% [NCEP]), while no gender differences were observed in the European and American studies [8, 9, 10]. In all cases and according to the three definitions, women are more affected by metabolic syndrome, with a high prevalence of central obesity (45.1% to 67.7%) and reduced HDL-C (60.6% to 62.3%).

Our data show distinct differences in the prevalence of metabolic syndrome. The variability in prevalence estimates reflects different cut-off points and different combinations of criteria among various definitions. The prevalence estimates of National Cholesterol Education Program Adult Treatment Panel III and AHA definitions are close to each other. But the prevalence of the metabolic syndrome according to IDF definition is high and closely related to the lowest waist circumference criteria. The IDF waist circumference criteria raise by 50% the syndrome prevalence among women and 300% among men. The question is whether this strong increase, especially among men, is a clinical combination with other risk factors.

It is now urgent to determine the thresholds values of waist circumference, the most adapted to the Algerian people, particularly men. The new recommendations should facilitate the assessment of patients at high risk for cardiovascular disease and diabetes.

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Prevalence and Possible Risk Factors of Blood Borne Infections Among Nurses of Mansoura University Hospitals, Egypt

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Key words: *Prevalence, risk factors, blood-borne infections, nurses, Egypt*

Abstract

Aim of the study. A cross sectional analytic study was conducted to identify the prevalence of blood-borne infections (BBIs) among nurses exposed to patients' blood and body fluids and to assess the possible risk factors that may expose nurses to the risk of BBIs.

Material and methods. The study was conducted in the Oncology Center and the Oncology Department of the Pediatric Hospital at Mansoura University during four months from March to June 2009.

The study covered two groups: a study and a control group. The study group consisted of all 88 female nurses who had been exposed to patients' blood and body fluids during direct patient care. The control group consisted of a sample of 29 administrative employees. All controls were females in the same age group of nurses. Two tools were used in the study: (1) risk factors of blood-borne viral infection assessment questionnaires, and (2) prevalence of blood-borne viral infections.

Results. The study showed that 31 nurses (35.2%) were positive for hepatitis infection as compared to 3 in the control groups (10.3%). The difference was statistically significant ($P < 0.05$). The proportion of HCV positive nurses was significantly higher compared to the control group (27.3% and 6.9% respectively, $P < 0.05$). The frequency of HBV positive subjects was 7.9% and 3.4% among the study and control groups respectively. However, this difference was not proved to be statistically significant ($P > 0.05$). Percutaneous injury was the commonest risk factor due to exposure of nurses to sharps and needle stick injuries during patient care (69.3%), and recapping of used needles by two hands (63.6%). Mucocutaneous transmission through contact and exposure of nurses' hands to patients' blood and body fluids occurred in 61.4% of nurses.

Conclusions and recommendations. The study concluded that nurses were at high risk of becoming seropositive for viral hepatitis as compared to controls. Occupational risk factors studied were proved to be highly significant. Non-occupational risk factors had the same impact on nurses and controls. Implementing an awareness program would markedly improve nurses' knowledge and performance regarding measures for the prevention and control of BBIs. The study recommended periodic staff training on a regular basis regarding infection control measures. In addition to HBV vaccination, an infection control manual containing all of the infection control policies and procedures would help nurses to avoid infecting themselves or the patients they serve. Nurses should have in place a system that includes written protocols for prompt reporting, evaluation, counseling, treatment, and follow-up of occupational exposures that may place a nurse at high risk of BBIs.

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Introduction

Exposure to blood-borne pathogens poses a serious risk to health care workers (HCWs). Transmission of at least 20 different pathogens by needle stick and sharp injuries has been reported [1]. Three blood-borne viruses are most commonly involved in occupational transmission, namely human immunodeficiency virus (HIV), hepatitis B virus (HBV), and hepatitis C virus (HCV) and are the focus of the present study.

Transmission of infection occurs predominantly by percutaneous, mucosal or mucocutaneous exposure of HCWs to the blood and body fluids of infected patients. This includes needlesticks and other sharps injuries; direct inoculation of virus into skin scratches, lesions, abrasions, or burns; and inoculation of virus onto mucosal surfaces of the eyes, nose, or mouth through accidental splashing [1].

Health care workers with frequent blood or needle stick exposures are reported to have a twofold higher prevalence of HBV infection than other HCWs [2]. Physicians and nurses in specialties that involve frequent blood or needle stick exposure have a significantly elevated risk of HBV infection compared to specialists with less-frequent blood or needle stick exposure [3]. The risk of transmission after a needle stick exposure to a non-immune person is at least 30% if the source patient is HBeAg positive but is less than 6% if the patient is HBeAg negative [4]. Studies on HCWs have estimated that the average risk of viral transmission after percutaneous exposure is 6 to 30% for HBV, and approximately 1.8% for HCV and 0.3% for HIV [5].

A lack of nurses' awareness regarding infection control measures, an absence of training programs, especially for the newly hired, insufficient safety devices for disposal of needles and sharps, and a lack of vaccination against hepatitis B virus infection are the main causes of acquiring BBIs among them [6]. Increased nurses' awareness, education and in-service training programs along with effective communication, convenient placement of sharps containers, and compliance with the practice of standard precautions [7] have been shown to decrease rates of exposure of needle stick injuries by 60% among HCWs, thus reducing the risk of BBI [8].

Aim of the Study

The aim of this study was to identify the prevalence of blood-borne viral infections (BBIs) among nurses exposed to patients' blood and body fluids during their routine nursing care, and to assess the possible risk factors that may expose nurses to the risk of infections.

Materials and Methods

Design and Settings

A cross sectional analytical study was conducted in the Oncology Center and Oncology Department of the Pediatric Hospital over four months from March to June, 2009.

Participants

Two groups were included.

The *study* group consisted of 88 female nurses employed in the previously mentioned setting, who had been at risk of exposure to patients' blood and body fluids during direct daily patient care for a minimum of two years.

The *control* group consisted of 29 administrative female employees, in the same age group as the nurses, from the same hospital setting, whose occupation did not expose them to patients' blood or body fluids. All of the participants lived in the same governorate and the same country; all of them were notified that these data would be used for the research study and that their confidentiality and their rights to withdraw at any time would be maintained.

Tools of the Study

Two tools were used for data collection.

Tool I

Risk factors of blood-borne infections assessment questionnaire. This tool was designed in Arabic by the researchers to assess the occupational and non-occupational risk factors that might predispose the studied groups to the risk of acquiring BBIs. It consisted of four pages and 80 questions, which generally required 30 to 45 minutes to answer. It included three main parts.

- Section 1 included questions about the socio-demographic characteristics of the study groups, including: sex, age, occupation, education, marital status, and duration of work in nursing.
- Section 2 consisted of 68 questions about work practices and occupational risk factors, including: attending infection control training programs, hospital policies for infection control and in-service training and educational programs, and systems for dealing with occupational hazards. Nurses were asked to recall the number of PIs sustained during their daily routine nursing care and the number of PIs and mucocutaneous and nonintact skin exposures they experienced and reported during the prior 6 months. Nurses were also asked how often (never, occasionally, or frequently) they came into contact with blood or handled contaminated needles as part of their current job duties. Several items addressed hepatitis B vaccination history, including the number of doses, the year of last dose, and the results of post-vaccination testing, if performed. Nurses were also asked to report their practices for the prior 6 months with respect to universal precautions and standard precautions.

Occupational risk factors. Occupational exposure was defined as percutaneous injuries (PIs) (i.e., contaminated needlesticks or cuts with contaminated sharp devices) and mucocutaneous or nonintact skin contact with blood.

- Section 3 consisted of 12 questions about non-occupational risk factors for infection with blood-borne pathogens. Participants were asked to report on a number of variables designed to assess the risks of HBV, HCV and AIDS infection related to personal and medical histories (e.g., number of lifetime liver diseases and history of jaundice, history of blood transfusion before 1990, hemodialysis, malpractice sexual contact, injection drug use, major/minor surgery, dentist visits, and bilharziasis in addition to family history of liver diseases. One mark was given when done correctly and zero if incorrect or not done. The total mean was taken and a percentage of 100% was calculated.

Tool II

Prevalence of blood-borne viral infections. This tool was also developed by the researchers to identify the prevalence of blood-borne viral infections (HBV, HCV, and HIV) among the studied groups. It included code number, date of withdrawal of blood sample, and results of serological testing.

Methods

Official permission to conduct the study was obtained from the Ethics Committee, the Directors, and a responsible specialist of the chosen setting after explaining the aim and nature of the study. Tool I was developed in simple Arabic language by the researchers. The validity and reliability of the tools were ascertained by a jury of 11 experts in the fields of medicine and nursing. Modifications were done accordingly. A pilot study was conducted with 10 nurses to test the clarity, arrangement, and applicability of the tools. Modifications were done for some items, and some were excluded from the tool. A preliminary contact with nurses was carried out to assess their willingness to share and participate in the study and to get their informed consent. Permission was obtained from the nurses; they were assured that their confidentiality and anonymity would be maintained throughout the study.

Risk Factors of Blood-Borne Infections Assessment Questionnaires (Phase I)

The questionnaire was distributed to participants and participants were given time to answer it in the presence of the researcher to ensure clarity and understanding. The right to withdraw was also given to respondents. Ethical commitment with regard to informed consent, confidentiality, and anonymity throughout the process was maintained. The names of respondents were not used in the study. The participants were informed that the findings would only be used for the study. During this phase the risk factors questionnaire sheet was completed by the study groups.

Surveillance of Infections (Phase II)

Blood samples of both groups were sent to the Medical Microbiology and Immunology Department to test for evidence of BBIs. Viral hepatitis serological testing of all serum samples obtained from the two groups included 2 main tests to detect positivity to HBV and HCV for the purpose of the current study.

- *HCV antibody detection.* The HCV antibody status was determined using the Murex anti-HCV (Version 4) from Murex Biotech S.A. according to the manufacturer's recommendations. The test is an enzyme immunoassay for the detection of antibodies to HCV in human serum or plasma. Positive serology for hepatitis C is defined by the presence of antibodies against HCV (anti-HCV) in serum.
- *HBs antigen detection.* The HBs antigen was tested using the commercially available HBs Enzyme Immunoassay kit from DiaSorin S.R.L., Saluggia, Italy. The method for qualitative HBsAg determination is a direct sandwich assay based on the ELISA technique.

Other serological tests were done to complete the battery of investigations for seropositive cases. Significance of these tests is shown in Table 1.

Table 1. Significance of Serological Tests

Interpretation	HBsAg	Anti-HBs	Anti-HBc Total	Anti-HBc IgM	HbeAg	Anti-HBe
Early HBV infection, asymptomatic	+	-	-			
Acute HBV hepatitis	+		+	+		
Chronic HBV infection	+	-	+	-		
Chronic HBV hepatitis, replicating	+			-	+	-
HBV exposure with recovery/ immunity		+/-	+			

* Hepatitis B surface antigen (HBsAg)

* Antibody to hepatitis B core antigen (anti-HBc)

* Hepatitis B e antigen (HBeAg)

* Immunoglobulin M (IgM) antibody to HBc

These tests included:

- *HBV core Total Antibody (IgG and IgM).* The HBc IgG was tested using the Anti-HBc Reagent Pack (Vitros Immunodiagnostic Products) for the in vitro qualitative detection of total antibody (IgG and IgM) to hepatitis B core antigen (total anti-HBc) in human adult and pediatric serum and plasma.
- *HCV RNA detection.* HCV RNA was detected using the RT-PCR using the Biosewoom HCV PCR kit (Catalog number BS 3204-2) from Biosewoom Inc. Seoul Korea. Total RNA was prepared from serum samples according to the manufacturer's instructions. RNA extraction from all samples in both groups was done under the same conditions. Each time, 20 samples (10 samples from cases with HCV and 5 samples each from HBV and control group) were extracted to equalize conditions for both groups. Amplified RNA products were visualized after electrophoresis on agarose gel containing ethidium bromide as described [10].

Statistical Methods

Results of the study were analyzed statistically using SPSS. This included descriptive statistics of categorical variables (percentages). The analytical part included comparison of frequencies by the chi-square test with comparison of seropositive and seronegative cases. The threshold of significance was fixed at the 5% level ($p \leq 0.05$). The relative frequencies were computed by division of prevalence among seropositive cases by prevalence among seronegative cases. The difference between prevalence in the 2 groups was tested for statistical significance using the chi-square test. The relative frequencies helped to rank risk factors related to seropositivity.

Results

Demographic Characteristics of the Nurses Under Study

The study consisted of 88 female nurses who had been at risk of exposure to patients' blood and body fluids during direct patients care during the study period. More than 50% of the nurses were between 30-40 years of age. Most of them were married (89%). The majority of them (80%) had a diploma in nursing and more than 45% of them had > 20 years of experience.

Blood Borne Viral Infections

All samples were HIV negative.

Thirty-one nurses (35.2%) were positive for hepatitis viral infection as compared to 3 in the control group (10.3%). The difference was statistically significant ($P < 0.05$).

The frequency of HCV was 27.3% and 6.9% in the study and control group respectively, and the difference was statistically significant ($P = 0.02$). The frequency of HBV was 7.9% and 3.4% in the study and control group respectively. However, this difference was not proved to be statistically significant ($P = 0.36$; see Table 2).

Table 2. Results of Surveillance of Blood-borne Viral Infections Among Study and Control Group

<i>Blood borne viral infection</i>	<i>Study Group (n=88)</i>		<i>Controls (n=29)</i>		<i>X² Value</i>	<i>P Value</i>
	<i>N</i>	<i>%</i>	<i>N</i>	<i>%</i>		
HCV positive	24	27.3	2	6.9	5.24	0.02
HBV positive	7	7.9	1	3.4	0.69	0.36 (NS)
Total	31	35.2	3	10.3	6.52	< 0.05

HBsAg positivity was observed only among the non-vaccinated (7.95% compared to 0.0% among the vaccinated). The difference in positivity among vaccinated and non-vaccinated groups was highly significant ($p < 0.001$). (Table 3).

Table 3. HBsAg Positivity in Relation to Vaccination Status

<i>Vaccination Status</i>	<i>Number of Subjects</i>		<i>HBsAg Positive</i>
Fully vaccinated	10	0	(0.0%)
Incomplete course of vaccination	6	0	(0.0%)
Not vaccinated	72	7	(7.95%)
Total	88	7	(7.95%)

Chi square test was significant for all risk factors at $p > 0.001$.

Occupational Risk Factors

Percutaneous injury, exposure of nurses to sharps, and needle stick injury during patient care were the most common risk factors (69.3%, Table 4). Recapping the used needles using 2 hands, bending or breaking needles was 63.6%.

Mucocutaneous transmission through contact and exposing nurses' hands to patients' blood and body fluids was the next most frequent risk factor, accounting for 61.4% of all nurses.

Percutaneous injury through giving intravenous injections and inserting a cannula was the next most frequent risk factor, accounting for 60.2% of nurses.

Percutaneous injury and exposure of nurses to sharps and needle stick injury from accidental exposure to bedding and handling linens as well as mucocutaneous transmission through accidental splashing of patients' blood and body fluids onto the mucosal surfaces of eyes, nose or mouth represented 44.3%.

The least frequent risk factors were mucocutaneous transmission through exposure of nurses' hands to patients' blood and body fluids due to uncovered abrasion/small wounds (39.8%), followed by percutaneous injury from giving intramuscular injection and during cleaning, disinfection and sterilization of instruments (36.4%). All these differences were highly significant statistically.

**Table 4. Potential Occupational Risk Factors
Among Nurses in the Study Group (n=88)**

<i>Work practice and occupational risk factors</i>	<i>No.</i>	<i>%</i>
I. Attending training program about		
• Hospital infection control	13	14.8
• Occupational health and safety	5	5.7
• Prevention and control of BBIs	3	3.4
II. Percutaneous injury (exposure to needlestick and other sharp injuries) among 88 nurses studied		
Exposure of nurses to sharps and needlestick injury during patient care	61	69.3
• When recapping the used needle using two hands, bending or breaking needles	56	63.6
• When giving intravenous injection and inserting cannula	53	60.2
• Accidental from bedding, linens...	39	44.3
• When giving intramuscular injection	32	36.4
• Cleaning, disinfection and sterilization of instrument	32	36.4
Measures taken after exposure (61 nurses)		
• Disinfect the injury site with alcohol	32	52.5
• Squeeze the injury site	24	39.3
• Handwashing with soap and water	17	27.9
• Nothing	8	13.1
Frequency of exposure to needle stick and sharps injuries (61 nurses)		
• Frequent	34	55.8
• Occasional (less than 5 times)	16	26.2
• Rare (once/twice)	11	18.0
Reaction of nurses to needle stick and sharp injuries (61 nurses)		
Report about exposure of needle stick and sharp injuries		
• Reported	12	19.7 %
• Not reported	49	80.3 %
Reasons for not reporting about exposure to sharp injuries (n = 49)		
• The patient did not complain of infectious diseases	48	97.9
• Unawareness of the importance of reporting	45	91.8
• Lack of knowledge about whom to report	44	89.8
• Needlestick and sharps injuries were too minor to be reported	43	87.8
• Lack of knowledge of the hazards and danger of needle stick and sharps injuries	40	81.6
• Reporting should only be when exposure to infectious patients	38	77.6
• Lack of time	20	40.8
• Feeling of security due to previous negative lab results	7	14.3
• Feeling secure for being vaccinated against HBV	3	6.1
Intervention and follow up after exposure		
• Counseling and /or receive post-exposure prophylaxis treatment of exposed nurses	8	66.7
• Follow-up after exposure	3	37.5

continued on next page

III. Mucocutaneous transmission (exposure to patients' blood and body fluids) among 88 nurses studied		
Contact and exposing nurse's hands to patients' blood and body fluids	54	61.4
Reasons of contact and exposing nurse's hands to patients' blood and body fluids (54 nurses)		
• Wearing gloves leads to more difficult to work and deal with patients	51	94.4
• Presence of disposable gloves but not sufficient	41	75.9
• Absence of disposable gloves	38	70.4
• No need for wearing gloves (no value/useless)	34	62.9
• Pressure of work did not permit wearing gloves	29	53.7
Accidental splashing of patients' blood and body fluids onto the mucosal surfaces of the eyes, nose, or mouth	39	44.3
Reasons of accidental splashing of blood and body fluids onto mucosal surfaces (39 nurses)		
• Load of work	32	82.1
• Insufficient amount of personal protective equipment (PPE)	28	71.8
• Wearing PPE is only for infectious patients	27	69.2
• Presence of personal protective equipment (PPE), but not used	13	33.3
	35	39.8
Exposure of nurses' hands to patients' blood and body fluids due to uncovered abrasion/small wounds		

Non-Occupational Risk Factors

The prevalence of non-occupational risk factors did not differ markedly between nurses and controls. History of blood and/or blood product or transfusion was higher among the study group compared to controls (6.8% and 3.4% respectively). All differences were statistically non-significant (Table 5).

Table 5. Potential Non-Occupational Risk Factors Among the Study and Control Groups

<i>Risk Factors</i>	<i>Study Group N=88</i>		<i>Control Group N=29</i>	
	<i>No.</i>	<i>%</i>	<i>No.</i>	<i>%</i>
Family history of liver diseases	28	31.8	10	34.5
Exposure to dental care and/or oral surgery	27	30.7	8	27.6
Past history of major/minor surgery	71	80.7	21	72.4
Past history of bilharzias diseases and IV treatment	12	13.6	5	17.2
History of blood and/or blood product or transfusion	6	6.8	1	3.4

The Relative Prevalence of Risk Factors in Seropositive and Seronegative Nurses

Table 6 displays the frequency of risk factors among serological positive and negative nurses.

1. All seropositive nurses (100%) were at risk of percutaneous injury, compared to 52.6% of seronegative nurses with a relative prevalence = 1.9.
2. All seropositive nurses were exposed to the risk of percutaneous transmission through recapping used needles using two hands or bending or breaking needles, as compared to 43.8% of seronegative nurse with relative prevalence of 2.1.

3. The relative prevalence of mucocutaneous transmission was 2.1 with prevalence 93.5% and 43.8% among seropositive and seronegative nurses respectively.
4. The relative prevalence of giving intramuscular injection and cleaning, disinfection and sterilization of instrument was 2.1 with a prevalence of 90.3% among seropositive nurses and 43.8% of seronegative nurses.
5. Accidental splashing of patient's blood and body fluids onto the mucosal surfaces of the eyes, nose, or mouths occurred in 77.4% of seropositive nurses and 26.3% of seronegative nurses (relative prevalence 3.1).

Table 6. Frequency of Risk Factors Among Serological Positive and Negative Nurses and Relative Prevalence (n = 88)

I. Occupational Risk Factors	Total Results		+ ve n=31		— ve n=57		X ² Value	Relative Prevalence
	No.	%	No.	%	No.	%		
Percutaneous injury (exposure to needle stick and other sharp injuries)								
Exposure of nurses to sharps and needle stick injury during patient care	61	69.3	31	100	30	52.6	21.18	1.9
• When recapping the used needle using two hands, bending or breaking needles	56	63.6	31	100	25	43.8	27.35	2.3
• When giving intravenous injection and inserting cannula	53	60.2	31	100	30	52.6	21.18	1.9
• Accidental from bedding, linens...	39	44.3	25	80.6	19	33.3	17.97	2.4
• When giving intramuscular injection	32	36.4	28	90.3	25	43.8	15.96	2.1
• Cleaning, disinfection and sterilization of instrument	32	36.4	28	90.3	25	43.8	15.96	2.1
Mucocutaneous transmission (exposure to patients' blood and body fluids)								
• Contact and exposing nurse's hands to patients' blood and body fluids	54	61.4	29	93.5	25	43.8	24.88	2.1
• Accidental splashing of patients' blood and body fluids onto the mucosal surfaces of the eyes, nose, or mouth	39	44.3	24	77.4	15	26.3	21.25	3.1
• Exposure of nurses' hands to patients' blood and body fluids due to uncovered abrasion/small wounds	35	39.8	22	70.9	13	22.8	19.44	2.9

Blood Borne Infection-Related Knowledge and Performance of Nurses

Nurses' level of knowledge was highest for general information about BBIs (32.9%), followed by measures to prevent and control BBIs (22.7%); it was lowest for establishing a written exposure control plan. After implementation of the program, nurses' knowledge of general information about BBIs and measures to prevent and control BBIs increased significantly to 97.7% and 98.9%, respectively.

Regarding performance evaluations, nurses were observed before and after for a set of procedures needed to prevent and control BBIs among nurses. The frequencies of procedures done correctly before the program were generally low, and some of them were almost never done correctly, as shown above. After implementation of the program, the frequencies of procedures done correctly increased significantly; some procedures were done correctly by more than 90% of nurses.

Discussion

This study was carried out with 88 nurses working at the Oncology Center and the Oncology Department of the Pediatric Hospital at Mansoura University. The majority of nurses had a diploma in nursing, while a minority had a bachelor's degree in nursing. A majority of nurses were between the ages of 30 and 40 years; a minority was between the ages of 40 and 45 years. A majority had more than 20 years of experience.

The present study aimed to first identify the prevalence of blood-borne viral infections among nurses exposed to patients' blood and body fluids and related risk factors. According to NNIS [11] the goal of surveillance of healthcare workers exposed to blood/body fluids and blood-borne pathogens is to monitor HCWs' occupational exposures to blood or body fluids and follow subsequent seroconversions to blood-borne viruses. Nevertheless, Lymer et al. (1997) stated that the purpose of health care workers' action strategies in situations that involve a risk of blood exposure was to identify processes and factors of importance for the choice of strategy in situations involving risk of blood exposure [12]. Also, Gaynes (1999) mentioned that to assess the risk of blood-borne transmission by such exposures, HCWs with blood exposure have been examined [13].

Kumar et al. (2004) added that the rationale for health surveillance is to detect adverse health effects resulting from occupational exposure at as early a stage as possible, so that appropriate preventive measures can be instituted [14].

Regarding surveillance of blood-borne infections: HCV represented the most BBIs among the study group (27.3%). In contrast, Lymers et al. (1997) reported that, although "occupational exposure" accounts for about 2% of all cases of hepatitis C [12], the seroprevalence of HCV among health care workers is roughly similar to that of the general population (about 1%) [15]. Seroconversion occurs in 1.2% to 10% of non-immune health care workers who receive needle stick from a source patient with hepatitis C [16]. Also, Puro, Petrosillo, and Ippolito (1995) added that follow-up studies of HCWs who sustained percutaneous exposures to blood from anti-HCV-positive patients have found variable rates of HCV transmission [17]. However, the average incidence of anti-HCV seroconversion after needle stick or sharps exposure from a known anti-HCV-positive source patient is 1.8% (range, 0 to 7%) [18]. Moreover Carman (1997) mentioned that HCV infection may be between 3% and 10% among healthcare workers [19]. In one study conducted in Japan, which included PCR testing for HCV RNA in source patients and HCWs, the risk of transmission after a needle stick exposure from a source patient with HCV RNA-positive blood was 10% [20].

The high HCV prevalence could be attributed to several occupational risk factors, including: percutaneous injury (69.3%); mucocutaneous transmission (61.4%); a lack of training programs in blood-borne diseases (96.6%); occupational health and safety (94.3%); hospital infection control (85.2%); an absence of administrative policy regarding a system to protect healthcare workers from occupational hazards (96.6%); an absence of in-service continuous training programs (90.9%); and an absence of policies and procedures (89.8%).

HBV positivity was recorded only in nurses who were not fully vaccinated. This stresses the importance of providing opportunities for full vaccination to all nurses exposed to the risk of acquiring HBV.

Conclusion and Recommendations

Nurses are at high risk of becoming seropositive for viral hepatitis as compared to controls. Occupational risk factors studied are proved to be highly significant as evidenced by the high prevalence among nurses compared to controls. Most of the non-occupational risk factors had the same impact on nurses and controls.

The study recommended periodic staff awareness and training on regular basis regarding infection control measures. Vaccination against HBV is an important protective factor; all nurses at risk should be fully vaccinated. Such awareness programs, together with hepatitis B vaccination, could markedly protect nurses against acquiring BBIs. In addition, infection control manuals containing all the infection control policies and procedures would help nurses to avoid infecting themselves or the patients they serve. Nurses should have in place a system that includes written protocols for prompt reporting, evaluation, counseling, treatment, and follow-up of occupational exposures that may place a nurse at risk of BBIs. Nurses should be covered by exposure control plans and comply with incident reporting.

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Pharmacogenetics and Health Care Rationing: Rough Justice, Ragged Edges, Rugged Moral Terrain

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Key words: *Pharmacogenetics, health care rationing, medical ethics, personalized medicine*

The phrase “personalized medicine” has a built-in positive spin. Simple genetic tests can often predict whether a particular individual will have a positive response to a particular drug or, alternatively, suffer costly and debilitating side effects.¹ In the case of these extraordinarily expensive targeted cancer therapies (with costs in the range of \$50,000 – \$130,000 for a course of treatment) these genetic tests would seem to yield nothing but unvarnished good for both individuals (spared pointless suffering from side effects) and society (spared the enormous waste of limited financial resources). Furthermore, the cost of acquiring the complete set of genetic data on an individual has plummeted from about \$2.7 billion a decade ago to about \$10,000 today and \$1,000 within the next couple years.²

Very challenging justice issues are raised by these advances related to cancer genetics. For example, how should we (citizens and physicians in a just and caring society) determine the precise characteristics of patients who would have a prima facie just claim to access very expensive drugs that would be more likely to be therapeutically beneficial because of either their own genetic characteristics or the genetic characteristics of their cancer? We need to keep in mind that what we are buying for \$100,000 or more are extra weeks or extra months of life on average.³ But those averages often hide wide variations in gains in life expectancy. We might have one sort of moral problem if those extraordinary gains in life expectancy were more or less randomly dispersed in a population of cancer patients being treated with a specific drug (and we had no way of identifying those patients before the fact). But what if those extraordinary gains are linked in some way to patients with a specific genotype and we have the capacity to test for that genotype before any of these costly drugs are given? That raises more challenging problems of health care justice.

Why is there a problem of health care justice? Should we not just provide these drugs to everyone with a cancer diagnosis who can benefit to any degree at all from access to these drugs? There are several possible lines of moral argument that might be offered to justify an affirmative answer to this question. We might say that human life is priceless, and, consequently, we ought not to deny patients access to these costly drugs merely because they cost a lot. Or, we might say that these drugs represent a “last chance” therapy. That is, these are patients who are facing a terminal outcome. They have no alternative for prolongation of their lives other than these drugs. It would be uncaring and inhumane (the argument goes) to deny these patients their last chance for some additional life. Or, we might argue that these patients are among the “medically least well off” because they are faced with a terminal illness, the implication being that they should have very high priority for access to these costly cancer drugs. Further, someone making any of these arguments might say that these were the moral considerations that justified our putting in place in 1972 the End Stage Renal Disease (ESRD) amendments to the Medicare program that paid for dialysis for all patients with end-stage renal disease who had no other life-prolonging options. In 2011 this program sustained the lives of about 470,000 patients at a cost of about \$32 billion. Hence, the additional

- 1 For examples, see the following articles: The International Warfarin Pharmacogenetics Consortium, “Estimation of Warfarin Dose with Clinical and Pharmacogenetic Data,” *New England Journal of Medicine* 360 (2009): 753-64. J. L. Mega et al., “Cytochrome P-450 Polymorphisms and Response to Clopidogrel,” *New England Journal of Medicine* 360 (2009): 354-62. The SEARCH Collaborative Group, “SLCO1B1 variants and Statin-induced Myopathy: A Genomewide Study,” *New England Journal of Medicine* 359 (2008): 789-99.
- 2 N. J. Samani et al., “The Personal Genome: The Future of Personalised Medicine?” *The Lancet* 375 (2010): 1497-98.

argument would be, there are “equal rights” considerations that would require that cancer patients receive a comparable level of social support as these renal patients.

This last conclusion is not obviously unreasonable. However, the cost of health care overall has changed dramatically in the forty years since those 1972 ESRD amendments were put in place. In 1970 in the US we were spending only a bit more than \$50 billion on health care in the aggregate, roughly 6% of our GDP at the time. In 2011 we spent \$2.7 trillion on health care, roughly 17.8% of our GDP (with projections to 2019 that we will be spending \$4.5 trillion then and 20% of our GDP). This is creating enormous political, economic, and moral problems as health care expenditures crowd out spending money on other important social goods, such as education. The problem we are faced with is what I have labeled the “just caring” problem. I formulate the problem with this question: What does it mean to be a just and caring society when we have only limited resources to meet virtually unlimited health care needs? We have only “limited resources” in the form of money. Roughly 46% of those \$2.7 trillion we spent on health care were publicly financed through taxes. Voters seem to be demanding that taxes be reduced, or at least not allowed to rise anymore. But health care costs have continued to increase at roughly 2.5 times the core rate of inflation in the economy for each of the past forty years. These increases are largely a product of the rapid emergence of new and costly medical technologies in virtually all areas of medicine. The other 54% of health care costs come from the private side of the economy where employers and workers are demanding that something be done to control health care costs that are otherwise either eroding the buying power of their paychecks or adding to the costs of the products they are selling, thereby making their business less competitive in world markets.

The other part of the just caring problem is that we have unlimited health care needs. Again, what is happening is that these emerging medical technologies are in fact creating new medical needs that are then met by those technologies. No one “needed” bypass surgery or coronary angioplasty before those procedures were invented. But about 1.6 million Americans needed one or another of those procedures in 2011 at an aggregated cost of more than \$80 billion. The same is true with regard to the extraordinarily expensive cancer drugs we mentioned above. Roughly 600,000 Americans die of cancer each year, all of whom would presumptively have a “need” for one or another of these cancer drugs.

The most important moral implication of the just caring problem is that the need for health care rationing is inescapable.⁴ If we have limited resources and unlimited health care needs, then we have to make choices regarding what we will or will not fund so far as health care needs are concerned. If we allowed any of the rationales mentioned above (“last chance” therapy, patients who are least well off, or the pricelessness of human life) to require the funding of these cancer drugs, the problem of health care cost escalation and the need to make just rationing decisions would become even more intractable as we purchased huge quantities of very marginal health benefits at excessively high cost. As things are now, individuals who are fortunate enough to be well insured can access almost anything the health care system has to offer at social expense, no matter how marginally beneficial. But such liberal access itself drives up the cost of health insurance to employers, some of whom will simply stop offering this as a benefit. This is why the US now has about 51 million uninsured individuals who have very little access to needed (and very effective) health care. The result, as demonstrated by the Institute of Medicine, is that 22,000 – 40,000 uninsured Americans die prematurely each year because they cannot afford to access in a timely way the health care that would otherwise save their life. This is one reason why there is a problem of health care justice that is intrinsic to the problem of health care rationing.

Fojo and Grady point out that we are paying \$800,000 per quality adjusted life year (QALY) when these cancer drugs cost \$100,000 or more for a course of treatment and yield such small gains (six weeks) in life expectancy. If every patient with every end-stage cancer had a right to this level of care, we would be saying (from a cost-effectiveness perspective) that it was worth \$440 billion per year for such modest gains. Economists ask whether this is affordable cost-effective health care. Health care ethicists ask whether this is either a just or prudent use of limited health care resources.

Consider: A recent trial of patients with advanced breast cancer compared their being treated with paclitaxel alone to paclitaxel plus bevacizumab (a targeted biologic).⁵ Median survival in those two arms was virtually indistinguishable: 25.2 months vs. 26.7 months. One could say that bevacizumab increased median overall survival by six weeks. However, when specific genotypes were analyzed there were very marked median differences in survival.

The median overall survival times for the subgroup with the VEGF-2578AA genotype was 37.0 months and for the subgroup with the VEGF-1154AA genotype 46.5 months. In addition, if the VEGF genotype of an individual was AA/AA,

4 The full argument for my claim that the need for health care rationing is inescapable is made in my book, *Just Caring: Health Care Rationing and Democratic Deliberation* (Oxford University Press, 2009), especially chapters 1 and 2.

5 B. P. Schneider et al. “Association of Vascular Endothelial Growth Factor and Vascular Endothelial Growth Factor Receptor-2 Genetic Polymorphisms with Outcome in a Trial of Paclitaxel Compared with Paclitaxel Plus Bevacizumab in Advanced Breast Cancer: ECOG 2100,” *Journal of Clinical Oncology* 26 (2008): 4672-78.

median survival was 49.7 months. But if their VEGF genotype was AA/GA, median survival dropped to 30.2 months. And individuals with a VEGF genotype of CC/GG had a median survival of only 21.7 months. Finally, the AA/AA subgroup represented 7.6% of the cohort; AA/GA represented 11.4%; and CC/GG represented 32.9%.

About 44,000 women die of breast cancer each year in the US. If all those women received paclitaxel plus bevacizumab, the cost would be \$4.4 billion. Which of these women should have a just claim to bevacizumab? What considerations of health care justice ought to determine our judgment? Should the fact that this is a “last chance” therapy be determinative, or that all these patients are among the “medically least well off,” or that human life is “priceless”? If any of these factors are determinative, then no distinctions will be made among these patients. But if we consider cost-effectiveness alone, then the AA/AA genotype subgroup has the strongest just claim. Each QALY achieved there would cost about \$50,000, and aggregate costs would be reduced to about \$350 million.⁶ Would the AA/GA subgroup have just cause to complain if their access to bevacizumab were not socially underwritten? They would only gain five months in additional life expectancy, which would yield a cost per QALY of \$240,000. Aggregate costs for bevacizumab would rise to about \$1 billion. However, the next genotype subgroup on the list, CA/GA, would achieve a median survival of 27.1 months. This group represented 20.9% of that patient cohort and an additional \$1 billion in costs. This group would gain on average only two extra months of life at a cost per QALY of \$600,000.

To many it might seem reasonable and fair to deny these individuals access to bevacizumab at social expense. However, we can imagine an egalitarian-based argument from those with this last genotype. In brief, if society is willing to spend \$100,000 to prolong the lives of each of those AA/GA individuals (same disease as me) for a very modest gain in life expectancy, then society ought to be willing to spend that same \$100,000 for each of us with the CA/GA genotype. We too want as much life as possible of acceptable quality, even if it is a bit shorter than someone else's.⁷

The moral challenge here is what Callahan has perspicuously dubbed the “ragged edge.”⁸ There is no perfectly neat, perfectly reasonable, perfectly just bright line that would distinguish socially worthy from socially unworthy health care expenditures. Ragged edges mean rough justice.

The European Medical Agency recently approved panitumumab and cetuximab as first line therapies with chemotherapy for patients with metastatic colorectal cancer “with no mutations in the codon 12 and 13 of the KRAS gene”.⁹ Both these drugs cost \$100,000 for a course of treatment. Neither drug will effect a cure for the cancer. If these drugs are given to everyone with metastatic colon cancer, then the average gain in life expectancy will be a few weeks. If these drugs are given only to patients lacking the specified mutations, those patients might gain two extra years of life.¹⁰ About 40% of these patients have a KRAS mutation predictive of non-response to these drugs. Another 35%-40% with wild-type KRAS will have an objective response.

If these patients had access to these drugs, that would add about \$5.5 billion per year to the cost of caring for them. In theory, several billion dollars could be saved if access to these drugs were restricted to individuals with a genotype that was most likely to be responsive to these drugs (the 35%-40% with wild-type KRAS). This seems morally and economically reasonable. However, future research will make this more morally complicated. Individuals with wild-type KRAS do not all show the same “objective response.” Only some will achieve maximal gains in life expectancy. Others will only gain extra months. Maybe additional genetic factors identified through future research will yield a picture of enhanced median survival comparable to the breast cancer research described above. Would it be unjust to do that further research that will yield more restrictive access for some patients?

Would it be unjust to deny the whole cohort of patients access to these drugs at social expense who would only gain extra months of life (less than a year)? This is again Callahan's “ragged edge.” We are faced with rugged moral terrain (not just a bump in the terrain) because this issue will become ubiquitous as the field of pharmacogenetics advances. The complexity

6 How do we know whether the cost of a QALY is reasonable? The reference point used most often is the cost of a year on dialysis, about \$70,000 in 2011. In the US we currently sustain about 470,000 individuals on dialysis at that average cost level. The implicit moral argument is that if we regard that as a reasonable purchase for sustaining the lives of patients with end-stage renal disease then we ought to be willing to pay at least that to sustain the lives of patients with other end-stage diseases.

7 John Harris would make this argument against advocates for the use of cost-effectiveness to determine which lives to save. He writes, “So long as people want to live out the rest of their lives, however long this may be, or looks like being, then they should be given the best chance we can give them of doing so and we should not choose between such people on any other grounds, but treat each as an equal.” *The Value of Life* (Oxford, UK: Routledge and Kegan Paul, 1985), 110.

8 D. Callahan, *What Kind of Life: The Limits of Medical Progress* (New York: Simon and Schuster, 1990), chap. 2.

9 A. Ruzzo et al. “Molecular Predictors of Efficacy to Anti-EGFR Agents in Colorectal Cancer Patients,” *Current Cancer Drug Targets* 10 (2010): 68-79.

10 E. Van Cutsem et al. “Molecular Markers and Biological Targeted Therapies in Metastatic Colorectal Cancer: Expert Opinion and Recommendations Derived from the 11th ESMO/World Congress on Gastrointestinal Cancer, Barcelona, 2009,” *Annals of Oncology* 21 (Supplement 6) (2010): vi1 – vi10.

and uncertainty associated with the science and clinical judgment will allow us to achieve no more than rough justice. That in turn raises the question of how rough “rough justice” can be and still be “just enough.” Age, for example, appears to be a prognostic marker for a poorer outcome with colorectal cancer. About 70% of deaths from colorectal cancer occur among those more than 65 years old.¹¹ Should we use age as a distinguishing criterion?

The same issue has arisen with regard to non-small cell lung cancer, which represents 85% of lung cancers in the US. There are 160,000 lung cancer deaths annually in the US. If all these individuals had access to \$100,000 worth of these drugs, that would add \$16 billion per year to the cost of caring for this cancer. Recent medical literature points out that epidermal growth factor receptor (EGFR) inhibition is the key to useful treatment for non-small cell lung cancer. The drugs that achieve this are erlotinib (Tarceva) and gefitinib (Iressa), known as tyrosine kinase inhibitors (TKIs). But, more specifically, “numerous studies have now shown that mutations in the EGFR exons 19 and 21 are associated with higher response rates to EGFR TKIs.”¹² Shepherd then goes on to write that a number of researchers went “so far as to suggest that EGFR TKI therapy should be limited to patients with mutations.” He added, “Subsequent studies clearly showed that patients with wild-type EGFR could also derive significant survival benefit from treatment even though they had lower response rates compared to patients with mutations (my italics).” There again is the “ragged edge.”

If there were a neat division between responders and non-responders, then we might well be able to make a strong moral and economic case for providing the drug only to the responders. But the medical reality is a gradient between the two ends of the spectrum. How can we possibly justly create a bright line that would determine who should have access to these extraordinarily expensive drugs and the medical benefits they seem to promise? As an aside, one of the “virtuous” features of these targeted therapies is that their side effects often tend to be mild compared to what are often debilitating side effects associated with most chemotherapy today (which makes these drugs even more desirable from the perspective of desperate patients). This leads Ramsey to conclude: “In the United States it is unclear whether selective use of erlotinib that is based on phenotypic or genomic information would be acceptable to clinicians or patients.”¹³

Again, we ask the question: How rough can the “rough justice” be that we ought to accept? We might be tempted to say that rough justice is not “just enough” and must be resisted. But what would the alternative be? Surely we could not defend the status quo in the US as being morally preferable. The status quo means that individuals who are fortunate enough to have excellent health insurance provided through an employer would have access to these extraordinarily expensive cancer drugs at relatively little direct expense to themselves. If nothing else, this has the psychological effect of solidifying the idea that they “have a right” to these drugs. This, in turn, makes all the more difficult generating sustained political support for health reform to cover the 50 million uninsured in our society with a reasonably comprehensive benefit package, especially if such a package included these drugs and we were barred from taking account of enhanced outcomes associated with specific genotypes.

Health reform will require defining a benefit package guaranteed to all. How should that benefit package be defined in clinical practice in the light of the “ragged edge” problem? Should such judgments be made at the bedside by individual clinicians responsive to the distinctive clinical circumstances of an individual patient? If so, what assurances would we have (other current patients in similar clinical circumstances, future possible patients in similar clinical circumstances) that we would be treated justly (not denied very expensive life-prolonging care arbitrarily)?

We said earlier that “rough justice” was all that we could reasonably expect, given the complexity of our health care system. Would this clinical judgment approach yield outcomes that were within the bounds of “rough justice”? Or would outcomes tied to individual clinical judgment be “too rough,” morally speaking, too arbitrary, too idiosyncratic, or too costly? Should we rely instead upon panels of clinicians in a range of specialty areas? Or should we rely upon managers and administrators of health plans and health facilities to trim the ragged edges and establish limits? And what should be the role of current patients in making these judgments? Or must we rely instead upon future possible patients who are currently ignorant of their future possible health needs, and therefore, better positioned to make such judgments more impartially? What I am referring to here would be some broad and inclusive process of rational democratic deliberation.¹⁴

Our moral theories (given their generality) have only limited utility for addressing the very complex problems of fair health care rationing and priority-setting, such as we find ourselves facing in connection with these cancer drugs and

11 Ibid., at vi2.

12 F.A. Shepherd, “Targeted Therapy in the Management of Lung Cancer: Is There More Hype Than Hope?” *Targeted Oncology* 3 (2008): 131-33.

13 S. D. Ramsey, “Economics and the New Generation of Targeted Therapies for Non-small Cell Lung Cancer,” *Journal of the National Cancer Institute* 102 (2010): 287-88.

14 I discuss the role of rational democratic deliberation in addressing a broad range of health care rationing issues in my recent book. See L.M. Fleck, *Just Caring: Health Care Rationing and Democratic Deliberation* (New York: Oxford University Press, 2009), especially chapter 5.

individual genotypes that predict different degrees of responsiveness. What we need to utilize instead are fair processes of rational democratic deliberation. Our general theories of health care justice demarcate the moral space within which these deliberative discussions need to occur. They function very much like constitutional principles reasonably balanced in relation to one another and always subject to future modification in the light of future experience that would justify their modification. That is, these principles constrain the democratic deliberative process and would de-legitimate deliberative proposals that violated these boundaries. We recognize that there is considerable moral space within these boundaries, and consequently, for any particular health care rationing problem there will often be multiple possible resolutions that could be deliberatively endorsed and that will be “just enough.” This will be true with regard to our genotype and cancer problem.

Consider the following scenario. We (currently very healthy Americans who have little knowledge of what future serious health vulnerabilities might afflict us) want to control overall health care costs and maximize the health good we accomplish with the dollars we spend on health care. We think of ourselves as moderate egalitarians and moderate utilitarians. We are increasingly aware of what personalized genomic medicine in relation to cancer (and other life-threatening medical disorders) might mean for us, both personally and collectively. We are reflective enough that we can say to ourselves (as individuals) that we would not want to pay \$100,000 of our own money for a cancer drug that promised us only an extra two months or an extra five months of life. We see that money as being better spent on a university education for our grandchildren. But we understand the logic of the “tragedy of the commons.” Our health insurance, whether public or private, is a shared resource. If others feel free to use \$100,000 of that resource to gain five extra months of life in connection with cancer treatment, then we might be tempted to do the same (since the perception in both cases is that it is “someone else’s money”). That, of course, is a mistake. So we (who have a right to access that common insurance pool) must talk to one another for purposes of identifying reasonable restraints on the uses of those common funds.

We are certain that five extra months of life is not worth \$100,000, but two or three years of extra life would be worth that as long as it was of reasonable quality. Should we then agree with one another that the 7% of individuals with a particular cancer and a particular genotype who are likely to get two or three extra years of life from a particular cancer drug should have access to that drug at social expense? I realize that there is only a small chance that I might have the favored genotype for that cancer. But, then again, the chance that I would have that cancer and need that drug is very small as well. We can imagine that technology has moved forward, that we now have available a \$1,000 genome test. That is, I can have my complete genome read for that very reasonable sum. I find out that I am not among the favored 7% who might have access to this drug for this type of cancer at social expense. What would I see as the practical implication of that knowledge for my currently very healthy self, trying to determine with my fellow citizens whether public resources ought to cover the cost of that drug for that favored 7%?

I might be tempted to be stingy since I would now know that I cannot be a beneficiary of having access to that drug. Of course, the same will be true of 93% of my fellow citizens. Now I know more than just this one medically relevant genetic fact about myself. I would know at least several thousand such facts, all of which will have only a tiny chance of having any practical medical relevance for me in the future. That would suggest I would vote down the vast majority of genetically linked funding for specific medical interventions. And the same would be true for every one of my fellow citizens. Nothing would be funded related to personalized genomic medicine. A result such as that might satisfy the radical egalitarian predilections of someone such as John Harris. But this would not strike me as either a fair or reasonable outcome. And I strongly suspect the same would be true as thoughtful citizens came to this realization through the deliberative process.

What do we imagine this deliberative process might look like? We start by emphasizing that this would be a “rational” deliberative process. That means two things. First, these public conversations would be informed by the best medical evidence available at a point in time (recognizing that that medical evidence might have considerable uncertainty attached to it, especially as medical researchers try to figure out which genetic facts are related in medically meaningful ways to disease processes and opportunities to interrupt those processes through pharmacologic interventions). This evidence would be presented in a way that was intelligible to most lay people and as unbiased as reasonably possible (free of language likely to precipitate common cognitive errors). Second, the core of the deliberative process would be the giving of “public reasons” to one another for the particular health care justice judgments we as individuals would be inclined to opt for with respect to a particular rationing issue. Public reasons are the sorts of reasons citizens in a liberal pluralistic democratic society can reasonably give to one another as justifications for one or another public policy. These are reasons that are separable from what Rawls¹⁵ would refer to as comprehensive religious or philosophic visions of what would count as a good life. These reasons are also public in the sense that they must be broader than considerations of personal self-interest.

15 John Rawls, *Political Liberalism* (Columbia University Press, 1993).

What do we hope to accomplish through this deliberative process with regard to our cancer and pharmacogenomics problem? We would have to create some “bright lines” in place of the “ragged edges” that are the clinical reality. Then we would have to judge how high a priority these targeted cancer therapies ought to have relative to all the other health needs we have in our society for which there are effective and cost worthy medical interventions. We can briefly work through an example.

Consider again our earlier paclitaxel/bevacizumab example in connection with advanced breast cancer. Perhaps we could agree that the minimal predicted gain in life expectancy ought to be one year at a cost of less than \$100,000 per QALY. The “gain” we are referring to would be over and above whatever the next best treatment reliably offered. If we did come to such an agreement, it would mean that only 7% of women with advanced breast cancer would have a just claim to this cancer therapy at social expense. Would any of the other 93% have a just complaint in being denied access to this treatment at social expense, especially if during the deliberative process they vigorously objected to this rationing protocol? The short answer is negative. We have to keep in mind that the deliberative process is occurring among individuals who are mostly healthy and largely ignorant of what their future possible health needs might be. Even those with an active and serious disease process are going to be rationally (prudentially) constrained with regard to the vigor of their advocacy for their own current health needs. Let me illustrate with a very personal perspective.

I am Medicare-eligible and I have had surgery for prostate cancer. That might incline me to be an excessively vigorous advocate for every somewhat promising form of prostate cancer treatment out there no matter what the cost. But this would be imprudent and unjust and unreasonable. It would be imprudent because I know (statistically) that I am vulnerable to many other medical problems associated with advancing age and that there are some costly but very effective therapies available that ought to be funded. And I would want them adequately funded for reasons of prudence and justice. Further, if I demanded that some number of very expensive marginally beneficial prostate cancer interventions be funded, then millions of others could make precisely the same demands for comparable kinds of therapies whatever their specific medical problems might be. And I am not willing to pay the increased taxes or insurance premiums that would be necessary to fund such an expansion of the medical armamentarium. So there is a consistency requirement, both moral and practical, that gets in the way of my justly demanding that all these marginally beneficial prostate treatments be funded at social expense.

If we achieve these sorts of agreements through a fair and reasonable democratic deliberative process, then individuals who disagree with a particular outcome will not necessarily have a just claim for their future possible self with a minimally responsive genotype to some expensive cancer drug. They have certainly not been discriminated against for morally corrupt reasons. Their fate may be unfortunate but it is not unjust. Again, to illustrate the point, we can imagine Mr. Smith at age 82 with end-stage cancer demanding access to these drugs at social expense. However, at age 71 Mr. Smith developed life-threatening cardiac problems which were very effectively responded to at that time with some costly interventions that were developed and funded through the dollars that we were no longer spending on very marginally beneficial end-stage cancer interventions. In other words, he has gained additional years of life at social expense that he otherwise would have been denied if we had a less just and less prudent approach to making these rationing and resource allocation decisions. The collective agreement that emerges from a fair and reasonable democratic deliberative process is what yields judgments that are both “just enough” and “legitimate enough.”

We can imagine yet another argument that might be offered by those in the 11% group, just below our 7% group. The median gain in life expectancy for that group was five months. Again, however, there might be wide variation. Perhaps a small number in that group would be capable of achieving an extra year of life or more if they have access to bevacizumab at social expense. Would knowing this as a statistical fact (no capacity to identify ahead of time who those individuals might be) morally require that we fund access to bevacizumab for the group as a whole? I would give a negative answer to this question. An actual deliberative process might yield the exact opposite answer (and there might be no compelling moral argument to show that this was morally unjustified). What explains the possibility of such radically different judgments? We are at another “ragged edge.” Those who advocate for either view need to explain to the others what they see as the most compelling, justice-relevant considerations supportive of their view. One obvious response from my critic would be that we had agreed to a one-year-of-life-gained rule. That was what required providing funding for bevacizumab for the 11% cohort. Otherwise, we would be treating unjustly those in the cohort who might gain that year, even if only a tiny fraction of the cohort. My response would be that the rule applied when we had a high degree of medical confidence (not certainty) that individuals would achieve that extra year of survival. We do not know that about any specific individual in that cohort. Should we concede that there is something “less than just” in the view I am defending? I concede that. This is what it means to say that “rough justice” is the best we can hope to achieve in these complex circumstances.

In conclusion, the option we do not have is that of ignoring the ubiquitous, morally challenging ragged edges being created in medicine by advances in our understanding of pharmacogenomics. That option is neither just nor cost worthy.

The Impact of the New Genomics of Lung Cancer on Treatment Planning: A Review

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Key words: *Genomics, lung cancer*

Abstract

Lung cancer is the largest single cause of cancer-related death in the world. For most of the past century the results of therapy were dictated by whether or not the patient had surgically resectable disease. Until the mid-1990s, there was very little in the way of effective chemotherapy for patients with advanced disease. With the advent of so-called third generation agents there was a small improvement in response and survival, and with the advent of the epidermal growth factor receptor antagonists, gefitinib and erlotinib, in the late 1990s there was a sense of optimism that was tempered by the inability to predict which patients would benefit. The effects of a series of angiogenesis inhibiting compounds was clarified when a large cooperative group trial showed a benefit to adding bevacizumab to standard chemotherapy in a controlled trial. With the discovery of specific mutations in the EGFR gene it became far easier to predict which patients would benefit from EGFR antagonist agents and a whole array of studies followed clarifying their exact role.

Increasingly, we have now elucidated a series of so called “driver mutations” that not only contribute to the development of the cancer but drive its prognosis and its response to agents that specifically inhibit the biologic effect of the mutation. We are now able to offer highly specific and effective therapy for patients with EGFR and ALK mutations and reports are rapidly accumulating of more driver mutations with specific inhibitors of their function. It would appear that most of these mutations are exclusive of each other so that individualized testing will need to be done. The vast majority of mutations have until now been found in adenocarcinoma but recently several mutations have been described in squamous cancer as well.

We are rapidly approaching a time when all lung cancer patients should have their initial tissue tested for molecular markers and therapy determined by those analyses. This may have a negative cost impact in countries with limited health care resources, although the availability of an oral targeted agent might obviate the need for fixed treatment facilities for some patients.

Introduction

Lung cancer is the leading cause of cancer mortality in the United States and the world,^{1,2} with overall survival varying from around 15% in the United States to well under 10% in some developed nations.^{3,4} Survival data are hard to obtain in many areas due to inherent issues in diagnosis, treatment and follow-up. The majority of lung cancer patients have non-small cell lung cancer (NSCLC) and the vast majority of cases present with locally advanced or metastatic disease.^{5,6} Their prognosis, untreated, is grim. Through the early 1990s there was very little in the way of effective chemotherapy for advanced NSCLC with a combination of etoposide and cisplatin as the best of a mediocre lot.⁷ The availability of several new agents, including paclitaxel, docetaxel, gemcitabine, vinorelbine and pemetrexed, seemed to herald an era of improved outcomes and led to a series of comparative trials demonstrating little difference between these combinations and only modest improvements over earlier regimens.⁸⁻¹⁰ A parallel paucity of biologic understanding about lung cancer accompanied the era of modest results for treatment of advanced disease.

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In the past decade there has been an explosion of knowledge about NSCLC at the molecular level with the concurrent development of specific inhibitors of these molecular aberrations. As of this writing, well over half of adenocarcinomas of the lung have identifiable “driver mutations” that allow selective use of targeted agents¹¹ and recently such mutations have been described for squamous NSCLC as well.¹² It is beyond the scope of this manuscript to provide an encyclopedic review of genomic alterations in NSCLC and the various therapies directed against them. I will discuss three particular pathways that have proven important in our understanding of NSCLC and use them as exemplars of how the approach to NSCLC is rapidly changing: (1) the vascular endothelial growth factor (VEGF) family, (2) the epidermal growth factor receptor (EGFR), and (3) anaplastic lymphoma kinase (ALK).

Vascular Endothelial Growth Factor

Neovascularization was recognized by Folkman and others over 30 years ago as a key driver of tumor growth and a potential target for disruption as a means of attacking tumors.¹³ Although there are several members of this family of angiogenic cytokines (fibroblast growth factor, hepatocyte growth factor, transforming growth factors α and β , platelet derived growth factor, tumor necrosis factor- α and interleukin-8) the most active is VEGF.¹⁴ VEGF is expressed in 42 to 75% of NSCLC cases and is associated with a poor prognosis.¹⁵ Several approaches were developed to inhibit VEGF with initially mixed results. Eventually bevacizumab entered clinical trials as a direct inhibitor of the VEGF ligand rather than as a receptor antagonist.¹⁶ A Phase 2 trial in conjunction with paclitaxel and carboplatin for patients with advanced NSCLC demonstrated an improved time to progression and response rate, although life threatening toxicity was seen in patients with central tumors or squamous histology.¹⁷ A subsequent Phase 3 randomized trial was conducted in the Eastern Cooperative Oncology Group with squamous cell patients excluded. This trial demonstrated a significant advantage for the bevacizumab containing arm and the combination of paclitaxel, carboplatin and bevacizumab became standard therapy for advanced non-squamous NSCLC.¹⁸ Subsequent efforts have attempted to use bevacizumab with other combinations, but its most important role seems to be as a maintenance agent after the completion of the requisite cycles of chemotherapy, an approach that appears to lead to further improvement in survival.¹⁹ One problem we face with VEGF inhibitors is that we do not have a reliable set of correlative or genomic markers.¹⁴

The largest group of anti-angiogenic compounds is the tyrosine kinase inhibitors (TKIs) directed against the VEGF receptor.¹⁴ Most have multiple targets in addition to VEGF and for this reason often have unusual toxicities. In this class of compounds, Vandetanib, Sorafenib, and Sunitinib have all been approved for cancers other than NSCLC, albeit with modest benefit.¹⁴ Literally dozens of oral TKIs targeting VEGF pathways have been developed and tested but a clear winner has not emerged.

Epidermal Growth Factor

One of the first proteins identified as a driver of NSCLC growth was the epidermal growth factor receptor (EGFR). EGFR contains an extracellular and an intracellular domain which interact to drive tumor cell growth via a complex series of dimerizations.^{20,21} EGFR is over-expressed on up to 80% of NSCLC and this over-expression was the initial impetus to test both gefitinib and erlotinib, two TKIs with anti-EGFR activity.²² Unfortunately, the companies involved chose to move directly to studies combining EGFR inhibitors and chemotherapy, all of which were negative.²³⁻²⁶ It was appreciated by clinicians, however, that there were dramatic responses in some patients (about 7-8%), and that those responses tended to cluster in younger Asian woman with adenocarcinoma and a history of developing NSCLC without a history of smoking.²⁷

Several authors then noted the appearance of activating mutations in the EGFR genome including deletions at exon 19 and point mutations in exon 21, both of which predicted a high rate of response to EGFR inhibitors.²⁸⁻³⁰ Subsequent studies have shown that erlotinib or gefitinib can be used as first line therapy, second line therapy, or maintenance therapy in patients with either of these activating mutations irrespective of ethnicity.³¹ Antibodies directed against the extracellular domain (cetuximab) have been less active in NSCLC.³² The recent development of irreversible covalent binders of the EGFR (afatinib) has shown greater activity, but also greater toxicity.³³ These covalent binders are also inhibitors of other members of the ErbB family (HER2, HER3), which may account for the slightly different toxicity profile. Afatinib may be active in patients who have developed resistance to erlotinib.³³

Anaplastic Lymphoma Kinase (ALK)

The ALK gene was originally described as an oncogene in lymphomas, with a tendency to form a fusion gene with the Echinoderm Microtubule-associated Protein-like 4 (EML4) known as an EML4/ALK fusion gene.³⁴ This fusion gene is found in 4-5% of NSCLC patients³⁵ and is usually referred to as an ALK mutation. This mutation is seen primarily in light or never smokers and in patients with adenocarcinomas.³⁵ Crizotinib, a novel inhibitor of both ALK and c-MET, has shown a > 90% response rate in NSCLC patients with this abnormality.³⁶

Biologic Implications of Genomic Alterations in NSCLC

At the 2010 to 2012 meetings of the American Society of Clinical Oncology (ASCO) there were a number of reports describing the presence of a whole array of driver mutations in over half of all adenocarcinomas (Figure 1) and initial reports of similar mutations in patients with squamous cell cancer (Figure 2).^{37,38} Many of these mutations have existing drugs that have been found to inhibit their function specifically. These mutations appear to be mutually exclusive so that specific personalized therapy may now become a reality for patients with NSCLC.³⁹

Figure 1. Incidence and Nature of Driver Mutations Seen in Adenocarcinoma of the Lung

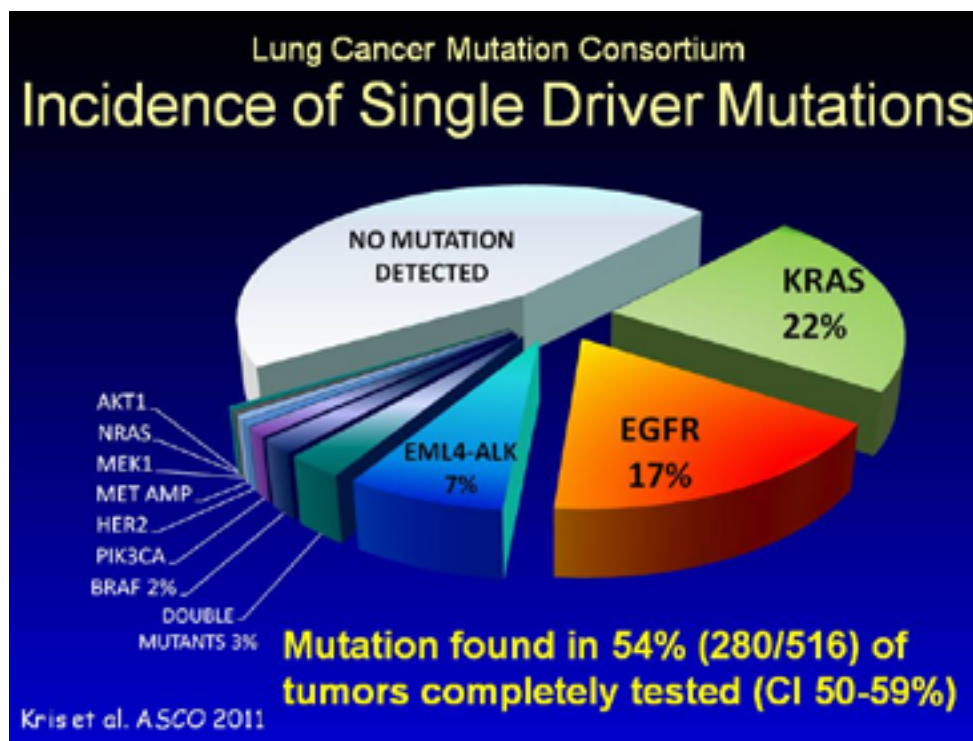
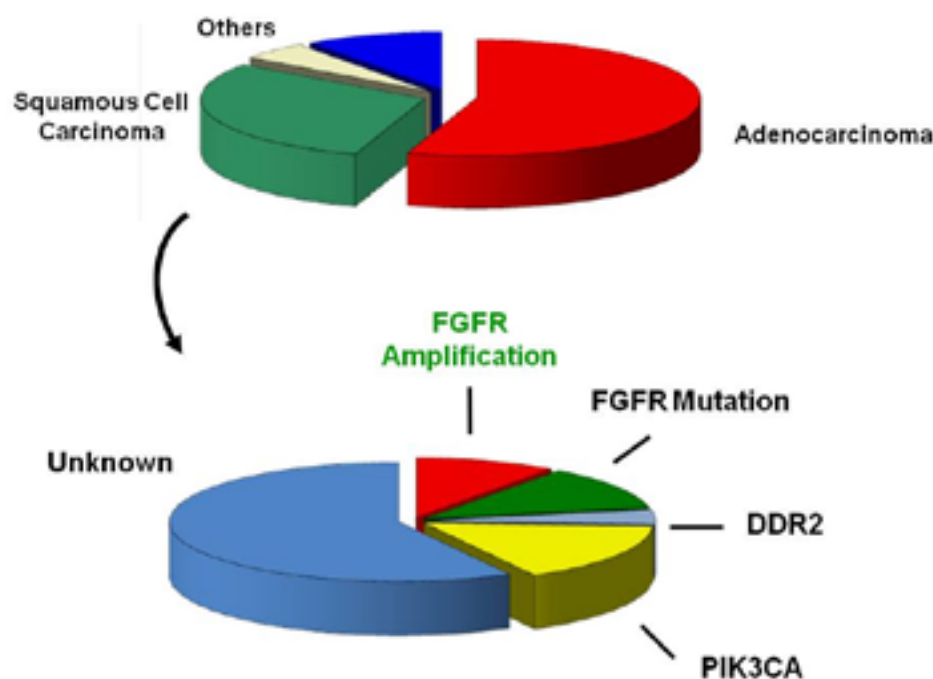


Figure 2. Incidence and Nature of Driver Mutations in Squamous Cell NSCLC

Clinical Implications of Genomic Alterations in NSCLC

Advanced NSCLC has traditionally been diagnosed with fine needle aspirations, as there was little need for tissue beyond delineation of the histologic subtype. This has hampered the ability to do retrospective studies of these genetic markers. It would appear that we should switch virtually all lung cancer tissue biopsies to so called core biopsies to allow testing for molecular markers. It has been shown to be feasible to test for multiple markers on paraffin fixed tissue⁴⁰ and many practices in the US are moving to perform molecular testing when tissue is first obtained, either at surgery or biopsy, rather than waiting for relapse. This opens up a wide variety of clinical options for the patient and physician that were not available with empiric treatment options. Many of us also feel that surgical specimens should all have an aliquot snap frozen for more elegant genetic testing, the full extent of which it is not possible to predict today.

These clinical implications are being explored in developed countries with sophisticated health care delivery (and payment) systems and are already bumping up against the need to control health care costs. None of the newly developed targeted agents is less than several times more expensive than a conventional chemotherapy regimen. Like all true advances in cancer care, we will not be able to put this genie back in the bottle. We need to find ways to integrate these new approaches, or better yet replace the older treatment paradigms, in a cost effective manner.

The implications for less developed economies are unsettling. It would appear that access to the latest personalized therapy will increasingly be available only to those able to afford it. It is conceivable that when the costs of drug development are amortized that the availability of oral agents may make treatment easier in countries with less developed treatment facilities, but that day is in the distant future for now.

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Cytologic Abnormalities Identified in a Subset of Arab American Women in the Metro Detroit Area

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Introduction

Although cervical cancer incidence has been declining over the years in the United States, 11,270 women were diagnosed with invasive cervical cancer and 4,070 women died of the disease in 2009 [1]. The main cause of cervical cancer is persistent infection with high risk human papillomavirus (HPV) types, a sexually transmitted disease. Other risk factors contributing to the development of cervical cancer include smoking, immune suppression and high parity. Screening for cervical cancer via Pap smears has provided the single most effective tool in the early diagnosis and treatment of cervical cancer, thereby reducing its incidence and mortality in the United States and other Western countries. Studies have shown that screening every 3 years reduces the cumulative incidence of disease by 91%. Thus, disparities in Pap test coverage/screening influence disparities in cervical cancer [2]. Social behavior also accounts for differences in the incidence of cervical cancer amongst different ethnic groups. Despite accessibility of this screening method, racial and ethnic differences exist in its usage in the United States. This may reflect differences in socio-demographic factors such as older age, lack of education or health care coverage, and differences in psychosocial factors such as fear, language barriers and embarrassment [3, 4].

In the United States, approximately 3½ million people claim Arab ancestry and constitute one of the largest and fastest growing immigrant groups in the metropolitan areas. A large segment (approximately 400,000) lives in the metropolitan Detroit area. In addition, previous studies [5] have reported a lower cervical cancer screening rate in the Arab American population in Michigan when compared to the general population. Other studies have shown that in general, the cancer incidence in the Middle East is noticeably lower when compared to the West [15]. This difference is maintained in first generation immigrants [7], but tend to diminish in subsequent generations as acculturation occurs [8]. However, few recent studies exist to assess cervical cancer prevalence and HPV infection rates and distribution in this large expatriate ethnic group in the United States.

This study aimed to assess the proportion of Arab American women in the Metro-Detroit area with cytological abnormalities.

Cervical Cancer Burden and Role of Screening

Approximately 500,000 cases of invasive squamous cell carcinoma occur worldwide and about half die of this disease. The distribution of the disease is uneven geographically, with less developed/low-resource countries bearing the brunt of the disease [6]. In the United States, about 20,000 cases of cervical cancer are diagnosed every year and approximately one-fourth of these patients die of this disease [9-11]. This disparity can easily be explained by the lack of screening programs in the underdeveloped/underserved countries.

Even within the United States, there are disparities in cervical cancer screening and subsequently, cervical cancer incidence. Numerous studies have identified marked disparities based on socio-demographic and health care access characteristics. According to the Surveillance, Epidemiology and End Results (SEER) database (2000-2004), Hispanic women were diagnosed with cervical carcinoma twice as often and African-American women were diagnosed 1.5 times as often as non-Hispanic white women. Asian American/Pacific Islander women were deemed to be at a slightly higher risk of cervical cancer diagnosis when compared to non-Hispanic white women. American Indian/Alaskan Native women were at a lower risk [12]. Disparities in screening also affect the age and stage at diagnosis in the various groups and subsequently mortality from this disease [13]. This is confirmed in studies which have shown that mortality rates for cervical cancer were twice that of white women for African American women and 1.5 times that of white women for Hispanic women [12]. As people of Middle Eastern origin are categorized as non-Hispanic whites by most classification systems, rate estimates in this group are not available in population-based registries (i.e., SEER).

The above studies highlight that the single greatest contributor to the development of cervical cancer appears to be the lack of screening. Differences in screening rates and practices have been established across various ethnic groups. Per the U.S Department of Health and Human Services, white and African American women are most likely to have had a screening Pap test in the preceding 3 years (79% and 80%, respectively), compared to 60% of women from the Asian population and 74% of women from the Hispanic population [13]. Reasons for lack adherence to screening programs include cultural and language barriers, lack of access to health care, lack of education, low income and lack of insurance, many of which are disparate in various ethnic communities.

Arab American Population in the United States and in the Metro Detroit Area

There are approximately 3.5 million Arab Americans in the United States, according to the Arab American Institute. As per the 2000 US Census, the city with the largest percentage of Arab Americans is Dearborn, a southwestern suburb of Detroit, with nearly 30% reporting Arab ancestry. The Detroit Metropolitan Area of Wayne, Oakland, and Macomb counties is home to the largest concentration of Arab Americans, at 400,000 [14]. The presumption is that the load of cervical cancer in this group is low owing to their cultural and religious practices. Data describing the prevalence of cervical cancer in the Middle East also suggests the same [17].

The Arab Community Center for Economic and Social Services (ACCESS) is a community-based organization that combines advocacy, direct services and community organizing in addressing needs and concerns of the Arab American community in Southeastern Michigan. Through its health and medical services programs, ACCESS provided 796,000 units of service to 50,000 individuals through 90 programs IN 2012. Approximately 1,000 Pap smears are done annually through this facility and sent to the Detroit Medical Center University Laboratories (DMCUL) for processing and interpretation.

Cervical cytology interpretations of 480 Pap smears were retrieved from the ACCESS site over a 2-year period during 2005-2006 (unpublished preliminary data). The prevalence of the different cytologic abnormalities was calculated (Table 1).

Table 1. Cervical Cytology Interpretations of 480 Pap Smears from ACCESS

<i>Category</i>	<i>Number (%)</i>	<i>Category</i>	<i>Number (%)</i>
Unsatisfactory	8 (1.7)	LSIL/CIN-1	25 (5.2)
NILM	416 (86.7)	HSIL/CIN-2	4 (0.8)
ASC-US	21 (4.3)	HSIL/CIN-3	0 (0)
ASC-H	4 (0.8)	AGC	2 (0.4)
NILM: Negative for Intraepithelial lesion ASC-US: Atypical Cells of Undetermined Significance ASC-H: Atypical Squamous Cells, cannot rule out High Grade Squamous Intraepithelial Lesion LSIL: Low Grade Squamous Intraepithelial Lesion HSIL: High Grade Squamous Intraepithelial lesion AGC: Atypical Glandular Cells – The Bethesda System, 2001			

Discussion

Although the available data are sparse, it appears that this group does not access cancer screening opportunities owing to cultural barriers. Small studies in the literature suggest that there are barriers to cancer screening within the group. In one such study by Al-Omron et al. [15], 44% of the study sample, which constituted Arab Americans in Michigan, had never had any screening tests for cancer (per American Cancer Society guidelines), and only 22% had all the age-appropriate recommended testing. Approximately 40% of the participants in the study had incomes < \$20,000, 38% were unemployed, and 32% were without insurance. About a third of the participants did not have adequate knowledge of screening recommendations and 20% suffered from language barriers that limited access to care. All of these variables indicate that lack of screening may be a significant problem in this population.

In another study by Yassine et al. [16], the cervical cancer screening rate amongst the Arab-American women in Michigan was lower (76.9%) compared to the general population (86.5%) and amongst this group, women in the older age group were less likely to receive appropriately timed Pap smears. Given the lack of screening in this population, estimating the prevalence of disease is critical to assess whether Arab American women would benefit from targeted screening programs.

Studies have documented that approximately half of the cases of cervical cancer in the United States occur in women who have not had a Pap smear in the preceding three years [18,19]. These findings highlight that regular screening is important to be able to identify precursor conditions and prevent the development of cervical cancer.

Summary

The success of cervical cancer control in the United States is largely based on a very effective screening program. The benefits of this program, however, are not equitable among different population groups and often financial, cultural and language barriers existing within newly immigrant communities prevent them from utilizing these services. It is important to identify these groups and provide them with specific resources if necessary to overcome these barriers so that they too can partake of this success.

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Arab-American Breast Cancer Education and Referral Program (AMBER)

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Key words: *Breast cancer, barriers to care, CBPR, screening*

Abstract

New York City is the US city with the largest Arab American immigrant population. Despite their growing numbers, the Arab American population receives very little attention from the public health community. There is evidence that the primary barriers to cancer services usage are transportation, lack of knowledge, and language barriers. Other studies published concerning health care access barriers experienced by Arab American immigrants had similar findings, indicating that lack of acculturation, language barriers, societal stigma against Arabs, concerns about confidentiality, and lack of public health related knowledge impede health care access and services utilization.

In response, New York University Cancer Institute and the Center for Immigrant Health started the Arab American Breast Cancer Education and Referral Program (AMBER) to increase the utilization of breast cancer early detection services for Arab American women in New York City, through culturally appropriate breast cancer education and screening coordination. Project activities include Arabic language health education, patient navigation services, cultural competency training for healthcare professionals, and support services for women diagnosed with breast cancer.

Program impact data were assessed during Year 3 when the program had reached steady-state. During the first three years of AMBER, 1,354 women were educated in 40 workshops. AMBER staff also participated in 20 health fairs and events for the Arab American community, reaching 3,150 additional participants. In Year 3, 235 of the workshop participants received follow-up based on their age, family history, and/or insurance status. Of these women 90 were screened, one new case of breast cancer was detected, and 4 active cases in need of follow-up reconnected with care.

Key to the success of this project have been the collaborations with religious institutions, community-based organizations and community leaders. This program increases the likelihood that culturally appropriate information will be accepted, an increased number of Arab American women will be screened for breast cancer, and patients will be treated appropriately and respectfully.

Introduction

According to the Arab American Institute, the Census Information Center designee to analyze Arab American community data, census figures account for only a third of a total Arab American population of 3.5 million [1]. New York State, often the first American destination for Arab immigrants, has the third largest number of Arab Americans, approximately 405,000 [1]. Syrians and Lebanese comprise the largest ancestral groups at 40%, with second wave subgroups coming from Egypt, Yemen, Morocco, and Palestine [1]. More than one half of Arabs reside in the New York City metropolitan area, with the largest and most diverse populations in Kings County (29%), Queens County (13%) and New York County (9%) [1,2]. Although there was a decrease in Arab immigration to New York City post September 11, 2001, the number of New York City Arab Americans increased by 22.6% from 2000 to 2005 [3,4].

The Arab American population receives little attention from the public health community, without much published about cancer incidence, mortality rates, and screening practices. The majority of published data on Arab American cancer incidence, mortality, beliefs, and practices has come out of Michigan, home to the second largest Arab American community [1]. The Michigan Public Health Institute reported that out of the 1,553 cases of cancer mortalities in the state for men and women of Arab ancestry (1985-2001), the leading cause for Arab women was breast cancer, whereas lung cancer has the greatest mortality for the female US population at large [5,6]. A study conducted in metropolitan Detroit tested a series of surveys translated into Arabic to investigate their applicability to the Arab community in correlating knowledge, attitudes, and practices of Arab American adults toward cancer screening and early detection. The primary barriers to cancer services usage were transportation, lack of knowledge, and language barriers [7].

The New York State Cancer Services Partnership (CSP) provides breast and cervical cancer screening services to uninsured and underinsured women through 54 local partnerships [8a]. Data provided by the Queens and Brooklyn partnerships show low participation rates by Arab American immigrant women (identified by country of birth). Only 70 Arab American women participated in the Queens program between 2004 and 2006, fewer than 1% of the 13,322 women seen in this period [8b]. Seventy-eight Arab American immigrant women were screened in the same three year period through the Brooklyn CSP. This comprised less than 1% of the 12,301 women seen during this period and less than 1% of the approximately 19,261 Arab American women age 35 and over living in Brooklyn [8b, 9].

Language and economic barriers, spirituality, societal discrimination, and psychosocial health impacted general and cancer health services access for Arab American women. A 2005 study in New York revealed that Arab American women had limited knowledge of the causes of cancer and were not adhering to National Cancer Institute and American Cancer Society screening guidelines. Their cancer beliefs included numerous etiological theories and strong notions of fatalism, as there is a strong association with god in all aspects of their lives. Many believed that wearing the hijab singled them out for discrimination and abuse and that they were presumed to be ignorant by health care providers. One focus group participant stated, "Hijab only covers my head and not my brains" [10].

Objectives

The Arab American Breast Cancer Education and Referral program (AMBER) was established in 2007 with a grant from Susan G. Komen for the Cure, Greater New York City Affiliate, to increase the utilization of breast cancer risk reduction strategies, early detection services, and treatment completion among Arab American women in New York City through culturally appropriate breast cancer education, screening coordination, and support.

Responding to the needs of the target population, AMBER aimed to: assess breast cancer risk for Arab American women through breast cancer education workshops; provide follow-up and support to women with abnormal mammograms; reach out to the Arab population through targeted outreach in churches, mosques, community based organizations (CBOs) and schools; provide screening coordination/patient navigation for the uninsured and women diagnosed; and provide assistance with finances, transportation, food, and childcare.

Program Description

Focus groups guided the development of an Arabic language curriculum [10]. Topics included breast cancer risk, early detection methods, and community resources. A breast cancer risk assessment and screening eligibility tool was developed for women attending breast health workshops. This enabled stratification into follow-up protocols based on age, family history, and insurance status. Two bilingual Arab American community members with health experience were trained as health educators and screening coordinators. They used the curriculum and the tool at breast health workshops at partnering community and faith-based organizations. Relationships with CBOs, mosques, churches, and a school were established. The sites either co-sponsored a health education workshop or assisted with linkages to other CBOs and religious organizations.

In AMBER's first three years, 40 education workshops were implemented at 18 religious and community-based organizations (6 mosques, 6 churches, 5 CBOs, and 1 school). Staff also distributed breast cancer information at 20 health fairs. Two protocols were developed. Protocol One, for uninsured women, consisted of (a) making appointments through the CSP, (b) accompanying the women to their appointments, and (c) assisting them with any necessary follow-up care. Protocol Two, for insured women, consisted of (a) calling women and encouraging them to make appointments, (b) providing assistance with referrals, (c) offering to accompany them to their appointments, and (d) assisting them with follow-up care.

An Arabic language video addressing risk factors for breast cancer and the importance of early detection was created. Two focus groups were convened with community leaders and health advocates in the Arab community (n = 22) to better understand the health care and cancer-related knowledge, attitudes, and beliefs of Arab immigrants. Focus group data guided the development of the video.

To bridge the culture of Arab American women with breast health providers and increase the likelihood that patients would be treated appropriately and respectfully, AMBER staff conducted three Arab American cultural responsiveness trainings at health care facilities in Arab American communities. Attendees included staff and providers from various breast cancer early detection and treatment areas. Focus groups guided training curriculum development. The resultant curriculum included the following topics: working with interpreters and the cross-cultural medical interview; health care seeking and cancer services access in the Arab American community; and overcoming linguistic, economic, legal, and cultural barriers.

Women who were uninsured and had not had a screening mammogram in the past year, Protocol One, were stratified into two groups based on their age and family history: over age 40 and under age 40. The screening coordinator made appointments for the women over age 40 with CSP. Travel costs were covered for all women who made screening appointments.

Women under age 40 determined to have a relevant family history of breast and/or ovarian cancer, or high cancer burden in the family, were offered an appointment through the CSP program or provided with a referral, where it could be determined what type of screening the women required.

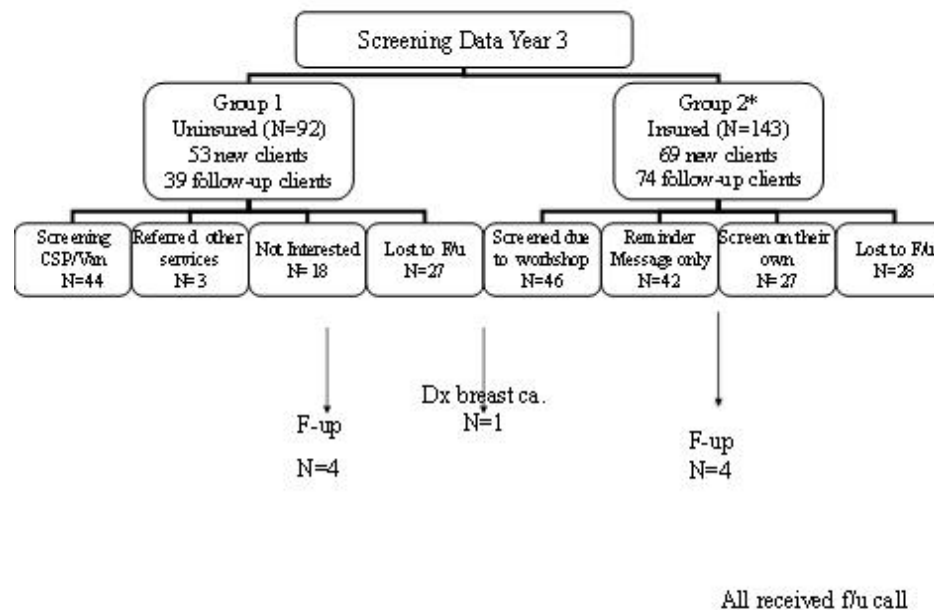
Women with insurance, Protocol Two, were also stratified into categories based on their age and family history. The women who needed screening received a phone call from the screening coordinator. Each woman received instructions on what was required by their insurance carrier to receive a mammogram, provided with phone numbers of breast imaging services in their area, and offered the assistance of the screening coordinator on the day of their appointment.

All women who were scheduled to be screened received follow-up calls from the screening coordinator to ensure that they had attended and had received their results. Any woman who required follow up due to an abnormality or inconclusive test result was assisted by the screening coordinator to access the needed services.

Outcome Data

Program impact data were assessed during Year 3 when the program had reached steady-state. During the first three years of AMBER, 1,354 women were educated in 40 workshops. AMBER staff also participated in 20 health fairs and events for the Arab American community, reaching 3,150 additional participants.

According to Year 3 screening data, approximately 235 of the workshop participants received follow-up based on their age, family history, and/or insurance status (Figure 1). Of these, 122 were new clients and 113 women were follow-up clients from the previous years. An additional four women with breast cancer, who were referred by community physicians or through word of mouth, received assistance with supportive services including transportation and financial assistance. Protocol One participants consisted of 92 women who initially reported lacking health insurance, and whose screening status, age, and/or family history necessitated their getting a mammogram. Forty-four women were screened through the CSP or mammography vans, 3 were referred to other services, 18 were not interested, and 27 could not be reached by the provided contact information. Four women required follow-up visits due to irregular results. One patient was diagnosed with late stage breast cancer. Two women received sonograms and one woman had a biopsy, all with negative results. Protocol Two participants consisted of 143 women who qualified for screening and had insurance. Of these women, 115 were called and encouraged to make mammogram appointments and offered help; 46 were assisted to make appointments and completed screening. Twenty-eight women were not reachable. Four women required additional testing: Two redid their mammograms, one had a biopsy, and one had a sonogram. All of the results were negative.

Figure 1. Year 3 Screening Data

CSP data reveal a significant increase in the screening of Arab American women in Brooklyn. In 2008, one year after AMBER was launched, the number of Arab American women screened in Brooklyn increased by 29% [11], even though the number of Arabs living in New York State decreased slightly from 2007-2008 [12].

Discussion

As with many immigrants who settle in the United States, Arab Americans bring with them age old health traditions and practices that may be different from Western medical care. AMBER led to a marked increase in the number of at-risk women being screened for the first time. AMBER demonstrated a willingness of Arab American women to participate in breast health education programming when information and practices were linguistically and culturally tailored. Culturally specific beliefs and practices were incorporated into program design, including the development of materials, timing of events, and selection of staff. The inclusion of religious and community leaders in the planning and implementation phases increased participation rates.

As the program continues, additional approaches will be tailored as issues arise. The fluid AMBER community-based participatory approach needs to be replicated where other Arab American communities reside, increasing resources so that more at-risk women can be reached, including those with insurance who are not accessing available services. Additionally, the AMBER model needs to be expanded to other types of cancer with an emphasis on early detection, and to other underserved communities.

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Initiating Regional Comparative Breast Cancer Research in the Eastern Mediterranean Region

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Key words: *Breast cancer, prevalence rates, Iraq, Eastern Mediterranean region*

Background

Globally, breast cancer is the most common cancer among women, comprising 23% of the female cancers [1]. It is also the leading cause of cancer-related deaths, case fatality rates being highest in low resource countries [1,2]. Although substantial improvement in survival from this disease has been reported in high-income countries such as the USA, the risk continues to increase and survival rates in middle-and low-income countries remain low. According to Globocan [1], in 2008 the total number of newly diagnosed breast cancer cases worldwide was 1.38 million, and the total number of deaths from the disease was 458,367; of these mortalities, 59% were recorded in less developed regions of the world.

Within the Eastern Mediterranean Region (EMR), according to WHO mortality estimates cancer is the fourth ranked cause of death, succeeding cardiovascular diseases, infectious/parasitic diseases and injuries [3-5]. The largest increase in cancer incidence among the WHO regions in the next 15 years is likely to be in the EMR [6], where breast cancer is reported as the commonest type of female malignancy in almost all national cancer registries [1].

Significance of Initiating Breast Cancer Control Programs in the EMR

In addition to being the most important cancer, there are other features that justify increasing efforts for breast cancer control within the EMR. These include the obvious rise in the incidence rates, the higher frequencies of younger ages and advanced stages at the time of presentation [7-12] and the likely prevalence of more aggressive tumours resulting in greater fatality rates [1,11,13]. These factors lead to low five-year survival rates (10-50%) from breast cancer in many low- and medium-resource countries (LMC) as compared to more than 85% five-year survival in high-income countries [1,14].

Information on the putative risk factors for breast cancer and the clinical profile of patients with the disease in terms of clinical stage at presentation, proportion of cancers with regional lymph node metastases, estrogen receptor positivity, treatment patterns and survival outcomes are of utmost importance in the context of breast cancer control in the EMR [7,15]. Two different approaches have to be undertaken to address these two distinct information needs: Properly designed analytical studies such as case-control or cohort studies are needed to address breast cancer risk factors. On the other hand, well conducted descriptive studies can address the pathological, clinical and survival outcome profiles in breast cancer patients.

At the level of national registration, most of the cancer registries of countries belonging to the EMR lack data regarding stages of the disease at presentation [7], age-specific incidence and survival rates. Furthermore, within hospital records, there is no proper documentation on critically important clinical factors such as tumor size, nodal status, stage distribution at the time of initial diagnosis, hormonal receptor status, proportion of women presenting with distant metastasis, proportion of patients treated with radical mastectomy versus breast conservation surgery, other prevailing treatment modalities (including radiotherapy, chemo and hormonal therapies) and two- and

five-year survival rates. A critically important factor in clinical research is an up to date medical record, which is often underemphasized. Collecting good quality data from breast cancer patients in LMC depends upon accurate documentation of clinical findings in medical records in cancer treatment centers [2,3,5,14].

In Iraq, breast cancer is the commonest type of malignancy among the Iraqi population in general. It accounts for approximately one third of the registered female cancers according to the latest Iraqi Cancer Registry [16], which shows a trend for the disease to affect younger age groups [9,16]. Within the last two decades, there has been an obvious increase in the incidence rates of breast cancer, which has become one of the major threats to Iraqi female health. Regrettably, many cases in Iraq tend to be diagnosed at advanced stages [9], with a prevalence of poorly differentiated pathological grades illustrated in DNA nuclear aneuploidy and thus yielding a mortality incidence ratio equivalent to 60% [1,13].

In one of the studies that was designed to review the demographic characteristics and clinico-pathological presentation of Iraqi patients complaining of breast cancer [9], it was observed that approximately one third were diagnosed at age 40-49 years; 71.9% came from urban areas; and 75% were married. History of lactation was reported in 63.1% and hormonal therapy in 29%. Positive family history was recorded in 16.2%. Although a lump was detected by the patient herself in 90.6% of cases, only 32% sought medical advice within the first month. Accordingly, 47% of those patients presented in advanced stages (III and IV). The main histological type was invasive ductal carcinoma, in which pathological changes signifying Grades II and III were observed in 56.6% and 39.9% respectively. DNA analysis showed that 80.3% of the carcinomas were aneuploid. Estrogen and progesterone receptor positive tumor contents were demonstrated in 65.1% and 45.1% respectively, while Her-2/neu positive expression was displayed in 46.4% of the examined cases.

In a more recent survey [17] that evaluated the knowledge, attitudes and practices towards breast cancer and breast self-examination (BSE) among a sample of educated Iraqis affiliated with two major universities, it was documented that almost half of the participants had a low knowledge score (< 50%). Although 90.9% had heard of BSE, only 48.3% practiced the technique.

The findings of those two studies clearly justify the demand for increasing efforts to establish comprehensive breast cancer control programs in Iraq and the region.

Introducing a Comprehensive Information System Data Base on Breast Cancer Control in Iraq and the EMR

In an attempt to address the aforementioned information needs on the clinical profile of breast cancer patients, and emphasizing the role of research as one of the basic pillars in the adoption of the cancer control strategy, a National Breast Cancer Research Program (NBCRP) was established in Iraq in 2009. In collaboration with the International Agency for Research on Cancer (IARC) and WHO, a comprehensive information system was developed for Iraqi patients diagnosed with breast cancer. Thereafter, that data base model was utilized to compare the demographic characteristics, clinico-pathological presentations and management outcomes of breast cancer patients inhabiting selected countries in the EMR (so far Iraq, Jordan, Lebanon and Egypt are included).

Objectives of the Regional Breast Cancer Research Program

The objectives of the program are:

- To promote the process of accurate documentation of clinical findings in medical records of breast cancer patients; to facilitate proper collection of data
- To support and facilitate national cancer registries in the participating countries through providing vital breast cancer statistics including stage distribution, age-specific incidence and survival rates
- To compare the demographic characteristics, clinicopathological presentations and management outcomes of breast cancer patients inhabiting selected countries in the EMR
- To enhance the advancement of cancer research in the region through conducting properly designed analytical and descriptive studies on the impact of putative risk factors and clinical profile of patients with the disease

Methodology

In 2009 a comprehensive breast cancer information system database was designed by the principal investigator under direct supervision of IARC to document the demographic characteristics, clinico-pathological presentations and treatment outcomes in Iraqi patients complaining of breast cancer. Following the development and installation of that data base another shorter proforma was devised in consultation with IARC for a Comparative Regional Breast Cancer Research Program. The main objective is to collect information on critically important clinical, pathological and risk factors from consecutive breast cancer patients attending major cancer facilities in selected countries within the EMR for comparative studies. The recorded clinical data include tumour size, nodal status, stage distribution at presentation, hormonal receptor status, proportion of women presenting with distant metastases, prevailing treatment modalities and survival rates.

A focal representative from each of the four participating countries has been nominated. The criteria for selection comprised being a well-known specialist in the field of breast cancer management, preferably directing a major national cancer facility. Country representatives, who will work collaboratively in that program, should have a keen interest in cancer research and should express a serious intention to deliver sincerely on that dedicated effort. Each focal country representative will be in charge of nominating five different specialists from his/her local cancer facility, who should actively participate in the research program through the various disciplines of breast cancer management (including registration, diagnosis and treatment), i.e., pathologists, radiologists, surgeons, statisticians and oncologists.

Currently, the online information system data base, supervised by the Screening Group of IARC, is operating in a major cancer facility within each of the four countries participating in that project; i.e., Iraq (Iraqi National Breast Cancer Research Center), Egypt (National Cancer Institute of Cairo), Jordan (King Hussein Cancer Center) and Lebanon (Lebanese Cancer Society). Data were collected systematically from consecutive breast cancer patients diagnosed and treated in those targeted breast cancer centers. Follow-up of the recorded cases will be sustained for 3-5 years.

The 1st International Consultative Meeting of the Regional Comparative Breast Cancer Research Program

The World Health Organization Regional Office for the Eastern Mediterranean (EMRO) in collaboration with the Iraqi National Cancer Research Program, the Susan G. Komen for the Cure Organization, IARC and IAEA/PACT organized a consultative meeting (Sharm Al-Sheikh, Egypt, 21-22 January 2012) to discuss the plan of action for the implementation of the Regional Comparative Breast Cancer Research Program.

In addition to representatives from the aforementioned international collaborating agencies, participants in that multidisciplinary meeting included focal representatives and expert statisticians/epidemiologists from the four participating EM countries. The main objectives of the first consultative meeting were to discuss the plan of action of the proposed research program, to endorse the devised breast cancer information system, and to agree on the collaborative process of data collection and overall analysis. Following the endorsement of the proposed questionnaire, the online data base was installed by IARC/Screening Group and is currently operating in the targeted cancer centers. The monitoring and training activities of that regional project are supervised technically by IARC and WHO/EMRO.

National Collaborating Agencies

The roles of the national collaborating agencies in the Regional Comparative Breast Cancer Research Program are described below.

World Health Organization / Eastern Mediterranean Regional Office (WHO / EMRO):

- Supervise and coordinate communication between the various stakeholders, focal country representatives and collaborating agencies.
- Collaborate in facilitating funding support to the proposed activities including the international meetings and workshops.
- Collaborate in enhancing publications, dissemination and exchange of relevant documentations and results of the research studies.
- Coordinate regional breast cancer research activities in collaboration with the concerned collaborative agencies.

International Agency for Research on Cancer / Screening Group, Early Detection and Prevention Section (IARC):

- Plan, develop, install and train in the use of the breast cancer information system to support information collection.
- Provide technical assistance on the utilization and application of the online data base.
- Facilitate and supervise the regional training workshops.
- Supervise the overall process of data collection, analysis and reporting of results.
- Enhance publications, dissemination and exchange of relevant documentations and results of the research studies.

Susan G. Komen for the Cure organization:

- Promote advocacy to empower breast cancer research grassroots, incorporating targeted community outreach and public awareness.
- Participate in supporting funds required to implement the program particulars including sponsoring the training workshops.
- Cover the requested expenses needed for advertisement, media exposure issues and health education materials.

International Atomic Energy Agency / Program of Action for Cancer Therapy; as WHO partner defined in the WHO/IAEA Joint Cancer Control Program (IAEA/PACT):

- Provide technical assistance in radiation medicine related activities including radiology (mammography/quality assurance), nuclear medicine and radiotherapy.
- Collaborate in promoting the utilization of recommendations for improving breast-health and cancer care in low- and middle-income countries (LMC).
- Contribute in supporting resource mobilization to ensure implementation of the plan of action in relevant areas.
- Support the implementation of the recorded program activities in collaboration with its partner organizations (i.e., WHO, IARC and Komen for the Cure), especially in PMDS (PACT Model Demonstration Sites).

The program will include experts in collaboration with its partners to address needs assessments as part of the impACT missions to related countries.

Expected Outcomes of the Regional Breast Cancer Research Program

Expected program outcomes include:

- Highlighting the clinical patterns of breast cancer in different EMR countries and the current opportunities to control the disease in LMC.
- Promoting the dissemination and exchange of accurate information required for breast cancer control in the region.
- Advancing cancer research through establishing a regional mechanism for obtaining up to date clinical data.
- Advocating the development of prompt diagnostic and optimum treatment technologies for breast cancer.
- Generating the evidence base to emphasize the need for the availability and accessibility of feasible options for early detection and treatment of breast cancer in EMR.
- Facilitating the development of evidence based, cost-effective, low technology approaches for early detection and multimodality treatment of loco-regional breast cancer in EMR.
- Documenting the profile of prognostic and predictive factors in breast cancer patients within the EMR.
- Correlating survival outcomes with known prognostic and predictive factors in LMC in general and EMR in particular.
- Facilitating the establishment of a resource virtual library on breast cancer control required for sharing data across local and regional boundaries in LMC.

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Delay in Breast Symptoms Presentation Among 25 to 70 Year Old Jordanian Women at King Hussein Cancer Center in 2009

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Key words: *Patient delay, breast cancer, Jordan, barriers to care*

Abstract

Introduction. A lack of public awareness about breast cancer is common in most developing countries, and has the consequence of delaying the pursuit of medical advice after the first appearance of cancer symptoms. Therefore, advanced disease diagnoses are associated with poorer prognoses.

Objectives. The aim of this study was to investigate factors that influence and/or are associated with patient delay, barriers to access, and the relationship between delay and tumor stage.

Material and methods. A cross-sectional design was used. The extent of patient delay among Jordanian women was rated at the King Hussein Cancer Center in Amman, Jordan, from June 2009 to September 2009. A convenience sample of 350 Jordanian women between 25-70 years old with breast cancer was recruited at outpatient clinics. Face-to-face interviews with participants were conducted using a questionnaire in Arabic created by the authors.

Results. The results showed that 51% of the sample sought medical consultation within one month of breast symptom discovery, whereas 23.3% of women delayed medical advice for breast symptoms for 1-3 months, and 25.6% waited more than (>) 3 months. Breast cancer patients who had a family member, relative, or friend with breast cancer were more likely to visit a health care provider earlier (62.2%, 56.8%, and 53.3%, respectively) than those who did not. Approximately 27.0% of women who discovered breast symptoms and 43.1% of women who did not disclose the discovery of symptoms to anyone were more likely to delay seeking medical advice for > 3 months. Nearly 30.0% of women who sought a general surgeon for breast symptoms were more likely to postpone their appointment > 3 months. Women who presented with a tumor that had an extension to the chest wall or skin (46.2%), lymph node involvement (26.8%), or presence of distant metastasis (40.4%) were more likely to delay in medical consultation for breast symptom discovery for > 3 months. About 44% of women who had Stage IV and 27.7% who had Stage III delayed > 3 months for medical consultation. Women who presented with low grade breast cancer were more likely to delay > 3 months. The main four reasons for patient delay stated by women were: the thought that symptoms were temporary; symptoms being not serious; lack of time; and fear of breast cancer or its surgery.

Conclusion. This study concludes that older, illiterate, single, retired, working, smoking, and childless women were at risk for patient delay. In addition, women who had a history of benign breast disease, self-symptom discovery, and having no social support were at risk for patient delay in seeking medical advice. Delays in seeking a health care provider were implicated in bigger tumor size and more advanced stages of cancer (stages III and IV).

Introduction

The breast is a symbol of womanhood and is a significant component of feminine beauty. Women with breast cancer may experience breast abnormalities or symptoms, but many of them might not show any of these symptoms at the time of diagnosis (American Society of Clinical Oncology (ASCO), 2009). The seriousness of breast cancer is strongly influenced by the stage of the disease and how far the cancer has spread when it is first diagnosed (American Cancer Society (ACS), 2009). Staging of any cancer is important because it helps the health care team to identify and recommend the best treatment, predict the outcome of the disease (prognosis), and compare the results of various treatment regimens (Smeltzer & Bare, 2004; ASCO, 2009).

Breast cancer is classified with the TNM (T = primary tumor, N = regional lymph node, M = distant metastasis) classification system which reflects prognosis (Townsend et al., 2007; AJCC, 2009). The TNM is one of the most commonly used staging systems and was developed and is maintained by the American Joint Committee on Cancer (AJCC) and the International Union Against Cancer (UICC). According to the Jordanian Cancer Registry (JCR; 2009), breast cancer has been the most common form of cancer among females (36.8%) from 1996 to 2009. In 2009, breast cancer accounted for 19.6% of all newly diagnosed cancers in Jordanian women. The main cause of death due to cancer in Jordan in 2006 was breast cancer (24.36%; Dababneh et al., 2006). Breast cancer poses an important health issue in Jordan, since 70% of breast cancer cases presented at advanced stages (III, IV) where survival rates are low and the disease is less curable (Jordan Breast Cancer Program, 2008). The early detection and more effective treatment of breast cancer leads to reducing the mortality and morbidity of the disease, and thus reduces the pressure on the health sector (Jordan Breast Cancer Program, 2008).

Breast cancer is the most common cause of cancer related death among women worldwide (Jamal et al., 2006; Hisham & Yip, 2004). It accounts for 26% of all new cancers, and 15% of deaths among women (Jamal et al., 2008). Despite that, early diagnosis of disease allows women more treatment choices and a chance of long survival (Chong et al., 2002; ACS, 2005). It depends on prompt presentation to a health care professional. Despite breast health promotion campaigns, many women delay for one month or more to seek medical advice for self-discovered breast symptoms (O'Mahony and Hegarty, 2009). Richards et al. (1999) found that the delay in seeking medical care after the discovery of breast symptoms is an important problem. Delayed presentation of symptomatic breast cancer is associated with lower survival (Ramirez et al., 1999; Richards et al., 1999; Facione 1993; O'Mahony & Hegarty, 2009).

In general, delay in diagnoses and treatment of cancer is divided into patient, provider, and system delay (Facione, 1993; Caplan et al., 2000). In many studies reviewed, patient delay is categorized into periods of less than one month, one to three months, and more than three months (O'Mahony & Hegarty, 2009; Arndt et al., 2002; Montella et al., 2001). Prolonged delay is usually defined as an interval greater than three months (Burgess et al., 1998).

Various factors may influence a woman's decision to seek help for breast symptom discovery. These factors may include socio-demographic variables, help seeking habits, symptom discovery matters, health seeking behaviors, and health characteristics (O'Mahony & Hegarty, 2009; Arndt et al., 2002; Burgess et al., 1998, 2001; Facione, 1993; Montella et al., 2001).

Patient delay and its relation to stage of breast cancer were examined in many studies. Montazeri et al. (2003) found that those who presented late had significantly bigger tumor size and presented with an advanced stage of the disease. Women may give many barriers for seeking medical care for breast cancer (Nosarti et al., 2000; Hisham & Yip, 2004; Ahmad, 2004), such as thinking the symptoms are not serious or having a strong belief in the effectiveness of traditional medicine. After a thorough literature search on patient delay for seeking health care for breast symptoms, we concluded that the topic had been inadequately studied in Jordan.

Because of the significant role of the breast in a woman's sexuality and self-identity, responses to any actual or suspected disease may include fear or loss of sexual attractiveness. These responses may cause some women to delay seeking health care (Smeltzer & Bare, 2004).

Jordan's breast cancer program aims to achieve early detection of breast cancer by using screening methods, shifting the state of breast cancer care from late to earlier stages, and increasing public awareness of breast cancer prevention (Jordan Breast Cancer Program, 2008). Despite the presence of a breast cancer awareness program in Jordan, an increased number of advanced cases were diagnosed. Due to the predominance of advanced cases of breast cancer among Jordanian women and the importance of our knowledge regarding the factors contributing to late presentation, we designed a study to investigate the extent or degree of patient delay among 25-70 year old Jordanian women with breast cancer at King Hussein Cancer Center (KHCC). The intent was to identify various factors that influence patient delay and to determine how tumor stage is subsequently affected by this delay.

Objectives

The study's objectives were:

1. To investigate the extent of and reasons (including social, personal appraisal of breast symptom, psychological, and beliefs stated by women) for patient delay among 25 to 70 year old Jordanian women diagnosed with breast cancer at KHCC.
2. To identify factors that influence patient delay among Jordanian women aged 25-70 years diagnosed with breast cancer at KHCC.
3. To determine the relationship between patient delay and socio-demographic variables, health characteristics, health behavior (health seeking habits), and symptom discovery issues.
4. To examine the association between patient delay and its impact on the stage of the disease.

Methodology

A cross sectional study of the extent of patient delay among 25-70 year old Jordanian women with breast cancer was conducted at KHCC, Amman, Jordan, from June 2009 to September 2009. The aims of the study were to identify the extent of patient delay, identify the various factors and reasons that lead to patient delay, the relationships between these factors and patient delay, and how patient delay may affect the stage of tumors.

A convenience sample of participants was selected from the KHCC at outpatient clinics, specifically from surgical clinics, medical clinics, and outpatient chemotherapy units.

Seven patients were excluded from the study due to unwillingness to participate, having bilateral breast cancer, having recurrent breast cancer, and having other types of cancers. Replacement for those who were excluded were recruited. An official approval for data collection was obtained from the KHCC Institutional Review Board (IRB). During the data collection period, a researcher visited the outpatient medical and surgical clinics, asking the clinical nursing coordinator to determine the available cases. After obtaining a written informed consent from patients who agreed to participate and showed their willingness, a face to face interview was used to collect data from the participants. An Arabic language questionnaire was developed by the author after an extensive review of literature. Face validity of the questionnaire was enhanced by a panel review consisting of three faculty members at the Department of Community Medicine. The interview took about 15-20 minutes for each patient.

The data were obtained from patients including socio-demographic factors, health characteristics, help seeking habits and symptom discovery matters, tumor characteristics and reasons for patient delay. Patient delay was defined as the period from self-discovery of breast symptoms to the time a woman seeks medical advice (Facione, 1993; Burgess et al., 1998; Ramirez et al., 1999; Montazeri et al., 2003). It was classified in periods of less than one month, one to three months, and greater than three months. Clinical data including TNM classification and tumor stage were extracted from patients' medical records. Each respondent was identified by a study serial number. Data were coded and entered into a computer, where statistical analysis was performed using the Statistical Package for Social Sciences (SPSS) program (Version 12). In order to summarize, evaluate and interpret the information that was gathered, descriptive statistics including means, medians, and standard deviations were used. Chi-square tests (χ^2) and Fisher's exact probability tests were used to identify the significance of association between different variables. If the p-value of the test was ≤ 0.05 , the association was considered significant at the 0.05 level.

Results

The overall response rate for the current study was 100.0% after replacement. The mean age of patients was 47.03 years (SD \pm 9.7). Only 5.2% of women were illiterate (n = 97); 27.8% of breast cancer patients in this study had graduated from secondary/higher schools, and nearly 19% of the study population (n = 67) had completed a bachelor's degree or graduate studies. Most women were housewives (72%) and married (80.4%). The vast majority of the women had children (93%), and most of these (n = 190, 60.3%) had \geq four children.

Most women reported the discovery of a breast lump (n = 290, 83.3%); more than one third (n = 110, 31.4%) had nipple changes and one-third (n = 108, 30.91%) had breast pain. When the type of first symptom was assessed, it was reported that 75% of the women reported a breast lump as their first symptom; nipple changes were reported as the first symptom by 6.5%. Most breast symptoms were self-detected by women (n = 326, 93.4%). Approximately half of the study participants reported that their husbands were the first person they spoke to regarding the discovery of breast symptom(s).

The results of the study revealed that more than one-half of breast cancer patients (52.3%) presented with tumor sizes between 2-5 centimeters (T2), and 7.9% had an extension to the chest wall or skin (T4). Approximately one-third of women had no axillary lymph node involvement, and about 13.0% had breast cancer that had spread out of breast tissue to other organs such as bone and liver. About 41%, 35% and 14% of women had stage II, III and V, respectively.

More than one-half of the study participants sought medical consultation within one month (short delay). About 23% ($n = 81$) of females delayed from one to three months before medical consultation, and more than one quarter of women delayed more than three months for medical consultation after breast symptom discovery. The average of patient delay in days was 135.8 ($SD \pm 535.2$).

Women who delayed \geq one month reported fear of breast cancer diagnosis (41%) or surgery (57%), or thought the symptom was not serious and temporary (64%) as the reason for their delay to seek medical help. Other barriers to seeking medical care were lack of time (43.2%), being in denial to seek medical help (33.1%), having a family member with breast cancer (9.4%), and use of traditional medicine and a belief that conventional treatment would hasten death (11%). The four main barriers to medical consultation were: a belief that symptoms would disappear (27.6%), fear of breast cancer or its surgery (24.7%), lack of time (21.2%), and a belief that the symptom was not serious (12.4%).

Study results have revealed that there was significant association between educational level and the duration of patient delay in breast cancer patients ($p = 0.042$). No other socio-demographic factors were significantly associated with patient delay. It was observed that illiterate women were three times more likely to delay > 3 months than women who had graduated with a bachelor's degree or participated in graduate studies.

Having a family member, relative, or friend who had breast cancer was not significantly associated with the duration of patient delay. In terms of smoking and having a history of benign breast disease, there was no significant association between smoking habits or/and having benign breast disease and duration of patient delay in seeking medical advice. However, non-smokers (51.3%) and ex-smokers (52.4%) were more likely to seek medical advice within one month than were smokers (48.3%).

Study findings revealed that there was a statistically significant association between the manner of detection of breast symptom(s) and duration of patient delay ($p = 0.017$). Women who discovered breast symptoms by themselves were three times more likely to delay > 3 months, compared with women whose symptoms were discovered by a doctor. In addition, women who had no one to talk to about breast symptoms were twice as likely to delay > 3 months compared with those who informed their husbands ($p = 0.004$). When the patient discovered a breast symptom and sought medical advice, there was statistically significant association between the type of health care provider that women sought and patient delay duration ($p = 0.005$). Women who consulted a general surgeon for breast symptom presentation were twice more likely to delay > 3 months compared with women who sought a gynecologist.

Results revealed that tumor size was significantly associated with the duration of patient delay. It was observed that women who had presented with a T4 tumor were twice as likely to delay > 3 months compared with those with T2 and T1 tumor size of 2 cm or less. There was no statistically significant association between lymph node involvement and/or presence of distant metastasis and patient delay duration in months. In terms of tumor stage, women who presented with Stage IV were three times more likely to delay > 3 months for medical help compared with those who had presented with Stage I ($p = 0.018$).

Discussion

Breast cancer is an important health issue for women in many countries. Any delay in diagnosis, seeking medical consultation and initiation of treatment is likely to result in tumor progression and a worsening prognosis (Arndt et al., 2003). There is no single cause for delay in seeking consultation after the discovery of breast symptoms (Elzawawy et al., 2008). Any reduction in delay may increase the proportion of early stage cancer diagnosis (Hansen et al., 2008).

Results of the current study showed that a higher proportion (51.1%) of breast cancer patients sought medical advice for breast symptoms within one month (non-delayers). The present study was analogous to research focused on delay in patient access to medical care (Arndt et al., 2002; Montella et al. 2001; O'Mahony & Hegarty, 2009). Although Arndt et al. (2002) and Montella et al. (2001) reported patient delay ranging from 17% to 20%, variations in methodology may account for the differences.

With regard to socio-demographic variables, results of the present study showed that approximately 30% of women aged ≥ 55 years were more likely to delay > 3 months, compared with 6.3% of women in the age 25-34 years group. The findings of this study were consistent with Arndt et al. (2002), who reported that nearly 25% of women aged ≥ 65 years delayed > 3

months compared to women who were aged < 50 years. Also, the findings of the present study were consistent with those of Harirchi et al. (2005), Richards et al. (1999), and Montella et al. (2001), where older women were more likely to delay medical consultation for breast symptoms. In the current study, the fact that older women were more likely to delay may have been due to the fact that they attributed breast symptom to normal aging or some morbid condition (Facione, 1993). Moreover, their concerns about other diseases may have prolonged their delay.

As others have reported (Meechan et al., 2002; Montella et al., 2001), delay time was not significantly related to marital status. Conversely, current findings were inconsistent with the study conducted by Montazeri et al. (2003) in Iran. They found that 64.6% of married women were more likely to delay > 3 months than single, widowed, or divorced women. Women who were divorced or widowed were at a high risk of delay > 3 months, whereas in our study it was observed that 33.3% of divorced women were more likely to delay 1-3 months to seek medical advice (although this represents a small number). The discrepancies between the results of this study and Montazeri et al. (2003) could be due to the difference in the sample size, which consisted of 190 breast cancer patients in the former study. Also, single women may have experienced more delay due to fear of breast symptom presentation and reluctance to disclose what they had discovered until the symptoms became advanced in nature. Jordan is an Arab country; any single female may have a general belief that any abnormality in her body might be detrimental to her prospects of marriage. So, she may keep that fact to herself and not convey it to anybody. This may indicate the significance of cultural differences regarding marital status among women with breast changes and how this may impact their intentions to seek medical advice.

It is surprising in this study that childless women were more likely to delay 1-3 months to seek medical consultation for breast symptom presentation. These results were inconsistent with those of Montazeri et al. (2003). This could be due to the following: First, childless women might have a fear of detecting any disease that may become a barrier toward attempted pregnancy. Second, Jordanian childless women may avoid disclosure of breast symptoms to their husbands because of feelings of inadequacy regarding their reproductive ability and the fear that breast cancer may cause their husband to leave the marriage. Third, since only 7.0% of women in this study were nulliparous, this could explain the discrepancy with the previous study. Cultural differences and beliefs could also have had an impact on patient delay.

Consistent with other research, there was a tendency among women who had a family member (62.2%), a relative (56.8%), or a friend with breast cancer (53.3%) to seek medical advice earlier for breast symptom discovery ($p > 0.05$) (Arndt et al., 2002; O'Mahony & Hegarty, 2009; Burgess et al., 1998).

While findings were inconsistent with those in Montazeri et al. (2003) and Meechan et al. (2003), the differences could be due to the fact that those women had observed a full range of treatment offered to their family members and friends, which encouraged them to seek medical advice and diagnosis, saving them from a potentially fatal outcome (Harirchi et al., 2005). However, the findings of the current study regarding women who knew a person with breast cancer and delayed for a longer period (≥ 1 month) before seeking medical advice need further investigation in order to determine the underlying causes that gave rise to barriers to access of medical care.

Having a benign history of breast disease (35.4%) was related to > 3 months delay in seeking medical advice for breast symptom presentation prior to breast cancer diagnosis. Conversely, 53.4% of women who did not have a history of benign breast disease sought medical help earlier. The finding of this study was in agreement with that in Arndt et al. (2002).

Findings of this study strongly emphasize the need to re-evaluate available training/education programs, especially their quality and efficiency, in providing information to women. The focus should be not only on a wide range of information on breast cancer but also on the concept of delay and its consequences.

Women who discovered breast symptoms by themselves were three times more likely to delay > 3 months compared with women whose symptoms were discovered by a doctor. Also, women who did not disclose the discovery of breast symptoms to anybody delayed > 3 months compared to women who did disclose breast symptom discovery (see also Burgess et al., 1998; O'Mahony & Hegarty, 2009).

The results of the present study revealed a highly significant association between the type of health care provider that the women consulted and the duration of patient delay. Approximately 30% of women who sought a surgeon's advice delayed > 3 months compared with 17.4% of women who consulted a gynecologist. To the best of our knowledge no other studies investigated that particular issue. Montella et al. (2001) conducted a study in Italy and found that women who consulted a general practitioner (GP) were more likely to have provider delay than those who did not.

Perhaps women who delayed their presentation to general surgeons might have been afraid of hearing bad news about the seriousness of their condition. Or, they may have been afraid of the type of surgery such as complete removal of their

breast (radical mastectomy). For women who sought their gynecologist earlier for breast symptoms, frequent visits and regular breast examinations may have raised their awareness about breast cancer symptoms. In Jordan, women can seek any type of physician immediately. Primary centers that are distributed in all parts of the country offer clinical breast exam (CBE) and further information about breast cancer. However, is the clinical breast examination performed by a health care provider (HCP) in these primary centers effective? This question should be sent to policy makers and everyone who is in a position of HCP, as there is a need for more training of physicians especially in diagnosis and management of breast cancer among women in Jordan.

The current study broached the subject of barriers that prevent women from getting medical care for breast symptom discovery. The most common barrier, which was reported by 63.7% of women, was the thought that the symptom would go away. The next most common barrier was the thought that the symptom was not serious (57.4%), followed by lack of time (43.2%), fear of breast cancer or its surgery (50.0%), being in denial and avoiding seeking HCP (33.1%), and use of traditional medicine and belief that conventional treatment would hasten death (approximately 11.0%).

Many explanations for the variations in the rank of the different reasons between the current and the previous studies could be given. One explanation is that a different methodology was used in the previous studies (Lauver et al., 1993; Nosarti et al., 2000; O'Mahony & Hegarty, 2009). Whatever the explanation, it should be mentioned that the reason for delay as stated by each woman may have included more than one of the categorized barriers: personal appraisal, psychological issues, social issues, and beliefs. For example, psychological reasons have accounted for patient delay, where fear of breast cancer or its surgery prevented some women from seeking medical help. Women might also fear losing a part of their body that reflects their femininity and attraction. Lack of time could be due to social problems (related to work, family members, and holidays) and prioritizing these above their personal health and reducing their time for seeking medical advice (Burgess et al., 2001). Also, using traditional medicine such as herbs or some types of oil may lead to delay among some of women. Hence, much time is wasted on ineffective treatment before discovering an advanced disease. Nowadays, many television channels show advertisements that attract and convince the general public to use alternative medicines. Some of these channels use religious symbols to convince people to try alternative medication and to motivate those with breast cancer to buy them, and this may discourage women from seeking medical consultation.

In the current study, results of tumor characteristics among women revealed that tumor size, tumor stage and grade were significantly associated with patient delay, while lymph node involvement and distant metastasis were not significantly associated with patient delay. Results showed that nearly 46.0% of women who had T4 delayed > 3 months, followed by 31.1% of women with T3 who delayed > 3 months. Also, approximately 27.0% of those with positive lymph node were more likely to delay > 3 months compared with those with negative lymph node (18.4%). In addition to that, 40.0% of women who presented with distant metastasis were more likely to postpone their appointment with a physician > 3 months compared with those who did not have metastasis. When tumor stage was assessed, it was observed that women who presented with stages I and II were more likely to visit their HCP earlier compared with those who had stage III and IV.

The results of the current study were in agreement with those of Arndt et al. (2002), who reported that women with late stage breast cancer were more likely to delay > 3 months compared with those who consulted the doctor in < 1 month. Also, the findings of this study were consistent with those of Ahmad (2004) and Montazeri et al. (2003), where those who presented late had a more advanced disease and a larger tumor size. Furthermore, our findings were in agreement with those of Richards et al. (1999), where they reported that tumor size and stage were significantly associated with delay. Also, the findings of this study were consistent with Hainsworth et al. (1993), where no significant relationship was found between delay and nodal status or metastasis.

Limitations

This study may have the following limitations. First, the study results cannot be generalized to Jordanian women with breast cancer who were treated in other private and public hospitals because the study was limited to Jordanian women who were diagnosed with breast cancer and attended the King Hussein Cancer Center. Second, there is a recall bias because questions pertaining to recall of the duration of delay from the onset of breast symptom discovery to medical advice may have been wrongly estimated, especially in cases of those with longer delay, those who had finished their treatment, and those undergoing regular follow up. Third, there is a possible reporting bias because some women might have provided inaccurate information. Due to the fact that all data were collected via interview, the potential exists for false or inaccurate information to have been given for some questions. Fourth, study participants might have been prone to selection bias since the available breast cancer women on each day during the data collection period that might have varied from one service to another.

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The Current Status of Breast Cancer in Resource-Limited Countries

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Key words: *Breast cancer, cross cultural, public perceptions, screening*

Introduction

As an urgent public health problem across the globe, breast cancer remains a devastating disease for which no cause or cure has been found. Breast cancer is the most common cause of cancer-related deaths among women worldwide. More than one million women are diagnosed with breast cancer each year and more than 500,000 women die from this disease [1,2]. The incidence of breast cancer is lower in resource-limited countries. However, when compared to resource-rich countries, the mortality rate is much higher [3,4]. Similar findings have been reported in the CONCORD study which showed that the five-year breast cancer survival rate in black women was substantially lower than in white women [5]. Thus assessments of the contributing factors to these differences among breast cancer patients are critically important.

Recent progress in breast cancer diagnosis and treatment has resulted in a reduction of the mortality rate from breast cancer in countries such as United States and Europe by 2% per year since the early 1990s [6]. The reported reduction in the mortality rate from breast cancer in resource-rich countries is attributed to early detection by screening mammography combined with timely and effective treatment. The results of several clinical trials started in the 1970s on screening mammography and clinical breast examination showed that early breast cancer detection within a specific population leads to down staging of breast cancer and improved survival. During the same period of time, results from several randomized clinical trials showed positive influence of endocrine therapy for estrogen receptor-positive breast cancer and chemotherapy for estrogen receptor-negative breast cancer patients. These therapies improved survival in lymph node negative, lymph node positive and even locally advanced breast cancer [7,9].

This trend, however, has not been observed in countries of limited resources. It is clear that breast cancer patients residing in these countries have limited ability to enjoy the impact of the recent advances in breast cancer diagnosis and therapy. These facts provide powerful evidence that it is possible to favorably influence patients' outcomes by applying incremental changes in breast cancer care within a population [10].

Reducing the rate of mortality from breast cancer is a major task and requires in-depth knowledge of the current status of breast cancer in different regions of the world and recognition of the barriers that are reportedly numerous. Aside from economic status, providing optimal breast cancer care to a geographically diverse population of patients with different genetic backgrounds, life styles, religious beliefs, social values, and cultural and political influences is difficult to achieve. In countries of limited resources, the high mortality rate associated with breast cancer is mainly because of late-staged disease presentation. This factor, combined with limited capacity for correct diagnosis and optimal therapy, results in poor outcomes [10-14].

Public Perception of Breast Cancer

Health illiteracy in general and breast cancer specifically remain as crucial obstacles in countries of limited resources where breast cancer commonly remains under diagnosed until it is late stage or metastatic, when treatment options are less effective or are not readily available [15,16]. In addition, misconceptions about breast cancer and traditional

beliefs hinder a woman's access to appropriate care. The loss of a breast as a result of breast cancer, for many women, is considered as the loss of their sexual identity. Serious emotional issues such as depression, anxiety and negative perceptions of self-image are not uncommon experiences. These experiences become more terrifying for women who live in countries of limited resources. In these countries, women have low social status and low income, and fear of loss of their husband as the result of breast cancer contributes to their reluctance to seek care in a timely fashion [17-19]. The associated negative social beliefs and the fear of being labeled as the one with bad genes within the family and the one who is no longer sexually desirable are powerful factors for a woman to stay silent about her disease. Thus instead of seeking medical care, these women often seek alternative care, or with beliefs of fatalism fall into social isolation and accept poor outcomes [20, 21].

In order to influence change, it is critically important to let the public know that breast cancer if detected early is not a fatal disease. It should be emphasized that not all breast cancers are aggressive in nature and require mastectomy. Public breast health education must be designed to deliver the right message not only to women, but also to men, physicians, other health care providers, administrators and more importantly, community health care leadership. Recent movements of several advocacy organizations such as Europa Donna in Europe and Komen Foundation for the Cure and American Cancer Society in the United States have contributed to enhanced public awareness and increased breast cancer research and education [22-24]. These organizations have extended their efforts at the global level. However, implementation of breast cancer advocacy and public awareness programs are incredibly challenging in countries of limited resources. Limitations in financial support, social barriers and competing illnesses are factors that adversely affect the progress of these efforts [21,25,26].

Screening and Early Detection

There is no doubt that early detection of breast cancer is associated with improved clinical outcomes [27, 28]. Therefore, communication campaigns to encourage participation in regular breast cancer screening activities in countries of limited resources are essential steps [29,30]. Currently, breast self-examination, clinical breast examination, and screening mammography alone or in some combination are being promoted across the globe. Anticipating that there is significant variability in the availability of these modalities and the acceptance and enthusiasm of participation in these programs, it is essential to study the culture and resources of each community and design a region-specific program for early breast cancer detection [31].

Interestingly, even in well-orchestrated population-based screening programs, there is no guarantee that women follow up with diagnostic studies once there is a finding on the initial examination. This is best exemplified by a large population-based randomized trial to study screening with clinical breast examination in the Philippines that found that 60% of women refused to return for follow up appointments. Thus the success of screening programs depends on implementation of effective educational campaigns with engagement of the community, politicians, religious leaders, the media, breast cancer survivors, and professional educators [32].

Clinical breast examination is considered an important diagnostic tool for the follow up surgical therapy of breast lesions. However, its value as a screening modality remains controversial, despite the promising results reported by Mittra et al. from India [33]. In this study it was suggested that clinical breast examination as a screening tool is effective in the down-staging of breast cancer and ultimately in achieving better patient outcomes. Similarly, the role of screening mammography in countries of limited resources has not yet been fully realized. It is clear that mass screening is not only limited because of lack of access to optimal mammography units and trained professionals; the resources are not available for follow up diagnostic tissue sampling and treatments. Ultrasound, alternatively, combined with a clinical breast exam can serve as an effective screening tool in countries of limited resources [34].

Breast ultrasounds are most useful for distinguishing solid masses from breast cysts. This information is critically important for the selection of breast lesions that require tissue sampling, and mammograms are not helpful. In addition, younger women who have dense breasts benefit more from ultrasound imaging. This imaging modality is less expensive and more readily available [35].

Breast Cancer Diagnosis and Tissue Sampling

Associated with clinical presentation of palpable breast lesions and for those lesions detected by breast imaging, the diagnosis of breast cancer has to be established by tissue sampling. The diagnosis of breast cancer carries prognostic and therapeutic implications that are life changing for a woman. A pathology diagnosis should not be bypassed even when health care resources are limited, because a misdiagnosis of breast cancer can lead to erroneous treatment of women

without breast cancer, which compromises patients' safety and results in unnecessary waste of treatment resources [35]. Aside from traditional excisional biopsy, minimally invasive procedures such as fine needle aspiration biopsy and core needle biopsy are commonly used. The choice of tissue sampling has to be determined by the availability of resources and adequately trained pathologists [36]. Minimally invasive biopsy has several advantages over surgical breast biopsy. The former is less invasive, less expensive, does not cause scarring or deformity, and can be performed in a clinic, obviating the need for an operating room. For women with late stage breast cancer, minimally invasive biopsy can provide a rapid diagnosis, enabling initiation of treatment. Fine needle aspiration biopsy is the most cost-effective sampling procedure if properly performed and interpreted by an experienced pathologist [35,36].

Accurate diagnosis of breast cancer forms the foundation of optimal breast care and defines the pathway for follow up therapy and ultimate outcome. Thus it is essential that the quality of practice of breast pathology be improved at global level [36-40]. Currently, access to adequately staffed pathology laboratories in countries of limited resources is a major problem. In order to facilitate the availability of access to the tissue diagnosis and biomarkers studies that are required for proper treatment planning, establishment of regional pathology laboratories will provide a cost-effective source of service as well as a suitable site for training and research [37].

Breast Cancer Therapy

The broad variation in the epidemiology of breast cancer between different regions of the world, differences in the stage of presentation of breast cancer and the biology of this disease, as well as the difference in the availability of resources of each area, make it difficult to formulate a uniform approach to breast cancer therapy. Thus, the realization of the complexity of breast cancer care at an international level is a necessary initial step. It is also critically important to acknowledge that the existing guidelines for optimal breast cancer screening, diagnosis and therapy designed for resource-rich countries are not practical for implementation in resource limited regions [38-40].

The suggested alternative approach is to develop region-specific guidelines that realistically take into consideration the financial, political, cultural, and social barriers existing in each resource-limited country. This approach provides an opportunity for every region of the world to make an effort to gradually improve the quality of breast care via an integrated system. This stepwise process of improvement can serve as a starting point that will pave the way for gradual progression to the delivery of optimal care for breast cancer patients. This process requires a significant degree of collaboration and endurance to make sure that the significance of attention to breast care as a national health care priority is realized by heads of governments, health care leaders, administrators, physicians, scientists, health care providers, technicians, nurses, social workers, religious leaders, and more importantly, by the people of the world. Aside from consideration for standard surgical, radiation and systemic therapy, palliative care and pain management should be integrated into breast care and sufficient resources should be developed to guarantee proper measures for adequate surveillance and support [38-41].

Access to Care

Despite the significance of breast cancer as a global public health problem, it is difficult to argue with health care leaders of resource-limited countries who have more urgent health care issues such as providing clean water, sanitation and infectious disease control. However, it may be possible to suggest low cost interventions that could make a difference [42]. Currently, differences in access to effective screening programs and therapy, as well as the risk factors and biology of breast cancer, can explain the difference in the incidence and mortality rates of this disease in different regions of the world [43]. It is hoped that breast cancer patients in countries of limited resources will become more aware of their right for access to a better quality of breast health care. It is anticipated that the international advocacy movement will become more effective in improving the knowledge about breast cancer among the public and health care providers. It is essential to develop strategies for establishment and maintenance of data registries and coordination of the multidisciplinary approach to breast cancer research, education and care within existing resources and possibilities. Implementing public policies for effective communication about breast cancer is needed to guide the development of culturally-sensitive messages to promote breast health. Among various approaches, the process that holds great promise to reduce the burden of breast cancer in countries of limited resources is the assessment of the costs and potential benefits of cancer prevention and control intervention to ensure that limited resources are used effectively [44,45].

Summary

Advances in science and technology and improved public awareness over the past few years have brought significant attention to breast cancer across the globe. In addition, there has been significant interest in breast health research by diverse teams of basic scientists, physicians, pharmacists, industries, nurses, social workers and health economists. This research has involved inquiries about fundamental biological alterations in breast cancer and the differences in screening, diagnosis and treatment options in different regions of the world. Advances in breast imaging and emphasis on screening programs, development of new chemotherapeutic agents and radiation therapies, and the availability of molecular genetic testings have brought new insights in breast cancer. These efforts have resulted in a reduction in breast cancer mortality in resource-rich countries.

At the global level, however, the rate has remained the same and there are indications that the burden of breast cancer is increasing in countries of limited resources. Interestingly, the medically underserved populations among resource-rich countries experience similar trends, indicating that access to optimal breast health care and implementation of effective educational and screening programs can play significant roles in improving patient outcomes. Other factors contributing to the differences in mortality rates from breast cancer are differences in genetic background, biology of the disease, socioeconomic status, level of education, religious beliefs, and perceptions of the public about breast cancer.

There is no doubt that more efforts should be placed on the significance of early breast cancer detection and the value of the delivery of cost-effective, region-specific, culturally-sensitive and integrated breast care across the globe. It is anticipated that the public in resource-limited countries will become more aware of their right to access better quality breast health care. There will be more collaboration among individuals from different spectrums of health care in order to better design strategies for opportunities to improve breast health care across the globe.

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Palliative Care in Arab Countries: Challenges and Achievements

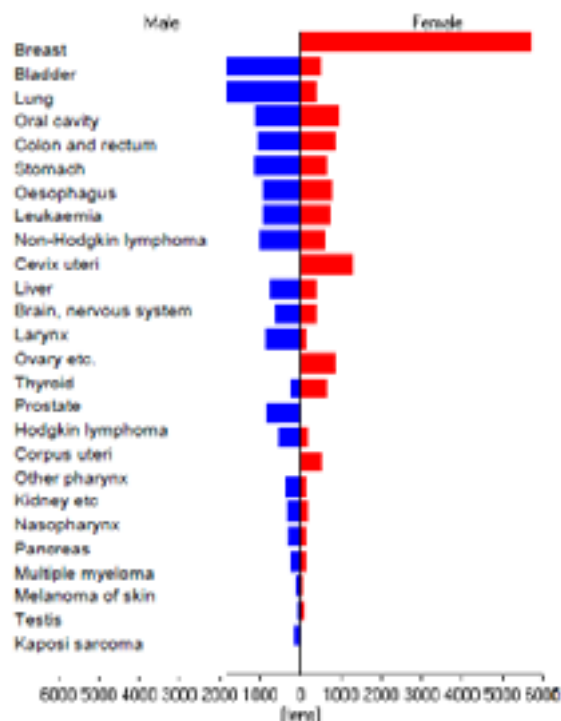
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Lebanese Cancer Society

Key words: *Palliative care, cancer, Arab countries*

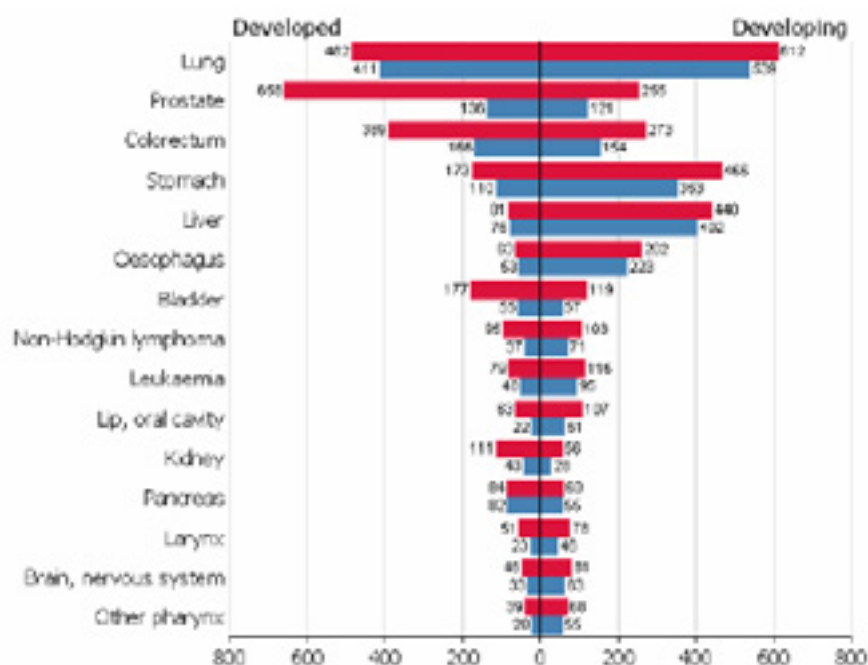
Palliative care is a new concept in the health care sector in Arab countries and it is mainly linked with cancer. Cancer is an increasing problem in the Arab countries. It is the fourth leading cause of death in this region. It is expected that deaths from cancer in these countries could reach 760,000 per year by the year 2020 (see Figure 1 and Figure 2) [1,2].

Figure 1. Cancers in the Eastern Mediterranean Region (Globocan 2008)



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Figure 2. Estimated Numbers of New Cancer Cases and Deaths in Men in Developed and Developing Regions of the World in 2008 (Globocan 2008)



Cancer in Arab societies is frequently a protracted illness causing great disability and suffering that finally leads to a painful death. At present, resources for cancer control in our countries as a whole are not only inadequate but directed almost exclusively to treatment [3,4]. The curability of cancer is directly related to its stage at the time of diagnosis, and in the majority of countries of this region, cancer is generally diagnosed when it is at a relatively advanced stage. For patients who have late stage cancer, the management of pain and other symptoms should be part of their overall treatment and the primary aim of national cancer control programs [5-7].

This region includes a wide range of economically diverse countries, from technically advanced countries with high level cancer care to countries with little or no cancer treatment capabilities. There are large differences in population size, wealth and health expenditures (Table 1).

Table 1. Countries of the Eastern Mediterranean Region by Income Group and Total Expenditure on Health

Country	Population (Thousands) ^a	World Bank Income Grouping ^b	Total Expenditure on Health Per Capita (US\$)
Qatar	1,305	High	2,186
United Arab Emirates	4,106	High	833
Kuwait	3,328	High	687
Bahrain	743	High	710
Lebanon	3,928	Upper middle	460
Saudi Arabia	24,242	Upper middle	448
Oman	2,557	Upper middle	312
Libyan Arab Jamahiriya	5,419	Upper middle	223
Jordan	5,600	Lower middle	241
Occupied Palestinian territory	3,762	Lower middle	NA
Tunisia	10,225	Lower middle	159
Iran, Islamic Republic of	70,495	Lower middle	212
Morocco	30,841	Lower middle	89
Syrian Arab Republic	19,172	Lower middle	61
Egypt	73,435	Lower middle	78
Djibouti	720	Lower middle	61
Iraq	29,000	Lower middle	59
Yemen	21,535	Low	39
Sudan	37,239	Low	29
Pakistan	156,000	Low	15
Afghanistan	24,500	Low	20
Somalia	7,960	Low	NA

* Source: *Demographic, social and health indicators for countries of the Eastern Mediterranean 2008*. Cairo, WHO Regional Office for the Eastern Mediterranean, 2008.

The availability and quality of treatment is another factor. Cancer is not only often caught sooner but is also usually treated more successfully in some countries compared to less developed ones. The relative survival rate can be 50% or better, but in less developed countries it is only 30%. Thus, recommendations are tailored, to the extent possible, to different resource levels, both among countries and in different regions or populations within the same country. Whether we consider incidence, mortality, early detection or treatment rates, it is clear that there exist significant opportunities to save lives and reduce suffering in Middle Eastern (ME) countries. Unfortunately, the single most important trend in cancer in these countries today (and in developing countries in general) is the growing gap between what we know and what is actually being done to reduce human suffering and to save lives [8,9]

Given the impact of the late presentation problem, palliative care is of paramount importance in ME countries. From the situation analysis of palliative care in ME countries, suggesting that pain relief is insufficient, improvements in palliative care delivery are a high priority [10]. In reality, the ME countries suffer from the same barriers to palliative care as other developing regions of the world [11,12], which include:

1. Restrictive policies from health care providers towards access to opioids; these are due in great part to an over-concern about drug abuse
2. Insufficient development of palliative care: too few palliative care programmes and of insufficient quality
3. Lack of awareness of the human right to pain relief and a peaceful death

Opioids are available in all Middle Eastern countries, but in half the countries only oncologists can prescribe narcotic analgesics. The duration of the prescription varies from 1 week to 1 month. Opioids consumption, which is a recognized surrogate marker for the quality and quantity of palliative care, is low (between 0.2 and 1.2 mg/capita, except for Israel) compared to most industrialized countries, where it is around 50 mg per capita. These amounts are undoubtedly not meeting the needs of patients. These results suggest that access to opioids is a major issue in ME countries, very probably because of concern about drug abuse.

Situation analyses of palliative care and opioids consumption in these countries have been made by the International Narcotic Control Board and by the Middle Eastern Cancer Consortium (MECC) through its program for promotion of palliative care in some ME countries [13]. Based on these data, three priorities for action emerged:

1. Ensure full access to affordable inexpensive opioids for all patients in need; this is an internationally recognized principle. Efforts to prevent drug abuse and diversion must not interfere with ensuring the availability of opioid analgesics for legitimate pain relief. In the presence of necessarily strict regulations regarding narcotics, it is not infrequent to attempt to minimize the amount of morphine available in the country [14,15]. The Pain and Policy Studies Group (a WHO collaborating centre) has developed guidelines that can be used by governments and health professionals to assess national opioids control policies; the administration of these policies must ensure the availability of opioid analgesics [16]. Countries should urgently examine their drug control policies to assess the legal and other barriers to opioid availability.
2. Develop human resources for palliative care. Studies performed in various ME countries have shown that the most important barriers to efficient palliative care are the lack of knowledge of correct usage, or concern that patients may become addicted to opioids. It is recommended to incorporate the management of cancer pain into all nursing and medical school curricula in the ME countries, and that continuing education be provided to all who care, directly or indirectly, for patients with cancer. An effective approach to the provision of training in palliative care is to designate one or more institutions as training centers for palliative care, local, regional (for example, King Hussein Cancer Centre in Amman or King Faisal Cancer Centre in Riyadh), or international. Health care providers should be educated about morphine use as well as other palliative care modalities.
3. Develop home care programmes. Most patients requiring end-of-life care prefer to receive such care at home. This usually has the advantage that they are surrounded by family members, who have an important role in care delivery. Home care is particularly appropriate in ME countries, where familial solidarity is still very strong, and has been shown to be feasible and cost-effective as in many other low-income and middle-income countries [17,18]. Unfortunately at present, most patients die in hospitals in spite of their desire to die at home, because actual reimbursement policies currently do not support care at home. Considerable savings for the health care system could be realized if an effective coordinated home care system were to be put in place [19,20].

Today we can say that in the past decades there have been significant advances in our understanding of the complexity of pain relief and palliative care and in our knowledge about the field. Significant developments have taken place in education, practice, and research but a number of challenges remain which need to be addressed at the national level. At the professional level, challenges include a lack of knowledge and skills as well as inappropriate attitudes and behaviors among health professionals. Practice and system challenges include lack of resources, inadequate financial coverage, poor coordination of care, problems with drug availability and accessibility, and lack of legislation and recognition of the specialty areas.

Many countries have initiated a national PC committee, whose mandate is defined as follows:

Education

- To recommend a core curriculum to be used in the training of health care professionals with emphasis on knowledge, attitudes, and skill development
- To recommend specialization trajectories of physicians and nurses in the field
- To institute the importance of continuing professional education in the field as a requirement for recertification and licensure
- To develop strategies for public education in the field

Practice

- To develop national standards and competencies for pain relief and palliative care
- To develop strategies to engage professionals from different disciplines in the care process such as the use of multidisciplinary care pathways
- To recommend models for service delivery such as home care and residential care and the use of palliative care teams in hospitals
- To develop mechanisms to empower the family and the patient to be actively involved in the care process, emphasizing the importance of family and patient-centered care

Research

- To develop national research priorities for the field of pain relief and palliative care that target gaps in treatment, knowledge transfer, education, and policy
- To recommend research methods to address the gaps in information related to pain relief and palliative care

Public Policy

- To develop strategies that will ensure the availability, accessibility, and prescription rights of opiates
- To recommend strategies that will ensure the practice of interdisciplinary palliative care teams in the care process
- To recommend appropriate legislation for the regulation of pain relief and palliative care for adults and children
- To recommend models for cost allocation and reimbursement for pain relief and palliative care services
- To recommend the institution of pain relief and palliative care as integral parts of the health care system

We can say that palliative care in Arab countries has made some important strides in the last decade but it is still in its infancy, and urgent attention needs to be given to the implementation of the recommendations listed above. However, despite all efforts, the subject of palliative care in Arab countries is still not approached scientifically. Research is lacking at all levels, and palliative care is delivered by non-specialized physicians and registered nurses. Making real improvements in pain management will require the proactive efforts of many organizations, and we believe that education as well as discipline should be the cornerstone of efforts to improve pain management. In ME countries, much of the progress in palliative care has largely been driven by the non-governmental sector. This has resulted from an extraordinary collaboration between the state, non-governmental organizations (NGOs), health-care professionals, and volunteers [21]. Until we can reliably and easily cure cancer, it is imperative that the principles of palliative care be incorporated into comprehensive cancer programs. While much progress has been made, there remains a great deal of suffering in the lives of the patients cared for in the ME countries [10].

Conclusions

At the end of this review, two main conclusions can be cited:

- Provision of PC provides better outcomes than usual care and is cheaper on the health care system in the long run.
- Continuing education programs in PC are needed in Arab countries.

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Rights of Cancer Patients in Arab Communities: Challenges and Opportunities

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Abstract

Human rights are universal and indivisible rights, possessed by all people, by virtue of their common humanity. The right to health is a fundamental right that influences all aspects of life. Cancer is a leading cause of death in many countries and its diagnosis/treatment affects the lives of patients in many ways that necessitate special and additional rights, which are considered to varying degrees in Arab and world communities.

The rights of cancer patients are not widely discussed in the literature. The most effective way for health care professionals to fulfill their obligations under the “right to health” approach is to ensure that they provide the highest possible standard of care while respecting the fundamental dignity of each patient. Governing bodies should respect, protect, account, and fulfill cancer patients’ rights. Nonetheless, these rights need further refinement from professional health-care providers, patient relatives and friends, and the patients themselves toward their own bodies.

Our results from this study showed that there are legislative and practical difficulties regarding human rights of the cancer patients in the Arab communities in general. This has been shown in selected aspects of this study, in the form of the required laws and regulations for cancer patients and through some of the cancer care facilities for their care, such as radiotherapy machines, strong analgesics for pain relief, and general compliance of the Arab countries with the “right to health” indicators.

The essential rights of cancer patients include: (1) the right to cancer prevention and health promotion procedures; (2) the right to financial assistance at the highest attainable standard of health by a multi-disciplinary team of oncology specialists; (3) the right to privacy and confidentiality; (4) the right to participate in the management plan protocol; (5) the right to know the side effects of cancer diagnostic testing procedures and treatment modalities, which also should be minimized to the extent possible; (6) the right of avoidance of unnecessary suffering and pain; (7) the right of access to continuity of care, palliative care and end of life care; (8) the right to gainful employment commensurate with their talents and abilities; and (9) financial compensation. All of the above rights have to be given without regard to age, race, gender, and economic status.

The authors conclude that for adequate fulfillment of cancer patients’ rights in Arab communities, much work is required to implement flexible and creative public policies, greater awareness of cancer and its management, tireless advocacy, comprehensive education, professional leadership, and continued calls upon individual compassion for this vulnerable group of people. Finally, the patient has the right to be treated and dealt with as a human being, rather than a disease. Sometimes caregivers overlook this issue. Addressing this topic is the purpose of this study.

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Introduction

Cancer diagnosis and subsequent treatment approaches often affect the life of cancer patients in various ways that necessitate special and additional rights, which are considered, to varying degrees, in world communities in general and Arab communities in particular. This variability prompted the authors to explore this issue and its related challenges and opportunities in Arab communities.

It is well known that in order to ensure high quality health care services for cancer patients, it is essential to observe their rights and meet their needs and expectations, as well as to offer the best service possible. Cancer patient rights, as an extension of human rights, can be taken as an application of basic human rights and values in cancer health services and are a fundamental tenet of medical ethics. The purpose of cancer patient rights is to receive health services under conditions that are compatible with an individual's human rights. The fundamental concern is to safeguard patients' personal rights. Accordingly, patients have the basic rights to receive equal, accessible and constant health care services, to be given information necessary in order to make their own decisions freely regarding methods of treatment, and to have privacy and respect regarding their psychosocial and spiritual values [1].

Historically, the health and human rights movement has grown with the expansion of the human immunodeficiency virus/acquired immuno-deficiency syndrome (HIV/AIDS) pandemic. Developments in the academic field are the development of health and human rights training programs, especially in medical and public health schools; the creation of specific professorships at universities; the addition of scientific journals focusing on health and human rights; and international conferences [2].

In this article the authors explore aspects of this subject among Arab communities, with the challenges and opportunities relating to this issue. While it is understood that Arab countries are multi-ethnic and multi-religious, we refer to them by this prevailing terminology—that is, those countries of the Middle East, and North Africa, where Arabic is the commonly used language of government and daily communication. The view expressed in this work is that the rights of cancer patients are universal and transcend all cultural, ethnic and religious divides, real or perceived.

Objectives

Studies of the human rights of cancer patients are useful to scientists involved in human rights advocacy, political decision-makers in the evaluation of cancer control policies, and teachers of human rights training programs. Such studies permit discovery patterns in the structure of scientific fields, identify processes of knowledge dissemination, and visualize the dynamics of scientific developments. In the context of new research areas such as healthcare (cancer control in particular) and human rights, such studies are necessary in order to obtain an overall view of the intellectual structure of the field, to consider scientific impact, or to suggest how a field might move forward [2].

In this article we aim to describe the diversity of application of patients' rights in different communities. The fundamental legal and humanitarian bases of the right to health in general, and the right to optimal cancer care in particular, guides providers of these rights in carrying out their responsibilities towards cancer patients. The successful incorporation of human rights impacts the effectiveness of health-care policies and programs in Arab countries.

Method

In this study we conducted a mini-review of the relevant international and Arab published literature, with additional personal reflections and insights pertinent to this topic and this group of patients. We used PubMed, Google Scholar, and Google Search in addition to other web sites to search for data about the rights of cancer patients in Arab communities. What kept coming up in abundance were general human rights regulations but without discussion of cancer patients' rights in detail. Lack of literature on this subject supports the aim of this study.

Terms and Definitions

Human rights are universal and indivisible rights, possessed by all people, by virtue of their common humanity, to live a life of freedom and dignity, irrespective of citizenship, nationality, race, ethnicity, language, gender, sexuality or abilities [3].

Health is a state of complete physical, mental and social well-being, not merely reflecting the absence of disease or infirmity [4].

Health care includes the entire range of preventive, promotive, curative and rehabilitation services, mainly bio-medical, which are carried out with the primary objective of maintaining or restoring health, including health infrastructure, human resources, drugs and equipment, and all the other facilities for addressing ill-health and diseases [5].

Right to health is a fundamental right that influences all aspects of life. It encompasses medical care, access to safe drinking water, adequate sanitation, education, health-related information, and other underlying determinants of health, and it is related to and dependent upon the realization of other human rights, e.g. the right to food, housing, work, education, human dignity, non-discrimination, equality, life, privacy, access to information and the prohibition of torture [6].

Cancer is a malignant disease and is a leading cause of death in many world countries [7].

Suffering is an uncomfortable instance of mental, psychological, emotional and/or physical pain or distress [8].

Ethical Bases of Medical Practice

Since their introduction by Beauchamp and Childress, autonomy, non-maleficence, beneficence and justice have been the dominant approaches to the teaching and evaluation of medical ethical dilemmas in health care. Whilst they have received some criticism, predominantly from the casuists (the other main method adopted in bioethics), they are still widely used and discussed, despite their limitations, both in practice and in the academic literature. Katie Page [9] concluded that “people state they value these medical ethical principles, but they do not actually seem to use them directly in the decision making process.” The reasons for this are explained by the lack of a behavioral model to account for the relevant situational factors not captured by the principles [9].

International Laws in Relation to Human Rights and Cancer Patients

In 1948, the Universal Declaration of Human Rights was unanimously proclaimed by the United Nations (UN) General Assembly as a common standard for all humanity. This declaration sets forth the right for each person to a “standard of living adequate for the health and wellbeing of himself and his family, including medical care, the right to security in the event of sickness, disability or other lack of livelihood in circumstances beyond his/her control” [10].

Right to health was not defined in the previous declaration; however, it was included in the International Covenant on Economic, Social and Cultural Rights (ICESCR) in 1966. Article 12 of the ICESCR explicitly sets out a right to health and defines steps that states should take to “realize progressively...to the maximum available resources...the highest attainable standard of health.” Right to health features are not just good management, justice, or humanitarianism; they are obligations under human-rights law. In 2000, the UN Committee on Economic, Social, and Cultural Rights, working in close collaboration with World Health Organization (WHO) and many others, drafted and adopted general comment 14 that provided a common right to health language for talking about health issues. It provides a method of analyzing the right to health, enabling policy makers and practitioners to use the covenant [6].

Kofi Anan, the former UN Secretary-General, stated in his report (Paragraph 174) that a “rights-based approach to development describes situations not simply in terms of human needs, or of developmental requirements, but in terms of society’s obligations to respond to the inalienable rights of individuals; empowers people to demand justice as a right, not as charity; and gives communities a moral basis from which to claim international assistance when needed” [11].

Internationally, there are some initiatives in this regard to outline the human rights of cancer patients. These can be found for example in the Cancer Patients Bill of Rights [12] and in the European Guidelines for Cancer Patient Rights [13]. It is also important to consider the impact of national legislation on cancer control. An example is the impact of the National Cancer Act of 1971 in the United States of America (USA). Following this Act, there were dramatic improvements in cancer outcomes. Since then, there has been an increase in the average 5-year survival rate for all cancers combined to 68% for adults and 80% for children and adolescents, up from 50% and 52%, respectively. Average 5-year survival rates for breast and prostate cancers now exceed 90%. Mortality due to colorectal cancer and prostate cancer also declined from 1990 to 2007. The death rate from all cancers combined decreased by 22% for men and 14% for women, resulting in nearly 900,000 fewer deaths during that period [14].

Arabic Laws in Relation to Human Rights and Cancer Patients

The authors could not find any specific law in Arab countries relating to cancer patients. However, there are laws enacted relating to healthcare in general. Arab constitutional legislation started to address health care in 1950. These laws are summarized as follows [15]:

1. The State shall protect the health of citizens and create hospitals, clinics and maternity homes and facilitate them with the means of treatment and medication.
2. The State has an obligation to protect public health by the continued expansion of free medical services in prevention, treatment and medication throughout the cities and the countryside.
3. The State shall protect the public health, combating diseases and their causes and working to provide medical services and accessories for citizens in prevention, treatment and medication in accordance with the law.
4. State bodies and members of the public have a responsibility to protect the environment from pollutants.
5. The State shall ensure the provision of cultural, social, health services and employment opportunities in urban and rural areas.
6. The State shall provide social insurance services, health and disability pensions, unemployment and old age security to all the citizens.

Cancer Care Facilities in Arab Countries

In the following three sub-sections, the authors highlight a few examples of cancer care facilities in the Arab communities and examine whether these facilities meet the human rights of cancer patients.

I. Radiotherapy Facilities in Arab Countries

The International Atomic Energy Agency (IAEA) estimated that approximately 50-60% of all cancer patients should receive radiation therapy, and that a country needs one treatment machine per 500 new cancer patients. The number of these machines in industrialized countries ranges from 8.2 machines in the USA to 5.5 machines in Western Europe per million people [16]. Comparing this rate with available treatment machines in Arab countries (Table 1), we notice a great contrast between these countries and their industrialized counterparts (mean: 0.6 machine/ million population, range: 0 – 3.75). This shortage of the availability of machines (and absence of modern treatment techniques) has an adverse effect on patients' outcomes.

Table 1. Arab Countries' Radiotherapy Facilities (19)

<i>Country</i>	<i>Population (2009)</i>	<i>Radiotherapy centers</i>	<i>Treatment Machines</i>	<i>Computed Tomography Simulator</i>	<i>Conventional Simulator</i>
Egypt	82,999,000	35	57	13	19
Sudan	42,272,000	2	8	1	3
Algeria	34,895,000	6	17	1	6
Morocco	31,993,000	13	26	9	6
Iraq	30,747,000	8	9	1	3
KSA	25,721,000	12	27	10	3
Yemen	23,580,000	1	1	0	0
Syria	21,906,000	2	7	0	2
Tunisia	10,272,000	10	15	4	6
Somalia	9,133,000	No information			
Libya	6,420,000	7	8	0	3
Jordan	6,316,000	4	11	4	2
Eritrea	5,073,000	No information			
UAE	4,599,000	3	6	2	1
Lebanon	4,224,000	8	15	6	6
Palestine	3,940,000	No information			
Mauritania	3,291,000	1	1	1	0
Kuwait	2,985,000	2	4	0	0
Oman	2,845,000	1	2	0	0
Qatar	1,409,000	2	5	1	0
Djibouti	864,000	No information			
Bahrain	791,000				
Comoros	676,000				
Arab countries	350,000,000	115	219	53	60

II. Chronic Pain Control in the Arab Communities

Chronic pain is one of the most significant causes of suffering and disability worldwide, and is a common symptom of cancer. Up to 80% of cancer patients suffer from moderate to severe pain that requires the use of strong analgesics (e.g. morphine). In Table 2, we extracted data from the Pain and Policy Studies Group. This center has been designated as the WHO Collaborating Center for Pain Policy and Palliative Care since 1996. These data highlight the current and ideal strong analgesic dosages (in kg) in order to achieve pain relief in cancer and HIV patients in Arab countries. This table provides an indicator for pain control coverage in these countries. Among 23 Arab countries, 8 indicate 100% of coverage.

Table 2: Pain Relief: Strong Analgesics' Consumption Rate in Arab Countries (20)

Country	Population (2009)	# of Deaths with Moderate/ Severe Pain	Average Consumption of Medications for Pain Relief (2007-2009) (kg)	Patients Receiving Analgesics (%)	National Morphine Requirement (kg)
Egypt	82,999,000	37,117	78.5	34.2%	229
Sudan	42,272,000	35,634	2.0	0.9%	220
Algeria	34,895,000	16,086	18.7	18.8%	99
Morocco	31,993,000	11,777	22.9	31.6%	73
Iraq	30,747,000	20,754	5.8	4.6%	128
KSA	25,721,000	9,684	98.2	100.0%	60
Yemen	23,580,000	9,434	4.1	7.1%	58
Syria	21,906,000	4,885	41.1	100.0%	30
Tunisia	10,272,000	3,638	33.9	100.0%	22
Somalia	9,133,000	6,295	No report	0.0%	39
Libya	6,420,000	2,529	11.6	74.3%	16
Jordan	6,316,000	3,063	28.7	100.0%	19
Eritrea	5,073,000	2,825	0.5	2.9%	17
UAE	4,599,000	629	17.3	100.0%	4
Lebanon	4,224,000	2,701	15.9	95.3%	17
Palestine	3,940,000	No information			
Mauritania	3,291,000	2,061	0.3	2.1%	13
Kuwait	2,985,000	518	13.7	100.0%	3
Oman	2,845,000	977	4.5	74.4%	6
Qatar	1,409,000	186	3.7	100.0%	1
Djibouti	864,000	844	No report	0.0%	5
Bahrain	791,000	331	5.3	100.0%	2
Comoros	676,000	262	0.3	19.3%	2

III. Assessment of Arab Countries to the Right to Health

Gunilla Backman and her colleagues published an analysis of 194 countries and their compliance with the international survey on the right to health in 2008 [6]. Seventeen indicators and their answers were selected and listed below in regard to 22 Arab countries (Palestine was not listed in this survey). See Table 3 for the details.

Table 3: Right to Health and the Compliance in Arab Countries (6)

Indicators	Number of countries with answer of:		
	Yes	No	Data not available
1. Does the state's constitution, bill of rights or other statute recognize the right to health?	3	18	1
2. Does the state law protect the right to seek, receive, and disseminate information?	0	22	0
3. Does the state have a comprehensive national health plan encompassing public and private sectors?	0	22	0
4. Does the state's national health plan explicitly recognize the right to health?	1	1	22
5. Does the state's national health plan include explicit commitment to universal access to health services?	2	1	19
6. What percentage of the rural and urban population has access to clean water?	4 countries answered 100% for both rural and urban populations.		
7. Is access to essential medicines or technologies, as part of the fulfillment of the right to health, recognized in the constitution or national legislation?	1	21	0
8. Is the per capita government expenditure on health greater than the minimum required for a basic effective public-health system?	13	9	
9. Total government spending on health as percentage of gross domestic product (GDP):	The range was 2.2 to 10.5 in Arab countries.		
10. Does state law require protection of confidentiality of personal health data?	9	2	11
11. Does state law require informed consent to treatment and other health interventions?	1	1	20
12. Does the state have a patients' rights charter?	0	0	22
13. Does the state have a national human-rights institution with a program of budgeted activities to raise awareness of the right to health among the public?	0	0	22
14. Does the state have a national human-rights institution with a program of budgeted activities to raise awareness of the right to health among the doctors?	0	0	22
15. Does the state have a national human-rights institution with a program of budgeted activities to raise awareness of the right to health among the nurses?	0	0	22
16. Are human rights a compulsory part of the national curriculum for the training of doctors?	0	0	22
17. Are human rights a compulsory part of the national curriculum for the training of nurses?	0	0	22

Summary of Required Rights for Cancer Patients in Arab Countries

Based on our common humanity, we believe (like our colleagues elsewhere in the world) that the required rights for cancer patients in Arab communities should include, and not be limited to: (1) the right to cancer prevention and health promotion programs; (2) the right to full financial coverage at the highest attainable standard of health by a multi-disciplinary team of oncology specialists; (3) the right to privacy and confidentiality; (4) the right to participate in the management plan protocol; (5) the right to know the side effects of the cancer diagnostic testing and treatment modalities, which should also be optimized; (6) the right to avoidance of unnecessary suffering and pain; (7) the right of access to palliative and end of life care; (8) the right of access to continuity of care; (9) the right to obtain gainful employment commensurate with their talents and abilities; and (10) the right for compensation. All these rights have to be available without due regard to age, race, gender, and economic status [17, 18].

Discussion

The human rights of cancer patients is a relatively new topic in the medical literature, not only in Arab communities, but in international communities as well. Emmanuel and his colleagues reported in their review for the decade 1999-2008 that of 377 journals and 928 published papers, only two papers dealt specifically with international issues related to human rights of cancer patients (one paper each in *Cancer* and the *European Journal of Cancer Care*). Most of the studies were related to global issues/settings (43.9%) or specifically to country settings, for example, the United States (9.3%), Great Britain (7.8%), South Africa (3.3%), Australia (3.0%), Canada (2.6%), France (2.3%) and India (1.9%). The authors of these papers were mainly from industrialized countries. Most of these papers were related to health systems (18.3%), mental health (11.5%), HIV/AIDS (10.3%), reproductive health (9.2%), rights of patients (2.7%), new technologies (2.5%), and handicapped people (2.5%) [2].

Several factors might explain the low or absent literature in the Arab communities. Funding is certainly one, as very little money is invested in research in Arab developing countries. Other factors also have a role, such as (a) general level of literacy, (b) level of good governance, (c) development of human resources, and (d) role of the patients and non-governmental organizations. Sami Al-Khatib (Secretary-General of the Arab Medical Association Against Cancer; AMAAC) stated that “the legislation governing clinical studies in Arab states lacked provisions to protect the rights of researchers and patients” and called for “the need to re-examine those laws and to be updated, especially for cancer patients. These laws permit studies that help attain the effective means for the treatment of cancer patients and to identify the reasons of the cancer in the Arab region.” [21]

Among the practical recommendations that one can suggest are the following: (1) ensure constitutional endorsement of the right to health; (2) specify government obligations in social welfare; (3) provide health care services with emphasis on vulnerable groups; (4) incorporate a rights-based approach in national policies; (5) collect statistics with monitoring; (6) create legal instruments for enforcement and redress; and (7) report regularly on progressive realization of the right to health.

The obligations that must be met for the full application of this right to health are: (1) Respect – refrain from discriminating, coercing medical treatment; (2) Protect – prevent violation by third parties, practice without standards/qualifications; (3) Provide required entitlements; (4) Fulfill national policies; (5) Facilitate measures of rights; (6) Provide required services; and (7) Promote measures to advance the health of the population [22-24].

Arab governmental health systems must meet certain standards, through: availability (in quantity to meet needs); accessibility (encompasses non-discrimination, physical and geographic access, affordable, information); acceptability (ethically sound/consent, confidentiality), culturally appropriate; quality (scientifically, medically sound). Failure of authorities to ensure adequate accessibility of cancer treatment raises the question of whether they have adequately discharged their resources to protect people under their jurisdiction and provide optimal cancer treatment.

There are many challenges in Arab countries, among which are the economy, health systems, and inappropriate vision and/or analysis. It is well known that it will not be possible to provide all forms of health care in every country, as they are different in many respects. Even if it is not affordable at present, a future plan is necessary. In this regard, Mary Robinson from the Office of the UN High Commissioner for Human Rights (OHCHR) stated that the right to health does not mean the right to be healthy, nor does it mean that poor governments must put in place expensive health services for which they have no resources; but it does require governments and public health authorities to put in place policies and action plans which will lead to available and accessible health care for all, in the shortest possible time [5, 25].

Since the rights of cancer patients is a relatively new topic, so too are ways to measure whether a clinical scenario or public-health decision is ultimately successful in upholding human rights. Efforts are needed to assess the effectiveness of existing methods of assessment and indicators of human rights concerns and the extent to which these indicators need to be changed. Eventually, through a process of trial and error, we might be able to know how the incorporation of human rights might increase the effectiveness of public health-care policies and programs in Arab communities.

The limitations of this study are: (a) it is an effort produced by a small group of medical professionals; (b) scarcity of resources in this field; and (c) difficulty of obtaining the required data to fill the gaps of the research.

The strengths of this study are: It is probably the first study dealing with cancer patients and human rights in Arab communities from different perspectives. It can be used as a baseline for further studies.

Conclusions

Human rights of cancer patients as a field of study have gained attention in the recent years worldwide, especially in developed communities. This is not the case in Arab communities in general. The literature on human rights and cancer patients' issues in Arab communities should be addressed.

For adequate fulfillment of cancer patients' rights, much work is required. There are many challenges, including, but not limited to: (a) flexible and creative public policies, (b) greater awareness of cancer as a group of diseases and their management, (c) ongoing advocacy, (d) comprehensive education, (e) professional leadership, and (f) continued emphasis on compassion for this vulnerable group of people.

Patients have the right to be treated and dealt with in a humane and respectful manner. Healthcare providers are urged to pay careful attention to this vital aspect of clinical management.

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The Social Determinants of Tobacco Use: A Moving Target

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Key words: *Smoking, health impacts, gender differences, adolescence*

Summary

Cigarette smoking is the leading behavior-related cause of avoidable illness and premature death, accounting annually for close to 6 million deaths worldwide. The World Health Organization predicts that, if nothing is done to stem the tide, smoking will claim over 1 billion lives in the present century. Other forms of combusted tobacco, including hookah, and some smokeless tobaccos are also lethal. The majority of tobacco-produced deaths occur in low- and middle-income countries, including Arab nations.

In Arab countries, men's cigarette smoking prevalence substantially exceeds that of women which is very low throughout the Arab world with only one significant exception, Yemen, where the female smoking prevalence equals 29%. In only three other Arab countries does female smoking prevalence exceed 3.4%. In a majority of Arab countries, men's smoking prevalence typifies male smoking prevalence in most countries throughout the world, ranging from 23.5% (Sudan) to 37% (Qatar). However, male smoking prevalence is particularly high in 5 countries: Yemen, 77%; Djibouti, 75%; Jordan, 61.9%; Tunisia, 46.5%; and Syria, 42.6%. In recent years, smoking prevalence has declined in far more Arab countries than it has increased, especially among women. Disturbing for the future, however, are data indicating that in 9 of 16 Arab countries for which data are available, smoking prevalence among 13-15 year-old boys exceeds 10%.

The principal factors influencing smoking are a society's traditions and norms; its dominant religion(s); role-modeling by family, friends, and celebrities; policies; and of course addiction. The most important manipulable determinants of smoking are policies, the most effective of which are dissemination of information on and education about the dangers of smoking; taxation to raise tobacco product prices; smoke-free workplaces and public places; banning tobacco advertising and promotion; and requiring large graphic warning labels on cigarette packages. Many Arab countries are adopting effective tobacco control policies. Smoking is banned in workplaces and public places to varying degrees in several countries, although only two—Iraq and Lebanon—are rated as having virtually completely smoke-free workplaces. Marketing is completely banned in half a dozen Arab countries. New, larger graphic warning labels are emerging. Using tax policy as tobacco control is of growing interest throughout the Arab world. In part, the adoption of tobacco control policies is motivated by membership in the Framework Convention on Tobacco Control (FCTC), the world's first global public health treaty.

Arab countries can learn from the experience of Western nations that are further along in the history of their smoking epidemics. Effective tobacco control has been demonstrated to dramatically reduce smoking, although this impressive success has taken decades. With knowledge of the hazards of smoking, an arsenal of evidence-based policy weapons, and the mandate of the FCTC, public health leaders within the Arab states have the opportunity to accomplish what has been achieved in the West much more quickly and much more efficiently. The challenge is immense, as is the need. The promise is enormous too.

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Introduction

Tobacco use is the leading behavior-related cause of avoidable illness and premature death. Globally, close to 6 million people die from tobacco use each year, accounting for one in every 10 adult deaths. The majority of those deaths occur in low- and middle-income countries (LMICs), including Arab nations. According to the World Health Organization, tobacco's death toll will rise to more than 8 million by 2030.² While tobacco killed an astonishing 100 million people in the 20th century, WHO predicts that, if nothing is done to stem the tide, tobacco will claim over 1 billion lives in the present century.

By far the principal cause of tobacco-related illness and death is cigarette smoking, the predominant mode of tobacco consumption for most of the world. However, other forms of combusted tobacco also have a high propensity to injure and kill, notably including hookah, also known as narghile or waterpipe, which is prevalent in many Arab societies. Certain high-nitrosamine smokeless tobacco products are also quite dangerous, although the general consensus is that smoked tobacco poses far more risk to health than do most non-combusted forms of tobacco.³

The prevalence of tobacco use is declining in the developed world while it has been increasing in many LMICs. In the traditional pattern of cigarette smoking, in most nations men begin smoking in large numbers two to three decades before women follow suit, with the epidemics of lung cancer and other tobacco-produced diseases showing a similar pattern.⁴ However, gender differences vary widely among countries, depending on their level of affluence, dominant religions and traditions, and they are subject to substantial change over time.

In this paper we focus on patterns of cigarette smoking in Arab countries and then consider the factors that influence those patterns. In particular, we consider how participation in the FCTC is likely to affect smoking in Arab nations. (Given the dearth of consistent data on other forms of tobacco use, we consider only cigarette smoking, by far the most important form of tobacco use in nearly all countries.)

Cigarette Smoking in Arab Countries

Prevalence

Table 1 presents data on cigarette smoking prevalence by gender in each of 18 Arab countries. Although the data are subject to multiple problems (discussed below), several interesting generalizations are observed. First, in all countries, men's smoking prevalence substantially exceeds that of women. A corollary: Cigarette smoking rates are very low among women in Arab countries, with only one significant exception, Yemen, where the female smoking prevalence equals 29% (still far below the shockingly high male smoking prevalence of 77%). In only three other Arab countries does female smoking prevalence exceed 3.4%: Djibouti (10%), Jordan (9.8%), and Lebanon (7%).

2 World Health Organization, Tobacco Free Initiative, "Why Tobacco Is a Public Health Priority," http://www.who.int/tobacco/health_priority/en/ (accessed June 3, 2012).

3 Levy DT, Mumford E, Cummings KM, et al. The relative risks of a low-nitrosamine smokeless tobacco product compared to smoking cigarettes: estimates of a panel of experts. *Cancer Epidemiology, Biomarkers and Prevention*. 2004;13:2035-2042.

4 Thun M, Peto R, Boreham J, Lopez AD. The tobacco epidemic today: stages of the cigarette epidemic on entering its second century. *Tobacco Control*. 2012;21:96-101.

Table 1. Adult Cigarette Smoking Prevalence in Arab Countries

Country	Male (%)	Female (%)	Country	Male (%)	Female (%)
Algeria	26.6 ^b	0.2 ^b	Morocco	26.1 ^b	0.2 ^b
Bahrain	25.6	2.4 ^b	Oman	24.1 ^a	0.3 ^b
Djibouti	75.0 ^a	10.0 ^a	Qatar	37.0	0.5
Egypt	24.5 ^b	0.9 ^b	Saudi A.	25.1	3.4 ^a
Iraq	25.1 ^b	1.9 ^b	Sudan	23.5	1.5
Jordan	61.9 ^a	9.8	Syria	42.6 ^b	nd
Kuwait	34.4	1.9	Tunisia	46.5 ^b	1.0 ^b
Lebanon	29.1 ^b	7.0 ^b	UAE	25.5 ^a	1.6 ^a
Libya	32.0	1.5	Yemen	77.0 ^a	29.0

^a Implies substantial increase since 2000.

^b Implies substantial decrease since 2000.

Source: *Tobacco Atlas Online*, accessed March 23, 2011.

In a majority of the Arab countries, men's smoking prevalence typifies male smoking prevalence in most countries throughout the world, ranging from 23.5% (Sudan) to 37% (Qatar). However, male smoking prevalence is particularly high in 5 countries: Yemen, 77%; Djibouti, 75%; Jordan, 61.9%; Tunisia, 46.5%; and Syria, 42.6%.

An encouraging finding, also shown in Table 1, is that over the past decade cigarette smoking prevalence has declined in far more Arab countries than it has increased, especially among women. For males, smoking prevalence decreased in 7 countries, while it increased in 5 and remained relatively stable in 6. For women, prevalence decreased in 8 countries, increasing in only 3 and remaining stable (and generally quite low) in the other 7 countries.

Several caveats must attach to the data in the table. First and foremost, methods and timing of tobacco use surveys vary widely across countries, making the comparisons imperfect. The reliability of much of the survey data is suspect. For example, the table shows male smoking prevalence in Syria as 42.6% and the Tobacco Atlas could not find reliable data for female smoking prevalence. The Syrian Society for Countering Cancer said that in 2010, 60% of men and 23% of women were registered smokers. We have been unable to reconcile the difference in the two data sources' conclusions. It is possible that "registered smokers" includes hookah smokers or users of other combusted products, which could account for the larger percentage reported by the Society. Whatever the explanation, the sizable difference raises questions about the reliability of data for specific countries.

Subject to similar caveats, Table 2 presents estimates of smoking prevalence by country for 13-15 year-old boys. The data range from a low of 3.5% in Oman to 17.7% in Kuwait. The data give pause: In fully 9 of the 16 countries for which data are available, smoking prevalence among these young boys exceeds 10%.

Table 2. Smoking Among 13-15 Year-Old Male Students

Country	%	Country	%
Algeria	nd	Morocco	4.3
Bahrain	17.5	Oman	3.5
Djibouti	8.6	Qatar	13.4
Egypt	5.9	Saudi A.	10.2
Iraq	nd	Sudan	10.2
Jordan	13.2	Syria	8.1
Kuwait	17.7	Tunisia	15.1
Lebanon	11.8	UAE	12.1
Libya	7.7	Yemen	6.5

Determinants

A large number of factors influence the rate of smoking in any country. Notable among these are a society's traditions and norms; its dominant religion(s); role-modeling by family, friends, and celebrities (athletes, movie actors, prominent politicians, etc.); policies; and of course addiction. Some of these factors do not change over time or change very slowly, while others can change quickly. Some evolve naturally, while others are manipulable. The latter are particularly important in determining changes in tobacco use. For example, on the negative side, in some countries, including the US, changing norms have rapidly converted hookah smoking from a nearly nonexistent practice to a common one among young people. On the positive side, in Muslim populations clerics can remind believers that tobacco use is haram (forbidden).

The most important manipulable determinants of smoking are policies. A wealth of worldwide evidence indicates that the most important policies in reducing cigarette smoking are the following:⁵

- *Information and education.* The essential first step of effective tobacco control is educating the public about the dangers of tobacco use, and especially cigarette smoking. In developed nations, nearly everyone is familiar with the basic information. In many LMICs, such is not the case and a concerted effort to inform the public about the dangers of smoking—and to get them to believe the information—is critical. Methods can include the issuance of government reports, with associated publicity; school health education (if it is taken seriously; it is ineffective when not taken seriously); media anti-smoking (or “counter-advertising”) campaigns, an approach that requires significant resources but is demonstrably cost-effective; and the adoption of large, graphic warning labels on cigarette packages and ads.
- *Taxation.* Raising the price of cigarettes (and all tobacco products), generally through taxation, is demonstrably the single most effective method of decreasing smoking quickly and potentially substantially. Research indicates that a 10% increase in the price of cigarettes decreases smoking by 3-7%, with approximately half of the decrease reflecting quitting and the other half representing a decrease in daily cigarette consumption among continuing smokers. Less affluent smokers—the majority of smokers in nearly all societies—are more price-responsive than are more affluent smokers. Importantly, children are 2-3 times more price-responsive than adults, making a large tax increase by far the most effective means of reducing smoking among young people. A particularly attractive feature of a tax increase is that it generates additional revenue for government, thus giving government the potential to do well financially while doing good for public health.
- *Smoke-free workplaces and public places.* Requiring that workplaces and public places, including restaurants and bars, be smoke-free serves several purposes. It protects workers from the adverse health consequences of exposure to tobacco smoke, reducing their exposure to the toxic chemicals in smoke by 80-95%. It increases quitting by about 3%. Among continuing smokers, such laws result in reduction in daily consumption. Going smoke-free saves employers money by reducing their employees' work loss from smoking-related illness and premature death and by reducing cleaning costs (including maintenance of sensitive electronic equipment). And finally, smoke-free laws have been demonstrated to reduce acute myocardial infarctions in the population. Indeed, if these findings are accurate, there is probably nothing in the fields of medicine and public health that a government can do to improve the public's health that will be more effective and less expensive than simply banning smoking in workplaces and public places. To date, 37 countries have banned smoking in virtually all workplaces, including all restaurants and bars.⁶ These laws are proving to be very popular with the public and to be largely self-enforcing.
- *Banning tobacco advertising and promotion.* Although the data are not definitive, the best study to date concludes that banning all forms of tobacco advertising and promotion reduces smoking by about 6%, compared to having no restrictions on advertising. While a 6% reduction in smoking is not the solution to the problem, it represents a significant piece of the problem as well as a significant contribution to public health, and can be achieved at little cost to government.
- *Requiring large graphic warning labels on cigarette packages.* The traditional pack warnings, composed of small print taking up only a small fraction of the surface of the pack, have not been demonstrated to have any impact on smoking. New warning labels, including graphic pictorial warnings and taking up at least one half of the fronts and backs of cigarette packs, have been documented to grab smokers' attention and to increase their intentions to quit. To date, in large part because such labeling is so recent, there is inadequate evidence to conclude that these new warning labels significantly reduce smoking.

5 Warner KE. Tobacco policy research: Insights and contributions to public health policy. In: Warner KE, editor. Tobacco control policy. San Francisco: Jossey-Bass; 2006. p. 3-86.

6 American Nonsmokers' Rights Foundation. Smokefree status of workplaces and hospitality venues around the world. April 2, 2012. <http://www.no-smoke.org/pdf/internationalbarsandrestaurants.pdf>, accessed June 9, 2012.

Many Arab countries are adopting effective tobacco control policies. Smoking is banned in workplaces and public places to varying degrees in several countries, although only two—Iraq and Lebanon—are rated as having virtually completely smoke-free workplaces. Marketing is completely banned in half a dozen Arab countries. New, larger graphic warning labels are emerging, as they have in some 40 countries around the world. Using tax policy as tobacco control is of growing interest throughout the Arab world. In part, the adoption of tobacco control policies is motivated by membership in the Conference of the Parties of the FCTC.

Framework Convention on Tobacco Control

The FCTC is the world's first, and thus far only, global health treaty. Initiated in the 1990s by the World Health Organization, the FCTC was adopted unanimously by the World Health Assembly in May 2003 and entered into force in November 2004. The FCTC is one of history's most widely and rapidly adopted treaties. To date, of 195 eligible countries, 175, representing 87.8% of the world's population, have become parties to the treaty.⁷

Among the Arab countries, all are parties to the treaty except for Morocco and Tunisia, each of which is a signatory but has not yet ratified the treaty. The treaty obligates members to meet policy requirements in multiple areas, including those designated in Table 3. The parties meet periodically to define more specifically the requirements in each of these areas, included in the Convention in relatively general terms (the standard approach of a convention, intended to establish principles with the details of specific actions worked out later by the parties). Arab countries have gotten together to determine how they can proceed to comply with the treaty, for example at a summer 2010 meeting at the American University of Beirut.

Table 3. Selected Policy Areas Covered in the Framework Convention on Tobacco Control

Taxation	Sales practices
Advertising and promotion	Smuggling (trade)
Warning labels	Product regulation
Second-hand smoke exposure	Legal liability
Counter-marketing	

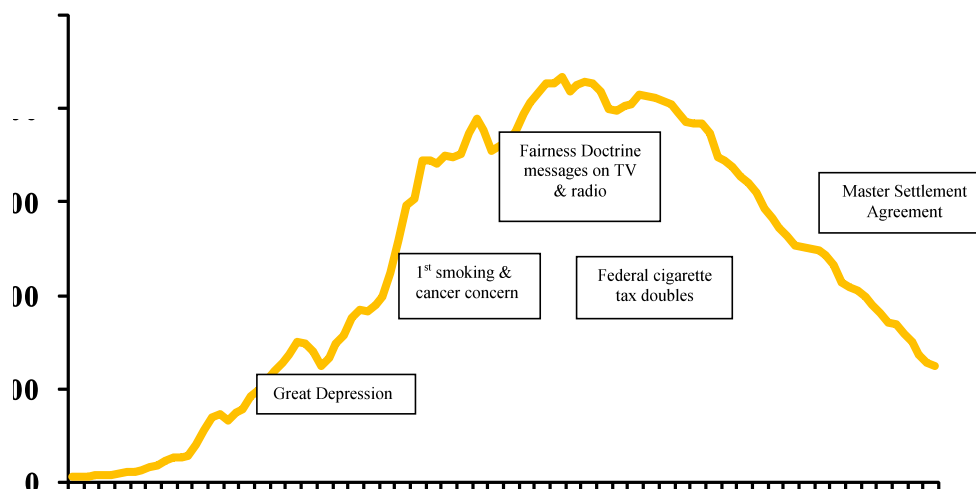
Effectiveness of Tobacco Control: A Case Study

Tobacco control has effectively reversed, if not ended, the tobacco-disease epidemic in many developed nations. In the US, for example, adult cigarette smoking prevalence, 19.3% in 2010, is less than half of what it was prior to the beginning of the American anti-smoking campaign in 1964, the year of the first Surgeon General's Report on Smoking and Health.⁸ The anti-smoking "campaign" in the US was never a well-orchestrated effort to reduce tobacco use, but rather it represents the collective (and often uncoordinated) efforts of governments at all levels (local, state, and national), major NGOs (American Cancer Society, American Heart Association, and American Lung Association), specific tobacco control NGOs (most notably the Campaign for Tobacco-Free Kids, Americans for Non-Smokers' Rights, and Action on Smoking and Health), and foundations (including especially the American Legacy Foundation and the Robert Wood Johnson Foundation).

Figure 1 illustrates two phenomena: First, that major individual anti-smoking events have been associated with discernible declines in adult per capita cigarette consumption (defined as the total number of cigarettes purchased divided by the population over the age of 17). Second, and of greater importance in the aggregate, the anti-smoking campaign has completely and dramatically reversed the direction of the smoking epidemic. Adult per capita cigarette consumption peaked at 4,345 in 1963, the year prior to the Surgeon General's report. In 2011 it stood at 1,236, just 30% of the peak. Furthermore, had smoking continued its rise from 1990 through 1963 uninterrupted by the campaign, adult per capita consumption would have reached about 6,000 cigarettes; so today's figure is approximately a fifth of what it would have been in the absence of the campaign. (Research in progress by the author and colleagues.)

7 Framework Convention Alliance. The Tobacco Control Treaty – FCTC. <http://www.fctc.org/>, accessed June 9, 2012.

8 Public Health Service. 1964. *Smoking and Health. Report of the Advisory Committee to the Surgeon General of the United States*. US Department of Health, Education, and Welfare, Public Health Service, Center for Disease Control. PHS Publication No. 1103.

Figure 1. Timeline of Major Anti-Smoking Events, 1900-2010

The most important consequence of the American anti-smoking campaign is its contribution to public health. Although it is just a “guesstimate” based on earlier research,⁹ conservatively some 5 million Americans have avoided premature smoking-produced deaths as a result of their campaign-induced decisions to quit smoking or not to start in the first place. Each of them has gained 15-20 years of life expectancy. It is a remarkable legacy of one of the major public health battles of the past half century. Arguably, tobacco control is the most important public health or medical endeavor in developed countries in the past 50 years.

The sobering note, however, is that as successful as the American anti-smoking campaign has been, nearly a fifth of US adults persist in smoking and the current toll of smoking continues to rank as America’s single most important determinant of avoidable premature death. Important battles have been won, but the war goes on.

Conclusion

Tobacco is taking a horrific toll throughout the Arab world today. There is no other source of chronic disease—and of chronic disease death—that is so important, and so avoidable. Public health leaders within the Arab states seem poised to push for significant progress in tobacco control. They have the opportunity to accomplish what has been achieved in the West, as represented by the US case, but to do so much more quickly and much more efficiently. They possess a strong knowledge base regarding the consequences of smoking; no significant medical or public health leadership should need to be convinced that smoking is a critically important public health issue. They have an arsenal of proven weapons, evidence-based policies that work. By virtue of having ratified the FCTC, they have a mandate to pursue tobacco control and a healthy competitive incentive to outperform their fellow member nations. While the resources for tobacco control remain limited, they are more available today than ever before. Those resources include some relatively new sources of financial support, such as funding from the Bloomberg Initiative and its collaborating partner, the Gates Foundation. More importantly, they include researchers and public health professionals who are gaining in strength and numbers. The challenge is immense, as is the need. The promise is enormous too.

9 Warner KE. 1981. Cigarette smoking in the 1970’s: The impact of the antismoking campaign. *Science* 211:729-731.

Examining Life Style Behavior Among Arab and Chaldean American Communities in Metro Detroit, Michigan, USA, 2009

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Introduction

Smoking arghile (hookah), an often intricately decorated water-pipe that burns various types of tobacco, has been a practice for many centuries in Southeast Asia, North Africa, and the Middle East. In the United States of America (USA), hookah is becoming a popular new trend in tobacco use, especially among young adults. Tending to be more open to new experiences, young people may be more attracted to hookah for its alluring shape, smell and flavors and now college and high school students are involved in this dangerous trend. It is a widely believed myth that hookah is less harmful than other forms of tobacco because the tobacco smoke passes through water, where people believe toxic substances are filtered out before being inhaled. It is scientific fact that the water only serves to cool the tobacco smoke. Analyses have shown that hookah smoke contains an abundance of several chemicals that can cause various cancers, cardiovascular diseases, and addiction.

Arab-Americans consist of immigrants and their descendants from the Arabic speaking world who reside in the USA. According to the 2000 Census, people of Arab ancestry in the USA were 1.2 million, and one third of them live in three states: New York, California and Michigan. The great majority of Michigan's Arab Americans live in the southeast region of the state, in densely populated Wayne, Oakland and Macomb counties, known as the metropolitan area of Detroit [1]. Studies on smoking in the Arab American community found a higher smoking rate and a lower quitting rate when compared with national and Michigan data for other population groups [2,3]. Smoking is part of the social culture where cigarettes and hookah (arghile) are offered like tea and coffee as a matter of hospitality and generosity [4].

Objectives

The objectives of our study were:

1. To determine the current arghile (hookah) and cigarette smoking prevalence and behavior among Arab and Chaldean Americans in the Metro Detroit area
2. To assess the life style behavior and determine the behavioral risk factors among the Arab Americans
3. To study their socioeconomic status and access to health care

4. To estimate the level of secondhand smoke exposure in homes, workplaces, vehicles and public places among the Arab Americans
5. To estimate the quitting behavior among Arab and Chaldean Americans
6. To compare all the above results of the Arab Americans to the white non-Arab Americans living in the same area of the study [5]

Methods

This is a community based, cross sectional survey study designed to provide a representation of Arab and Chaldean American attitudes and beliefs related to hookah smoking among metropolitan Detroit residents. A study team was convened from Michigan Tobacco Prevention Program staff, Michigan Diabetes Prevention Program, the director and other members from ACCESS community health, and ACC. The study used a multi-stage cluster sampling design based on the 2000 Census. The survey was administered throughout ten cities across the Metro Detroit area. The interviewers were trained in culturally appropriate topics about the project procedures, especially random sampling and their approach to participants. A total of 2,025 adults, 18 years and above, were surveyed between May 2009 and October 2009. Demographic, socioeconomic, and behavioral information was also collected from participants. Data was analyzed using SPSS statistical software. Comparisons are made between the Arab American respondents in this survey and white, non-Arabs in the same geographic area from the MiBRFSS (Michigan Behavioral Risk Factor Surveillance Survey) to highlight the differences between the two populations. The MiBRFSS is a statewide telephone survey of Michigan residents aged 18 years and older. A question was added to the MiBRFSS in 2007, 2008 and 2009 to specifically capture Arab ancestry of respondents [5].

Results

Demographics

Of the 2,025 participants in our study, males constituted 52% compared to 48% females, which indicates a good sample representation for gender. The average age of the participants was 37.3 (\pm 13.3) years. Those who were born inside the US were fewer (19.6%) than those who were born outside the USA (80.4%), but were of younger average age (26 ± 7.3 years).

Socioeconomic Status

More than one quarter (26.4%) of the participants had a low educational level (less than high school) compared to only 4.9% of non-Arab white Americans. The difference between both samples in all levels was highly significant ($X^2 = 807$, $P > .001$). For the annual household income level, one fifth of the Arab sample had a very low income ($< \$20k$) per year, compared to only 9.3% of the white non-Arab sample. The difference between both samples in all income levels was highly significant ($X^2 = 766$, $P > .001$).

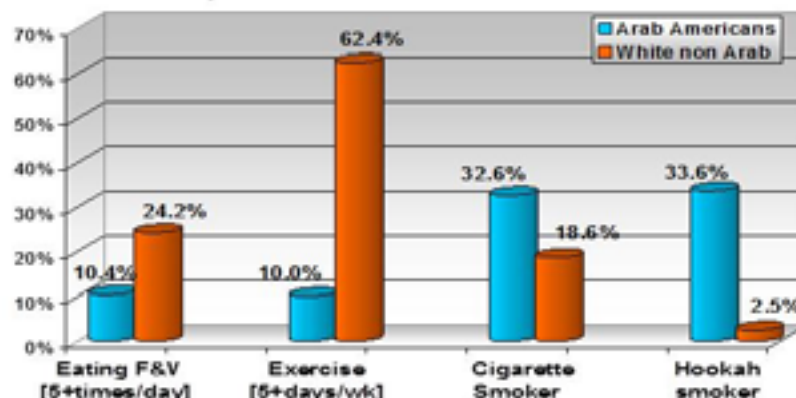
Access to Health Care

The Arab Americans in the Metro Detroit area had significantly lower health insurance coverage than the non-Arab whites (68.7% vs. 90.3%; $X^2 = 530$, $P > .001$). Of the Arab American participants 81.5% had a family doctor and 64% had a routine check-up visit to their doctor within the past year, and these numbers are lower than the comparison population (89% and 72% relatively).

Lifestyle Behavior

Arab Americans who eat fruit and vegetables 5 times or more a day were only 10.1% compared to 24.2% among the non-Arab whites. Exercise among Arab Americans seemed to be less practiced; only 10% of the participants exercised 5-7 days a week while 62.4% of the white non-Arab Americans exercised 5-7 days a week. We also asked about cigarette smoking, and found that the current smoking prevalence was still high (32.6%), and higher than the comparable white, non-Arab group (18.6%). Michigan's statewide smoking rate in 2009 was 19.8% and for the USA the smoking rate was 20.6% [6]. Current hookah users were 33.6% among Arab Americans compared to 2.5% among the white non-Arab Americans. All the differences between the Arab and non-Arab Americans in the above four criteria and life style factors were highly statistically significant ($P > .001$; see Figure 1).

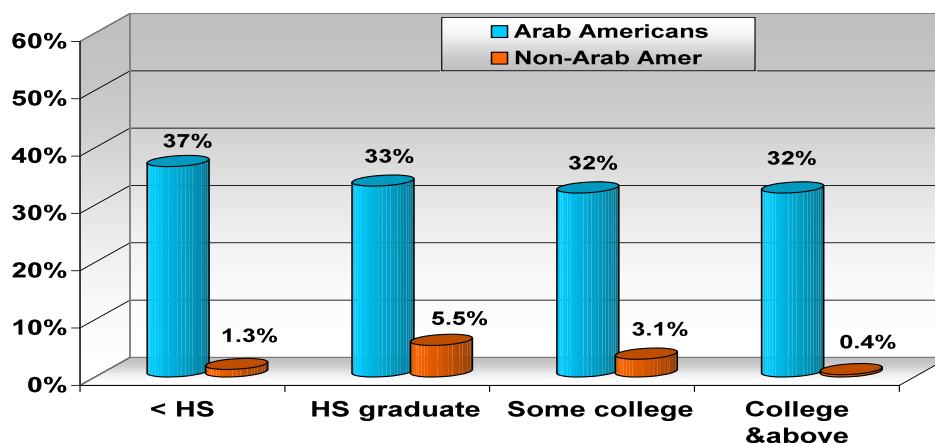
Figure 1. Lifestyle Behavior Among Arab Americans Compared to White non-Arab Americans



Hookah (Arghile) Use

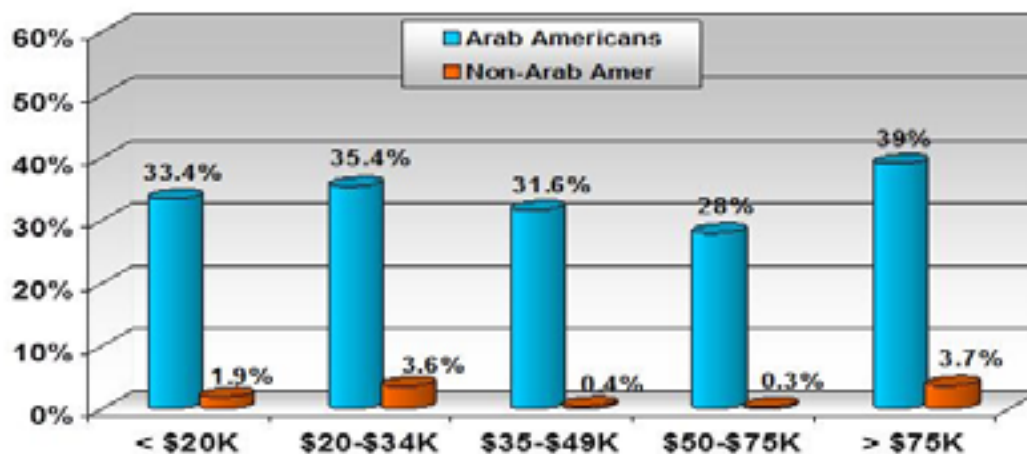
Our study revealed that the current arghile (hookah) smoking rate was 33.6% (n = 678) with more males reporting use vs. females, 65% (n = 438) vs. 35% (n = 240) respectively. The rate of arghile smoking was found to be similar at all educational levels and there were no statistical differences among them (Figure 2).

Figure 2. Current Hookah Users Among Arab Americans by Educational Level Compared to White non-Arabs



The same relationship was found among hookah smokers at all levels of annual household income (Figure 3) and in all age groups. There were no significant statistical differences among all these levels and groups related to hookah use.

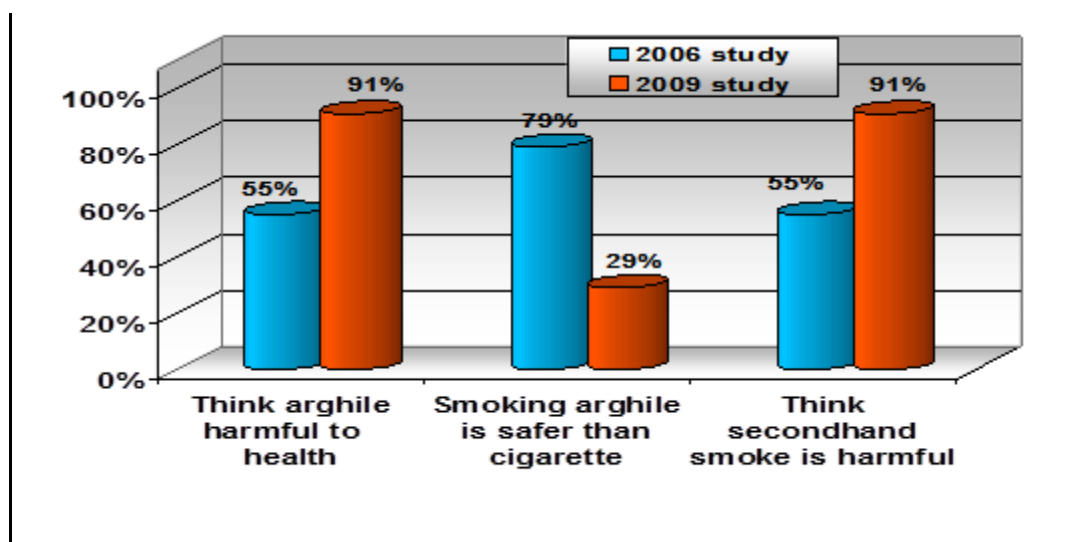
Figure 3. Current Hookah Users Among Arab Americans by Income Level Compared to White non-Arabs



More than a third (35%) of the hookah smokers reported smoking cigarettes too.

The salient feature about the reason for using hookah is to socialize with others (55%), while the second reason is because of its attractive taste (18%). Interestingly, the large majority of arghile smokers (91%, $n = 532$) continue to smoke despite the fact that they believe hookah is harmful to their health. Additionally, only 29% ($n = 152$) of arghile smokers believe that arghile is safer than smoking cigarettes compared to 79% of arghile smokers from a 2006 survey study completed in the same region, [7], shown in Figure 4.

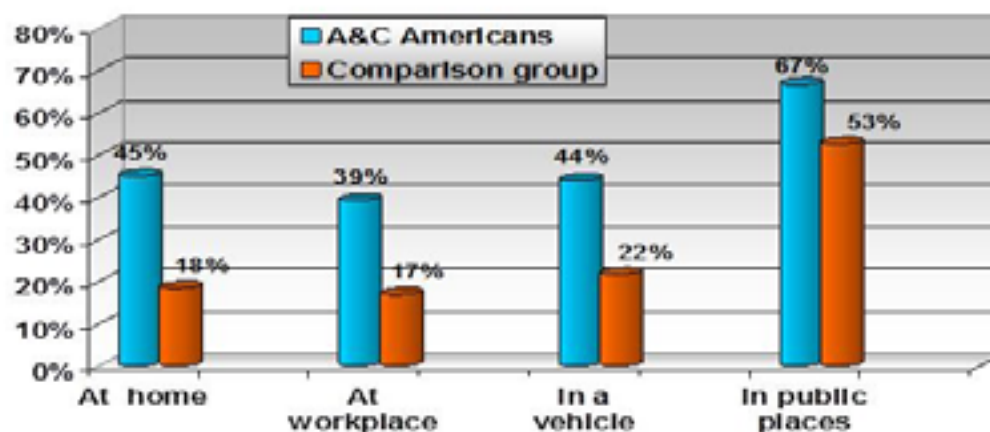
Figure 4. Knowledge and Beliefs among Current Hookah Users



Secondhand Smoke Exposure

Arab Americans reported a significantly higher exposure rate to second hand smoke in their homes (45%), in their workplaces (39.2%), in vehicles (44%), and in public places (67%) than the comparable white non-Arab group (18.4%, 17%, 21.7%, and 52.6% respectively, as shown in Figure 5). For having a smoking rule at home, whether smoking inside the house is always allowed, allowed sometimes or never allowed, 24.6% of the Arab Americans reported smoking always allowed, 29.3% allowed smoking sometimes, and 46.1% never allowed smoking in their houses. The rates among the comparison population were 10% for always allowing smoking, 12% allowing smoking sometimes, and 78% never allowing smoking in their houses.

Figure 5. Exposure to Secondhand Smoke Among Arab Americans Compared to White non-Arab Americans



Quit Smoking Behavior

Quitting behavior among current smokers was also estimated in the sample. Out of the total number of current smokers, those who attempted to quit during the past 12 months were 43% compared to 57.6% among white non-Arab Americans, and out of those attempted quitting who utilized nicotine replacement therapy (NRT) were 17.8% among Arab Americans compared to 36.6% among white, non-Arabs. Current smokers who received advice from a health care professional to quit smoking were 45% among Arab Americans compared to 81.1% among white non-Arab Americans; all results are shown in Table 1.

Table 1. Quitting Behavior Among Current Smokers

Quitting Behavior (By Current Smokers)	Arab and Chaldean Americans		Comparison* Population	
	N	Percentage	N	Percentage
Quit attempts during the past 12 months	282	43%	538	57.6%
Nicotine replacement therapy or prescription medication utilized	66	17.8%	219	36.6%
Telephone quitline or smoking cessation classes utilized	2	0.5%	N/A	
Advice to quit from HC professional	255	45%	171	81.1%
HC professional prescribes or recommends a nicotine replacement therapy	81	33%	63	36.9%

* Data source: 2007-2009 Michigan Behavioral Risk Factor Survey.

Discussion

Adult Arab Americans in this study had lower income levels, lower educational levels, and lower health insurance coverage, so were less likely to access health care services and more likely to delay getting health attention.

Hookah use was considered wrongly by Arab Americans to be a cultural practice and it was for this reason accepted as a habit to be practiced inside homes and shared by all family members including females and adolescents; this may explain why hookah use rates were similar among all educational, income and age group levels.

Knowledge and beliefs about the harmful effect of hookah smoking was significantly improved when compared to results of past studies in the Metro Detroit area, indicating a successful awareness campaign that has been led by the Michigan Department of Community Health (MDCH) since 2003 with two main partners (ACCESS and ACC).

Higher rates of exposure to secondhand smoke, especially inside homes, was mainly due to lack of smoking rules inside homes; this may have been as a result of the Arab family structure which is governed by the grandfather or the father who can smoke anywhere at any time.

Conclusion

Arab Americans in Metropolitan Detroit have significantly lower socioeconomic status and more limited access to health care services than white non-Arab Americans.

They have a relatively unhealthy life style behavior, eating less vegetables and fruits, exercising less, smoking cigarettes more, and overall smoking hookah at a high rate.

The above factors may be the reason why they have more diabetes rates and more co-morbid conditions.

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Systems of Care: A Framework for Evidence Based Practices

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Key words: *Systems of care, mental health, children, emotional problems*

Systems of Care is an approach to serviced delivery for children's mental health that grew out of the landmark publication by Jane Knitzer, *Unclaimed Children*. Knitzer (2000) found that "At least two-thirds of the 3,000,000 seriously disturbed children and adolescents in the United States do not get the mental health services they need; countless others receive inappropriate care." This publication uncovered critical issues that changed how professionals and policy makers look at the issue of children's mental health services. The study found that "public agencies with responsibility for disturbed children and adolescents are spending money on these children too late and often inappropriately. Preventive or intensive community-based services are in scarce supply. Over reliance on costly institutional and residential care is the norm" (Knitzer, 2000). The key recommendations in *Unclaimed Children* laid the groundwork for increasing federal and state attention to this ongoing problem:

1. Strengthening services and systems of care within state mental health departments
2. Protecting the rights of children and adolescents in need of mental health services
3. Increasing the response of non-mental health agencies to the mental health needs of children and adolescents
4. Increasing the mental health policy focus on children
5. Maximizing the impact of existing federal programs
6. Increasing effective advocacy

An outgrowth of this work was increased federal and state focus on developing Systems of Care as an approach to transforming services for children with serious emotional disturbance. The definition first published in 1986 (Stroul & Friedman) states that a system of care is: "A comprehensive spectrum of mental health and other necessary services which are organized into a coordinated network to meet the multiple and changing needs of children and their families" (p.3).

Stroul and Friedman (1996) further defined systems of care by establishing core values. The core values of the system of care philosophy specify that services should be community based, child centered and family focused, and culturally competent. The guiding principles specify that services should:

1. Be comprehensive, with a broad array of services
2. Be individualized to each child and family
3. Be provided in the least restrictive, appropriate setting
4. Be coordinated at both the system and service delivery levels
5. Involve families and youth as full partners
6. Emphasize early identification and intervention

Communities gained support for developing systems of care through the Comprehensive Community Mental Health Services for Children and Their Families Program administered by the Child and Adolescent Family Branch of the

Center for Mental Health Services (CMHS) in the Substance Abuse and Mental Health Services Administration (SAMHSA). This program was first authorized by Congress in 1992 by Section 561 of the Public Health Service Act, and reauthorized in 2000, providing communities with funding and technical assistance to develop systems of care.

In 2002 President George W. Bush created the New Freedom Commission on Mental Health to address problems in the mental health system. The Commission (2003) recommendation was:

To improve access to quality care and services, the Commission recommends fundamentally transforming how mental health care is delivered in America by addressing the following foundation goals to achieve true transformation:

1. *Americans understand that mental health is essential to overall health.*
2. *Mental health care is consumer and family driven.*
3. *Disparities in mental health services are eliminated.*
4. *Early mental health screening, assessment, and referral to services are common practice.*
5. *Excellent mental health care is delivered and research is accelerated.*
6. *Technology is used to access mental health care and information.*

The Commission's report further solidified children's mental health professionals' need for and focus on system transformation efforts. An outgrowth of these transformation activities was greater focus on outcomes for children and families through the use of evidenced based practices (Freidman & Drews, 2005). Evidence based practices and systems of care are conceptually compatible and warranted development within systems of care to expand the services array for children, provide quality services, and assure individualized care. Systems of care continue to evolve by including promising and evidence informed practices within their array of service. Those provided by Detroit Wayne County Community Mental Health Agency's network of providers include:

- Parent management training Oregon model
- Trauma focus cognitive behavior therapy
- Wraparound
- Infant mental health
- Multifamily psycho-educational psychotherapy

The expansion of the DWCCMHA service array has allowed increased access to services for children, services that provide family support and positive outcomes for children and families. The focus of DWCCMHA on evidence based and evidence informed practices within its system of care for children has propelled the system reform efforts toward actualizing the vision of the landmark publication *Unclaimed Children*.

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Emotion Meaning-Making in Global Health Contexts: Implications for Care

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Key words: *Mental health, ethnographic approach, social norms, diagnosis*

Abstract

Debates surrounding depression as a leading cause of global disability, as well as increased migration associated with globalization, call attention to why it is important to better understand the complexities involved in arriving at mental health diagnoses. This presentation describes the theoretical framework and preliminary findings of an ethnographic study whose goal is to discover how a group of Arab immigrant health care providers, who diagnose and treat mental illness in one clinic in the US, assign meaning to emotion. Anthropological theories acknowledging emotion as emerging within intersections of identity, language practices and social interaction are applied to ethnographic data harvested from one local setting in order to more broadly consider the fluid nature of emotion meanings, and, in globalizing health care contexts, implications for the making of mental health diagnoses. One preliminary finding is that there is intriguing intra-group variation in explanations for emotion among the different groups of providers in this setting.

Introduction

The World Health Organization (WHO) projects that by the year 2020 “mental and neurological disorders” will account for 15% of the global disease burden (WHO, 2001). Depression alone continues to be cited as a leading cause of disability in both developed and developing countries (WHO, 2001, 2008). For the past decade, these trends have been used to highlight the significance of mental illness as an important global health issue. However, what these trends indicate and mean is unclear. In the case of depression, there is evidence suggesting that depression is actually under-recognized and under-treated throughout the world (Ballenger, Davidson, Lecrubier, Borkovec, Rickels, Stein, Wittchen & Nutt, 2001). Still others, seeking to explain the seemingly increased global prevalence of the disorder, point to flawed diagnostic categories (Horwitz & Wakefield, 2007), processes of pharmaceuticalization (Abraham, 2010) and local instances of medicalization (e.g., Kitanaka, 2010). So, while the above trends highlight the significance of mental illness, they also call attention to why it is important to better understand the complexities involved in arriving at mental health diagnoses.

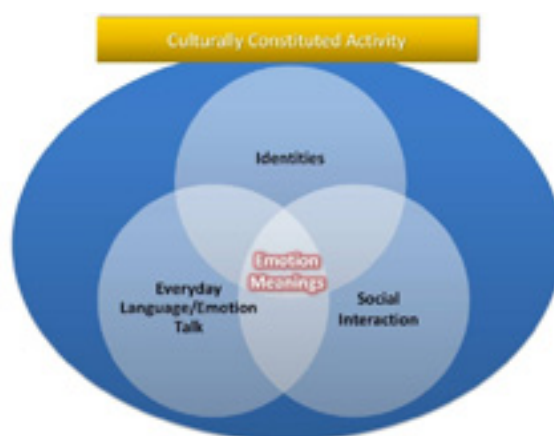
These complexities may be heightened by the increase in migration associated with globalization. Individuals suffering from mental illness often find themselves in cultural contexts far different from home, with health care providers who may not understand their symptoms. Immigrant health care providers (HCPs) are, themselves, part of migratory movements. They, in turn, may originate from home cultures with explanations for emotion and mental illness that differ from those of their patients. Currently, little is known about how the experiences of immigrant HCPs influence health diagnostic processes. In particular, little is known about how immigrant HCPs assign meaning to emotion, one aspect central to the formation of mental health diagnoses.

Anthropologists have played a role in addressing cultural issues related to mental health diagnoses (e.g., Jenkins, 1991; Kleinman & Good, 1985). Two important developments stemmed from this work. The first can be seen in the inclusion of cultural factors in the *Diagnostic and Statistical Manual-IV* (DSM-IV; American Psychiatric Association, 1994; Lopez & Guarniccia, 2000). A second development was the *World Mental Health* report's (Desjarlais, Eisenberg, Good and Kleinman, 1996) acknowledgement of the close linkage between mental illness and social worlds, with

social worlds referring to people's daily routines and how these routines are tied to families, neighborhoods and social networks (Lopez & Guarnaccia, 2000). This intimate relationship is especially relevant to communities where the mental illness of individuals is not perceived to sit apart from family experience and where there are concerns about stigma.

The importance of the social world is also recognized in the scholarship on emotion, and a number of key studies within anthropology focus on the social settings and situations in which emotions are expressed in order to understand their meanings (Abu Lughod & Lutz, 1990; (Delvecchio Good, Hyde, Pinto, & Good, 2008; Rosaldo, 1984). In keeping with these emphases, the concept of "emotive institution" (see Figure 1) is one theoretical framework that has been used to help discover the conditions or factors that may contribute to how meaning is given to emotions (White, 2005).

Figure 1. Emotive Institution Framework



A decades-long researcher on the topic of emotions, Geoffrey White defines "emotive institution" (EI) as being composed of culturally constituted activities containing patterns of social interaction, identities and everyday ways of talking about emotion (White, 2005). It is through the intersection of these factors that meaning is thought to be assigned to emotion and it is also here that meanings are potentially redefined and transformed.

This paper describes the theoretical framework and preliminary findings of a study whose goal is to discover how a group of Arab immigrant health care providers who diagnose and treat mental illness in one clinic in the US assign meaning to emotion. Using the concept of EI as a guiding theoretical framework, ethnographic fieldwork was conducted in order to: (1) identify and describe the everyday practices, routines and social interactions associated with the process of arriving at mental health diagnoses at this clinic site; (2) identify and describe the personal, cultural and professional factors contributing to providers' identities and the meanings they associate with various emotions at this clinic site; (3) identify and describe the everyday speech and communication practices involving emotion present among these providers within the course of mental health diagnostic processes; and (4) integrate and analyze the findings from the above three aims for how they may contribute to the meanings given to emotions by the providers in this setting.

The clinic setting for the proposed research provides an especially rich site in which to examine the conditions or factors involved in emotion meaning-making. The clinic is part of a larger community center situated in a large Midwestern metropolitan area, in the heart of one of the largest concentrations of Arab immigrants living in the US (Schopmeyer, 2000). The community center was initially founded in the 1970s in order to provide health and social services to a rapidly growing population of Arab immigrants and refugees settling in the area. Although the center now serves a low income population more reflective of the surrounding area's ethnically diverse communities, most center staff culturally identify as Arab, and many are immigrants from the Middle East themselves. Based on ethnographic accounts of Arab immigrants living in the US (Antoun, 1999; Naber, 2006; Seikaly, 1999), it is likely that the HCPs practicing within the center draw on experiences originating in Arab homelands, as well as those of their current American context. As such, the identities, ways of communicating and patterns of social interaction of these providers are subject to the influence of multiple social worlds. Given these conditions, in utilizing the EI framework this study considers how the meanings associated with emotion in this setting might become redefined and transformed as a first step to better understanding the process of emotion meaning-making, its relationship to mental health diagnoses, and the implications for the delivery of mental health care.

Methods

Ethnography is a research approach used to study the influence of culture on individual and group human behavior. A central premise of ethnography is that human behavior, and the ways in which people construct and make meaning of their worlds and lives, is highly variable and must be understood in its local context. This includes looking at how culture shapes all kinds of phenomena, including the process of making mental health diagnoses. In this study, ethnographic research was conducted over a 15 month period among the health care providers and staff responsible for the delivery of mental health and general medical care at one community center and its medical clinic. Qualitative methods of participant observation and semi-structured interviewing were used among center and clinic staff in order to discover the everyday routines and practices associated with mental health diagnosis and to capture the everyday speech practices on emotion occurring within diagnostic routines and practices. After receiving institutional review approvals and permission from the community center's director of research, study methods and rationale were explained to staff and HCPs at staff meetings or on an individual basis. All individuals were given the opportunity to either consent or refuse participation in private and all participants were reminded that they could choose not to be observed or interviewed at any time.

Interviews contained a combination of open-ended questions designed to elicit personal, cultural and professional factors contributing to providers' identities and the meanings they associate with various emotions. Interview questions and initial observations were informed from the literatures of cultural psychology and anthropology on identity and emotion, as well as from ethnographic studies of Arab culture and Arab immigrants living in the US.

Figure 2 illustrates how these literatures are operationalized within the EI framework.

Figure 2. Operationalization of Literatures Within the EI Framework



In this schematic of EI, the “clinic” refers to areas of specific mental health activity, as well as general medical care occurring at the community center. The highlighted circles, containing various aspects of identity, social interactions and everyday emotion talk, contain elements that were identified through the literatures, or on initial observation, as being important to consider in this clinic setting. This framework is not fixed, but serves as an initial sorting device in which to make sense of data. Table 1 lists the sources of the data.

Analysis triangulates data from: (1) interviews; (2) observational field notes of staff meetings, case conferences, and other routine practices in which patient diagnostic and treatment communications containing some assessment of emotion were exchanged; and (3) archival sources on the history and development of the clinic and the surrounding Arab immigrant community. A system of codes was assigned to the elements contained in the now operationalized framework of “emotive institution” (Figure 2) as well as to additional elements found to emerge within the data. This coded data is then examined for themes.

Table 1. Data Sources

<i>Ethnographic Data</i>	<i>Archival Data</i>
19 semi-structured interviews with HCPs and clinic staff (audio recorded)	Center and clinic promotional literature and on-line publications
Observational field notes (total of 15 months):	Clinic formal assessment tools, i.e., intake and admission, psych surveys
<ul style="list-style-type: none"> 8 months observation in medical clinic and informal interviews with staff 	News media (local, national, international)
<ul style="list-style-type: none"> Community center sponsored meetings (staff in-services), lectures, awards programs and volunteer events 	
<ul style="list-style-type: none"> Community events (i.e., festivals, cultural and art programs) 	

Formal in-depth interviews took place with HCPs who worked in specific mental health settings, as well as with HCP's who worked in an areas providing general medical care (see Table 2 for demographic characteristics of interview participants).

Table 2: Demographic Characteristics of Interview Participants

Interviews from mental health areas (9):
<ul style="list-style-type: none"> Education: BA (3), MA (5), PhD (1), JD (1) Occupation: Case workers, therapists, psychologist, attorney
Interviews from medical clinic (10):
<ul style="list-style-type: none"> Education: BA (3), MPH (1), High school diploma (3), some college (3) Occupation: Medical assistants, RN, receptionist, facility coordinator
Country of origin:
<ul style="list-style-type: none"> Iraq (3) Lebanon (9) Sierra Leone (1 of Lebanese ancestry) Yemen (3) US (3 – first generation Lebanese ancestry)
Religion:
<ul style="list-style-type: none"> 18 Muslim 1 Christian
Gender:
<ul style="list-style-type: none"> 15 female 4 male
Years in USA:
<ul style="list-style-type: none"> 9-35 years

Preliminary findings reveal interesting intra-group variation in explanations for emotion between different groups of HCPs. One interesting difference was noted when moving between HCPs with specific mental health training and HCPs without mental health training. When asked to define emotion, HCPs with specific mental health training listed positively valenced emotions, such as joy, happiness and love, as well as negatively valenced emotions, such as anger, sadness, and fear. HCPs without mental health training tended to emphasize positively valenced emotions, using English terms for caring, compassion, and love. In an interview with one male HCP with mental health training, he stated that before getting his training, emotion for him usually meant emotions such as love and joy and that in discussions of “sha-oor” (Arabic word for emotion) with his Arab clients he has to spend time to get them to recognize other emotions besides love. When a female HCP from his same Arab homeland, but without mental health training, was asked why anger is not spoken of more often she explained that not only was there not the freedom to speak openly of anger, anger is not talked about out of a need to protect the family.

Discussion

The comments from these two HCPs reflect a larger pattern found within the data and represent one intriguing difference in explanations for emotion that may be the result of many influences. The next step in the analysis is to more closely examine these explanations using the EI framework. The EI framework helps to sort out the aspects of provider identity, explanations for emotion contained in interviews, and data gathered from the observation of the settings and social interactions in which spontaneous emotion talk resides. These aspects of the data are further examined alongside archival data, in the form of mental health and general health assessment tools, community center program literature and news media. This detailed weaving back and forth between data points helps to assemble a richer, fuller understanding of the meanings assigned to emotion present in this one local setting. Some broad questions to consider include how the experience of collective societal norms influences the observations on emotion from different kinds of providers and whether the explanations for emotion illustrated here potentially influence the ways in which HCPs elicit information from their clients and then assess their mental and emotional states.

Using the framework of EI, this ethnographic study into emotion meaning-making in one local US health care setting in which immigrant HCPs make mental health diagnoses provides new information about what contributes to emotion meanings that can inform the assessment and treatment of mental illness in a globalizing world.

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Infant Mental Health: Building Social-Emotional Relationships Between Infants and Caregivers

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Key words: *Infant mental health, historical basis, training programs, standards*

Abstract

We provide a brief historical review of the infant mental health movement, including its international status. Clinical perspectives of infant mental health as a practice are described, as are issues related to the multidisciplinary nature of assessment and intervention/treatment. We also review infant mental health workforce standards that were developed in Michigan and are now licensed to 13 additional states. These standards, known as the Competency Guidelines[®], can lead to infant mental health Endorsement (IMH-E[®]) at four different levels of practice.

Origins of Infant Mental Health as a Clinical Science

Grounded in three major theoretical traditions and with input from multiple clinical and empirical disciplines, the interdisciplinary field of infant mental health has grown from a serendipitous beginning into a major international organization focused on the social and emotional development of infants and young children. The historical development of the field and its scientific and clinical organization have been described in considerable detail elsewhere (Fitzgerald & Barton, 2000; Fitzgerald, Weatherston & Mann, 2011), so we provide only a brief overview in this paper.

During the 20th century, four theoretical perspectives (evolutionary, systems, psychoanalytic, and cognitive) converged to draw attention to the earliest years of human development (Fitzgerald et al., 2011). Toward the end of the 20th century and robustly in the 21st century, the study of infant neurobiological development, gene-environment interplay, and toxic stress honed attention tightly to those areas of the brain that mediate the organization of the attention, learning, and emotional/behavioral regulation systems. The broad consequence of these changes across many developmental sciences and clinical fields is that public attention to the importance of the first five years of life reached unprecedented levels and continues today.

Behind the scenes the organizational structures for two professional organizations were taking shape. One of the organizations was an offshoot of the Michigan Association for Infant Mental Health, the very first infant mental health association ever formed. Incorporated in 1977, MI-AIMH has offered infant mental health training and education opportunities to individuals and groups for 35 years. With an annual membership of more than 500 infant and family professionals and 13 affiliate chapters within the state of Michigan, MI-AIMH is proud of its role as an infant mental health training association. In the context of this presentation, MI-AIMH developed an Endorsement program (IMH-E[®]) designed to generate training criteria and performance based evidence for infant mental health professionals. MI-AIMH's role in this part of the story, however, stems from a 1979 decision made by

its Board of Directors to (a) establish the International Association for Infant Mental Health (IAIMH), and (b) to establish the *Infant Mental Health Journal*, both of which came into being in 1980.

In the same era, the American Academy of Child and Adolescent Psychiatry established a Committee on Infant Psychiatry, which incorporated in 1985 as the World Association for Infant Psychiatry and Allied Disciplines (WAIPAD; see Fitzgerald & Barton, 2000; Fitzgerald et al., 2011). In 1986 a joint committee began discussions and in 1992 the IAIMH and WAIPAD joined to form the World Association for Infant Mental Health. Because the IAIMH wanted infant mental health interventions to reflect local culture and professional practices, it had developed an Affiliates program to accomplish that goal. Initially, the Affiliates were within the United States (Texas, 1980 and others) but within a year, the international reach had begun (Mexico, and Ontario, Canada, 1982). Soon thereafter, international affiliates were established in Quebec, Canada (1985), Australia (1988), and the Nordic Countries (1992). After the merger, the internationalization of WAIMH accelerated to the 59 Affiliate organizations listed in Table 1.

The *Infant Mental Health Journal* (Hiram E. Fitzgerald, Editor-in-Chief, fitzger9@msu.edu) also benefited from the merger and expansion. Initially it was a quarterly journal and then it moved to six issues annually; over time the number of pages allocated to the journal expanded to its current 720 page allocation. It is the leading journal in the field for emphasis on social and emotional development during infancy and early childhood. WAIMH also published a newsletter, *The Signal*, that in 2012 transitioned to a major quarterly professional journal, renamed as *Perspectives on Infant Mental Health*. *Perspectives* has a particular focus on dissemination and active discussion of clinical case studies, program descriptions, training programs, cultural context of infancy interventions, professional development, and Affiliate activities (Deborah Weatherston, Editor-in-chief, dweatherston@mi-aimh.org). The goal was to develop training materials that would be applicable for individuals from any discipline, which could be translated into their disciplinary practice and simultaneously guided by the evidence-based practices that have demonstrated the validity of the infant mental health model.

But what is infant mental health? Although several different definitions have been offered, one that has broad appeal is that offered by Zero to Three: “the developing capacity of the child from birth to age three to experience, regulate and express emotions; form close and secure interpersonal relationships; and explore the environment and learn—all in the context of family, community, and cultural expectations for young children. Infant mental health is synonymous with healthy social and emotional development” (Parlakian & Seibel, 2002, p. 2).

Clinical Perspectives on Assessment and Intervention/Treatment

Infant Mental Health Practitioners

Infant mental health (IMH) practitioners are master’s degree or higher-prepared professionals with specialized education, training, and experience in culturally sensitive, relationship-focused practice toward improving developmental and mental health outcomes for infants/toddlers and their families. IMH professionals can come from psychology, psychiatry, social work, nursing, education, pediatrics, counseling, child and family development, marriage and family therapy, etc. In Michigan, the largest IMH service delivery system is through Medicaid-funded home-based services of Community Mental Health (CMH) via the Michigan Department of Community Health. The home-based therapists in the CMH system who provide IMH services are all licensed mental health professionals. In other programs and in other systems, IMH practitioners may not be licensed mental health professionals, but they will have had training in relationship-focused therapeutic practice, cultural competence, disorders of infancy and early childhood, psychotherapeutic and behavioral theories of change, mental and behavioral disorders of adults, ethical practice, screening and assessment, intervention/treatment planning, developmental guidance, supportive counseling, parent-infant/very young child relationship-focused therapies and practices, and conflict resolution.

Service Population Characteristics

Families who are appropriate for IMH services are those in which the parent’s history, condition, and/or life circumstances or the characteristics of the infant/toddler threaten the parents’ ability to respond. When the parent is unable to respond conditionally, there are consequences for social, emotional, behavioral and cognitive development of the infant/toddler.

Infants may be: premature, underweight, failing to thrive, medically compromised, temperamentally difficult to care for, irritable, inconsolable, experiencing regulatory disturbances (e.g., sleeping, eating), unresponsive, listless, hypersensitive, and/or highly active.

Toddlers may have: regulatory disturbances, sensory processing difficulties, behavioral difficulties (tantrums, biting), traumatic stress, suspected or confirmed developmental delays, identified disabilities, relationship disorders or disturbances (DC-O to 3R; Zero to Three, 2005).

Parents may be: adolescent, impoverished, undereducated, unemployed, substance abusing, severely depressed, in relationships with domestic violence, and significantly stressed. Parents can be biological, foster, or adoptive.

Assessment

In the practice of infant mental health, a number of standardized screening and assessment tools are available. In Michigan (and in many states) the most commonly used developmental screener is the Ages & Stages Questionnaire (ASQ-3; Squires et. al., 2009) and the ASQ: Social Emotional (ASQ: SE; Squires et. al., 2002). Designed as self-report tools for parents, the ASQs are straightforward and can be used to help both parent and practitioner determine if the infant/very young child's development is on target or if a more in-depth developmental assessment is required. When developmental delay is suspected or identified, a referral to Early On (Part C of IDEA, US Department of Education, 1990) is made for an individualized family service plan that will address the delay and the resulting family needs. Eligibility for Early On must be determined by professionals from at least two disciplines agreeing on the degree of the infant/toddler's delay and/or chronic medical issue. IMH practitioners often work collaboratively with Early On professionals.

Other observation, screening, and assessment tools commonly used include the Devereaux Early Childhood Assessment for Infants/Toddlers (DECA I/T; LeBuffe & Nagileri, 1999), the Massie Campbell Attachment During Stress (Massie & Campbell, 2007), and the Parenting Interactions with Children: Checklist of Observations Linked with Observations (PICCOLO; Cook, Innocenti, & Roggman, 2010). Others include the Bayley Scales of Infant Development (BSID; Bayley, 2005); the Nursing Child Assessment Satellite Feeding and Teaching Scales (NCAST), developed by Kathryn Barnard (Sumner & Spietz, 1994); and the Home Observation for Measure of the Environment (HOME; Caldwell & Bradley, 2003).

The Diagnostic Classification: 0-3 Revised (DC: 0-3R; Zero to Three, 1997) is a multi-axial system used to diagnose disorders of infancy and early childhood. It is often "cross-walked" with the DSM-IV.

In addition to these standardized tools, a hallmark of IMH practice is the use of informal observation and assessment of infants and toddlers in their caregiving environments. Because infants and toddlers are pre-verbal, IMH practitioners are trained to watch very closely to see if the infant/toddler is able to give clear signals to caregivers, and to see if the caregivers are able to read and appropriately respond to those signals. IMH practitioners watch for moments of shared attention and shared pleasure (or the absence of them). They listen carefully to the stories parents tell about the pregnancy, labor and delivery, early days of adjusting to this newborn, and who was there to offer support (if anyone). They listen to stories of what it has been like to be the mother/father/caregiver of this baby. They take in the environment in which the family lives, the neighborhood, home, presence (or absence) of food, formula, diapers, toys, and books. They ask about access to health care. They listen very carefully to stories about the parents' own caregiving histories, paying special attention to stories of trauma, grief, and unresolved losses. And they attend to their own reactions to the sights, smells, words, or lack of them. They assess for evidence of substance abuse, mental illness, and/or domestic violence. They take time out, regularly, to meet with a reflective supervisor or consultant to ensure there is a place in which and a person with whom they can share these reflections. Reflective supervision/consultation (RSC) is a critical part of the assessment and intervention/treatment planning process. In homes where multiple risk factors compete for attention, RSC provides an opportunity to wonder about how this caregiving environment is affecting or is affected by this infant/toddler.

Cultural differences will influence the ability to accurately assess the caregiving environment and capacities. For example, IMH practitioners are trained to recognize picking up a crying infant as a sensitive response. However, in some families, parents are discouraged from picking up a crying baby for fear of spoiling the child. Culturally competent IMH practice suggests that the IMH practitioner will ask about a parent's caregiving behavior and explore how and why the parent responds the way that he/she does. Remaining curious and open helps the IMH practitioner to better understand the cultural context of parenting practices and establishes trust with the parent(s).

Intervention/Treatment

As described in *Case Studies in Infant Mental Health* (Shirilla & Weatherston, 2002, pp. 4-5), the skills and strategies often employed by IMH practitioners include:

- Building a relationship with parent(s) and using the relationship as an instrument of change
- Meeting with the infant/toddler and parent together throughout the period of intervention

- Sharing in the observation of the infant/toddler's growth and development
- Offering anticipatory guidance to the parent that is specific to the infant/toddler
- Alerting the parent to the infant/toddler's individual accomplishments and needs
- Helping the parent to find pleasure in the relationship with the infant/toddler
- Creating opportunities for interaction and exchange between parent(s) and infant/toddler and therapist
- Allowing the parent to take the lead in interacting with the infant/toddler or determining the "agenda"
- Identifying and enhancing the capacities that each parent brings to the care of their infant/toddler
- Reflecting the parent's thoughts and feelings related to the presence and care of the infant/toddler and the changing responsibilities of parenthood
- Reflecting the infant/toddler's feelings in interaction with and relationship to the caregiving parent
- Listening for the past as it is expressed in the present
- Allowing conflicts and emotions that are related to the infant/toddler to be expressed by the parent—holding, containing, and talking about them as the parent is able
- Attending and responding to parental histories of abandonment, separation, and unresolved loss as they affect the care of the infant/toddler, the infant/toddler's development, the parents' emotional health, and the early developing relationship
- Attending and responding to the infant/toddler's history of early care within the developing parent-infant relationship
- Identifying and treating disorders, delays and disabilities of infancy and early childhood, parental mental illness, and family dysfunction
- Remaining open, curious and reflective

Relationship-Focused Interventions and Treatment Modalities

There are six major service components. Some or all may be appropriate. For the most vulnerable families, all are often incorporated into the services that an IMH practitioner offers.

1. Concrete assistance
2. Emotional support
3. Developmental guidance
4. Early relationship assessment and support
5. Advocacy
6. Parent-infant/very young child relationship-focused therapies and practices (parent-infant psychotherapy, interaction guidance, parent-child psychotherapy)

A fuller description of developmental guidance and parent-infant psychotherapy is offered here.

Developmental Guidance

An IMH practitioner uses multiple strategies to help parents/caregivers understand their role in the social emotional development of the infant/toddler and to understand what the parent/ caregiver can do to promote health, language, and cognitive development in infancy and early childhood. Tools like the ASQ and ASQ-SE can be used to help the parent/ caregiver know what infants/toddlers are typically able to do at this age and to anticipate the developmental milestones to come. Developmental guidance can help the parent/caregiver to acquire a more realistic set of expectations about what the infant/toddler can do, say, and know.

Parent-Infant Psychotherapy

Parents with multiple risk factors such as mental illness, unresolved grief and loss, abandonment, or trauma need time and therapeutic support to separate these experiences from their identity and behavior as a parent. According to Lieberman & Van Horn (2008, p. 66),

In joint parent-child sessions, sustained therapeutic exploration of how the parent's problems affect the parent's feeling and behaviors toward the infant is most feasible in the first year of life... The therapist can draw inferences about how the parent's conflicts, pathogenic beliefs, and distorted cognitions are visited upon the baby and transform the child into a transference object that is bereft of individuality while serving the parent's psychological needs... The primary interpretive mechanisms of classical infant-parent psychotherapy are wrapped up in a dual message: compassion for what the parent endured as a child and forthrightness in helping the parent recognize the damage that the old pain now inflicts on the new baby. This two-pronged message is conveyed through carefully orchestrated statements designed to support the parent in finding new ways of coping with the past and becoming the parent she wants to be.

Professional Workforce Development Standards for the Infant-Family Field Michigan Association for Infant Mental Health (MI-AIMH) Competency Guidelines (Excerpted from Weatherston, Kaplan-Estrin, & Goldberg, 2009).

As infant mental health practice evolved in Michigan, clinicians, university faculty, and policymakers became increasingly concerned about the training needs of professionals for quality service in the infant mental health field. Competency, as determined by expert consensus, requires the development of a unique knowledge base, clinical assessment, intervention/treatment skills specific to infancy and early parenthood, and reflective clinical supervisory experiences that lead to best practice.

Created over a span of eight years with input from nearly 100 professionals from multiple disciplines and backgrounds, the *Competency Guidelines* (MI-AIMH, 2002) were built from the *MI-AIMH Training Guidelines* (1986), the TASK documents published by Zero to Three (1990) and the competencies developed by the Michigan Department of Education (in response to IDEA legislation) in 1996. By 1997, the MI-AIMH Board had approved a set of competencies that were framed around eight areas of expertise. The eight areas included theoretical foundations; law, regulation, and agency policy; systems expertise; direct service skills; working with others; communicating; thinking; and reflection. The work on the competencies reflected the following belief (Zero to Three, 1990, p. 18): "The development of competence to work with infants, very young children, and their families involves the emotions as well as the intellect. Awareness of powerful attitudes and feelings is as essential as the acquisition of scientific knowledge and therapeutic skill." Significant to these standards was the inclusion of reflection as integral to best practice in the infant and family field.

During the next few years, the MI-AIMH work group expanded the competencies to detail the practice of professionals from multiple disciplines who worked in many different ways with infants, very young children, and families. The core competencies were expanded to four levels, four ways in which professionals work with or on behalf of infants, toddlers, and families, the framework for the MI-AIMH Endorsement*.

Endorsement

The MI-AIMH Endorsement for Culturally Sensitive, Relationship-Focused Practice Promoting Infant Mental Health* was developed over a 10-year period and launched in 2002. Based on the *Competency Guidelines*, the endorsement is a reflection of MI-AIMH's commitment to best practices in the infant and family field.

The intent of the MI-AIMH Endorsement* is to recognize the professional development of infant and family service providers within the diverse and rapidly expanding infant and family field. Endorsement verifies that an applicant has attained a specified level of functioning and understanding about the promotion of infant mental health and provides a level of assurance to families, agencies, and the public at large that the person who provides services to infants and their families meets standards that have been approved by a professional organization devoted to the optimal development of very young children.

The MI-AIMH Endorsement* offers individuals in the infant and family field a professional development plan that focuses on knowledge, best practice skills, and reflective work experiences that lead to increased confidence and credibility within the infant and family field. The MI-AIMH Endorsement* will inform prospective employers, agencies and peers about culturally sensitive, relationship-focused practice promoting infant mental health. Those who earn the MI-AIMH

Endorsement® will be recognized for their education, training, leadership roles, and work experiences within the infant and family field.

There are four levels of competency within the MI-AIMH Endorsement®:

- I. Infant Family Associate
- II. Infant Family Specialist
- III. Infant Mental Health Specialist
- IV. Infant Mental Health Mentor

Each level recognizes the educational experiences, specialized in-service training experiences, and work experiences appropriate for best service outcomes for infants, very young children, and families. Detailed information about the requirements for specialized education, work, in-service training, and reflective supervision/consultation experiences are different at each level and can be found within this publication. Details regarding how one can apply for and earn endorsement can be found at <http://www.mi-aimh.org/endorsement>.

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Table 1. Current WAIMH Affiliates and Their Websites

(last updated 12/30/2011 from WAIMH website: <http://www.waimh.org> and Infant Mental Health Journal cover page).

AFRICA

Gauteng Association for Infant Mental Health (South Africa)

Western Cape Association for Infant Mental Health (South Africa)
<http://www.infantmentalhealth.co.za>

ASIA

Korean Association for Infant Mental Health (South Korea)
<http://www.imentalhealth.org/>

AUSTRALIA AND OCEANIA

Australian Association for Infant Mental Health (AAIMHI, Australia)
<http://www.aaimhi.org/>

Australian Association for Infant Mental Health (New South Wales)
http://www.aaimhi.org/state_nsw.php

Australian Association for Infant Mental Health (Queensland)
http://www.aaimhi.org/state_qld.php

Australian Association for Infant Mental Health (South)
http://www.aaimhi.org/state_sa.php

Australian Association for Infant Mental Health (Western Australia)
http://www.aaimhi.org/state_wa.php

Australian Association for Infant Mental Health (Victoria)
http://www.aaimhi.org/state_vic.php

New Zealand Association for Infant Mental Health (IMHAANZ)
<http://imhaanz.org.nz/>

EUROPE

Dutch Association for Infant Mental Health (Netherlands)
<http://www.daimh.nl/>

Finnish Association for Infant Mental Health (PIRPANA, Finland)
<http://www.pirpana.fi/>

France Group Francophone (France)
<http://www.psynem.org/Waimh/Francophone/>

German Speaking Association for Infant Mental Health (GAIMH, Austria, Germany, Switzerland)
<http://www.gaimh.de/>

Greek Society for Infant Mental Health (Greece)

Irish Association for Infant Mental Health (Ireland)

Italian Association for Infant Mental Health (Italy)
<http://www.aismi.it/>

Latvia Association for Infant Mental Health

Nordic Association for Infant Mental Health (Denmark, Norway, Sweden)
<http://www.nfsu.org>

Portugal Association for Infant Mental Health (Associação Ser Bebê Portugal)
<http://serbebe.pt/>

Spain Association for Infant Mental Health Since Gestation (ASMI)
<http://www.asmi.es/>

Turkish Association for Infant Mental Health (Turkey)
<http://www.bebekruhsagligi.org.tr/>

United Kingdom Association for Infant Mental Health (AIMH UK)
<http://www.aimh.org.uk/>

WAIMH Belgo-Luxembourgeoise (Belgium, Luxembourg)

WAIMH-VLAANDEREN (Belgium)
<http://www.waimh-vlaanderen.be/>

Table 1. Current WAIMH Affiliates and Their Websites, *continued*

(last updated 12/30/2011 from WAIMH website: <http://www.waimh.org> and Infant Mental Health Journal cover page).

MIDDLE EAST

Israel Association for Infant Mental Health (Israel)
<http://infant-mh.co.il>

NORTH AMERICA

Canada

Ontario Association for Infant and Child Development
(OAICD)
<http://www.oaicd.ca/>

Quebec Association for Infant Mental Health (AQSMN)
<http://www.aqsmn.org/>

Western Canadian Association for Infant Mental Health
(WCAIMH)
<http://www.vcn.bc.ca/wcaimh/>

United States

Arizona Infant Toddler Mental Health Coalition
(ITMHCA)
<http://www.itmhca.org/>

Colorado Association for Infant Mental Health
(CoAIMH)
<http://www.coaimh.org/>

Connecticut Association for Infant Mental Health (CT-
AIMH)
<http://www.ct-aimh.org/>

Florida Association for Infant Mental Health (FAIMH)
<http://faimh.org/>

Hawai'i Association for Mental Health
<http://www.haimh-firstrelationships.org/>

Idaho Association for Infant and Early Childhood Mental
Health (AimEarlyIdaho)
<http://www.aimearlyidaho.org/>

Illinois Association for Infant Mental Health (ILAIMH)
<http://www.ilaimh.org/>

Indiana Association for Infant and Toddler Mental
Health (IAITMH)
<http://www.iaitmh.org/>

Kansas Association for Infant Mental Health (KAIMH)
<http://www.kaimh.org/>

Louisiana Infant Mental Health Association

Maine Association for Infant Mental Health (MeAIMH)
<http://www.infantmentalhealth.org/>

Massachusetts Association for Infant Mental Health

Michigan Association for Infant Mental Health (MI-
AIMH)
<http://www.mi-aimh.org/>

Minnesota Association for Infant and Early Childhood
Mental Health (MAIECMH)
<http://www.macmh.org/>

Nebraska Association for Infant Mental Health
(Nebraska Children and Families Found.)
<http://www.nebraskachildren.org/>

New Jersey Association for Infant Mental Health
(NJAIMH)
<http://www.njaimh.org/>

New Mexico Association for Infant Mental Health
(NMAIMH)
<http://www.nmaimh.org/>

Ohio Association for Infant Mental Health (OAIMH)
<http://www.oaimh.org/>

Oklahoma Association for Infant Mental Health (OK-
AIMH)
<http://www.okaimh.org/>

Pennsylvania Association for Infant Mental Health (PA-
AIMH)
<http://www.pa-aimh.org/>

Pennsylvania - Delaware Valley Group (DVG-WAIMH)
<http://www.phillybabies.org/>

Rhode Island Infant Mental Health (RIAIMH)

Texas Association for Infant Mental Health (TAIMH)
<http://www.taimh.org/>

Utah Association for Infant Mental Health (UAIMH)
<http://www.hope.usu.edu/uaimh/>

Table 1. Current WAIMH Affiliates and Their Websites, *continued*

(last updated 12/30/2011 from WAIMH website: <http://www.waimh.org> and Infant Mental Health Journal cover page).

Virginia Association for Infant Mental Health

Washington Association for Infant Mental Health (WA-
AIMH)
<http://wa-aimh.org/>

SOUTH AMERICA

Argentina Association for Infant Mental Health (SAPI)
<http://www.sapi.org.ar/>

Brazil Association for Infant Mental Health (ABEBE)
<http://www.abebe.org.br/>

Determinants of Health for Palestine Refugees in the 21st Century: Double Burden of Non-communicable Diseases and Mental Health Conditions

Akihiro Seita

United Nations Relief and Works Agency

Key words: *Palestine refugees, diabetes, smoking, mental health*

Introduction of UNRWA and UNRWA Health Services

United Nations Relief and Works Agency for Palestine Refugees in the Near East (UNRWA)¹ provides assistance, protection and advocacy for some five million registered Palestine refugees in the Middle East. Following the 1948 Arab-Israeli conflict, UNRWA was established by United Nations General Assembly Resolution 302 (IV) of 8 December 1949 to carry out direct relief and works programs for Palestine refugees. The Agency began operations on 1 May 1950. In the absence of a solution to the Palestine refugee problem, the General Assembly has repeatedly renewed UNRWA's mandate, most recently extending it until 30 June 2014.

UNRWA provides education, health, relief and social services to the refugees in its five fields of operation: Jordan, Lebanon, Gaza Strip, Syrian Arab Republic, and West Bank, including East Jerusalem. More than 1.4 million refugees, around one third of the total, live in 58 camps. The Agency currently operates or sponsors over 900 installations with nearly 30,000 staff across the five fields. UNRWA cooperates closely with governmental authorities in the area of operations.

The total amount of UNRWA's general budget, or core budget, was USD \$551 million in 2011. Almost all funding (98 per cent) received came from voluntary contributions, and mostly from donor states including the United States and the European Union. The United Nations Secretariat finances over 100 international staff posts each year from its regular budget. UNESCO and WHO also fund on average 10 posts in the education and health programs, respectively.

UNRWA delivers basic health services and is responsible for providing a healthy living environment for Palestine refugees.² UNRWA has been the main primary health care provider of Palestine refugees for 62 years and is the largest humanitarian operation in the occupied Palestinian territory. UNRWA aims to ensure a "long and healthy life" for refugees as stated in its Medium Term Strategy 2010-2015,³ through: ensuring universal access to quality comprehensive services; preventing and controlling disease; and protecting and promoting mother and children and family health.

The Agency's network of 138 primary healthcare facilities and mobile clinics provides the foundation of its health services. Such centers offer primary health care including preventive and curative services tailored for each stage of life and health needs of refugees. UNRWA has a total of 3,525 staff in health services including 504 doctors, 1,127 nurses, and other supportive staff.⁴ In 2011, UNRWA staff performed 11 million medical and dental consultations.

1 UNRWA website: www.unrwa.org

2 Sabatinelli G, Pace-Shanklin S, Riccardo F, Shahin Y. Palestinian refugees outside occupied Palestinian territory. *Lancet*. 2009;373:1063-1065.

3 UNRWA Medium Term Strategy 2010-2015, UNRWA.

4 United Nations Relief and Works Agency for Palestine Refugees in the Near East (UNRWA). 2012. The Annual Report of the Department of Health, 2011.

UNRWA also helps refugees to access hospital care services. The total expenditure on health was around USD \$100 million in 2011, of which 60% were for human resources, 20% were for hospital reimbursement, 13% were for medicines and medical supplies procurement, and the remaining 7% were all other expenses.

Health Conditions of Palestine Refugees

The refugee populations continue to grow in number: from 4,766,670 in 2009 to 4,966,664 in 2010, and to 5,115,755 in 2011. Almost two million of these refugees resided in the occupied Palestinian Territory in the Gaza Strip and the West Bank. The remaining were spread over three host countries: Lebanon, Syria and Jordan. The refugee populations are generally a young population. Thirty-five percent (35%) of refugees are children below 18 years of age. The dependency ratio, measured as the proportion of the population below 15 and above 65 years of age, is around 80%.

Through the support of UNRWA, governmental and other health-care providers, health conditions of Palestine refugee mothers and children have shown continued improvement. Progress against Millennium Development Goals 4 (reduce child mortality) and 5 (improve maternal health), for example, has been on track.

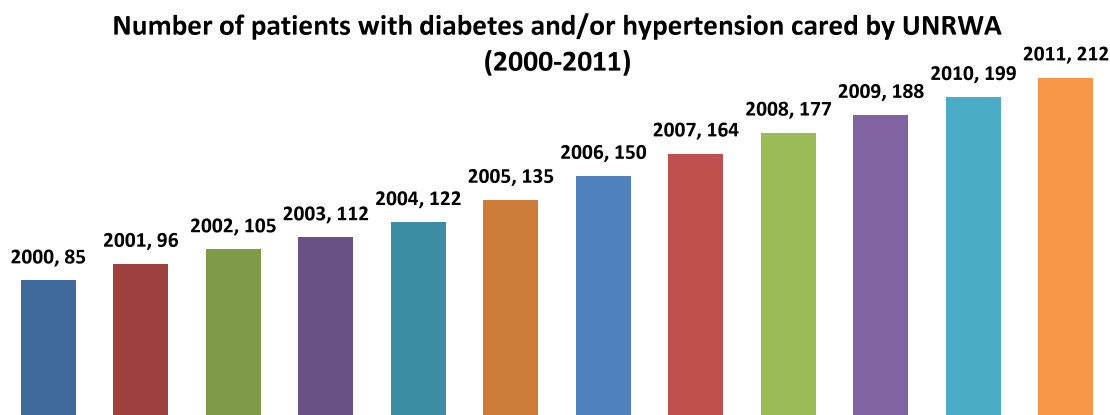
UNRWA conducts infant mortality surveys every five years. The last survey took place in 2008, assessing the period 2005-2006. This survey found infant mortality rates per 1,000 live births of 22.0 in Jordan, 19.0 in Lebanon, 28.2 in Syria, 20.2 in Gaza and 19.5 in the West Bank.⁵ These rates are comparable to those of host countries and many middle income countries. The three main causes of infant deaths among Palestine refugees during this period were related to low birth weight/prematurity, congenital malformations and respiratory infections.

Non-communicable Diseases

The main determinant of health of Palestine refugees in the 21st century is non-communicable diseases. Non-communicable diseases include diabetes, cardiovascular diseases, cancer and chronic lung diseases. The epidemiological transition from communicable diseases to non-communicable diseases has taken place among Palestine refugees, as observed in many countries in the Near East. It is estimated that non-communicable diseases account for approximately 70% of total deaths.⁶

The number of people with diabetes and/or hypertension under care in UNRWA's health services, for example, has been continuously increasing. At the end of 2011, a total of 211,533 patients with diabetes and/or hypertension were registered for UNRWA services across the five Fields. This represents an increase of more than 12,000 patients from 2010 and is more than twice the number registered in 2001 (Figure 1).

Figure 1. Number of Patients with Diabetes and/or Hypertension Cared for by UNRWA (2000-2011)



At the end of 2011, patients 40 years of age and older represented 91% of patients under care. Sixty-one percent (61%) of patients were female, probably reflecting the predominant attendance of female patients to UNRWA clinics. Hypertension only (45.7%) was the most common diagnosis, followed by patients with both hypertension and diabetes (Table 1).

5 Riccardo F, Khader A, Sabatinelli G. Low infant mortality among Palestine refugees despite the odds. Bull World Health Organ. 2011 Apr 1;89(4):304-11.

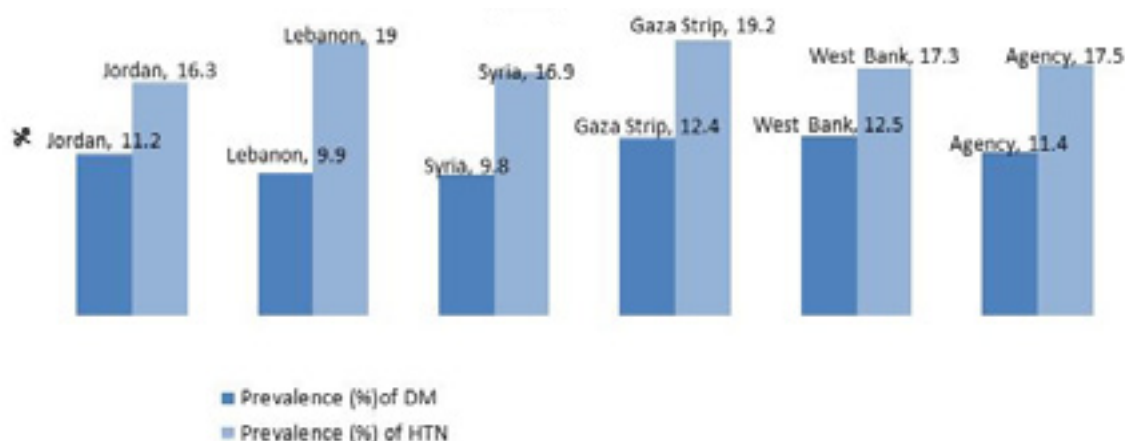
6 The global burden of disease: 2004 update. Geneva, World Health Organization, 2008.

Table 1. Total Number of Registered Patients with Diabetes and/or Hypertension at End of 2011

Morbidity type	Jordan	Lebanon	Syria	Gaza Strip	West Bank	Agency
Diabetes Type I only	1,154	224	425	1,028	587	3,418 (1.6%)
Diabetes Type II only	10,675	2,304	3,337	10,852	5,565	32,733 (15.5%)
Hypertension only	29,010	12,276	12,753	29,093	13,490	96,622 (45.7%)
Diabetes and hypertension	27,470	8,437	9,598	19,458	13,797	78,760 (37.2%)
Total	68,309	23,241	26,113	60,431	33,439	211,533

The Agency-wide prevalence of diagnosed diabetes mellitus and hypertension among the served population 40 years of age or older was 11.4% and 17.5% respectively during 2011 (Figure 2).

The high prevalence of diabetes, hypertension, and other non-communicable disease is the reflection of the high prevalence of the underlining behavior risk factors among Palestine refugees. Such prevalent risk factors include tobacco use, physical inactivity, and unhealthy diet. In Jordan, Lebanon and Syria, countries that host Palestine refugees and are also the member states of the World Health Organization, the reported behavior risk factors and metabolic risk factors are considerably high.⁷

Figure 2. Prevalence of Diabetes and Hypertension Among Refugees 40 Years of Age or Older (2011)

In these three countries, the current rate of smoking is very high among males: 48.8% in Jordan, 44.1% in Lebanon, and 36.8% in Syria. Overweight and obesity is extremely high in both genders. More than 60% of adults are overweight: 64.1% (66.0% among females and 62.3% among males) in Jordan, 61.8% (57.9% among females and 66.1% among males) in Lebanon, and 61.2% (63.6% among females and 58.7% among males) in Syria. Obesity is almost 30% in both genders: 30.0% in Jordan, 27.4% in Lebanon and 27.1% in Syria.

The latest global school-based health student survey results (unpublished) indicated that the prevalence of tobacco smoking is also high among young Palestine refugees (aged 13 to 15 years) in Jordan: 33% of them have ever smoked tobacco (44% among boys, 20% among girls), and 13% of them are currently smoking tobacco (19% among boys, 6% among girls).

7 Noncommunicable Diseases Country Profile. Geneva: World Health Organization. 2011.

Mental Health and Stress-Related Conditions

Mental health and stress-related conditions are also an important determinant of health for Palestine refugees, particularly in the occupied Palestine territory, namely West Bank and Gaza Strip.⁸ The social and economic difficulties continue, if not exaggerate, particularly in the Gaza Strip. The unemployment rate increased in the Gaza Strip to 39.3 per cent in the second quarter of 2010, while in comparison in the West Bank it was around 15.2 per cent. The unemployment rate of 20 to 24 year olds in the Gaza Strip stands at 66.6 percent.⁹

Children and adolescents are particularly vulnerable to such situations. The stress of the occupation, inability of men to provide for their families, and consequent reversal of gender roles sometimes result in a higher prevalence of domestic violence. According to the Palestinian Central Bureau of Statistics,¹⁰ 30% of ever-married women in the West Bank have been exposed to some form of violence by their husbands from July 2010 to July 2011. Two-thirds of women in the West Bank who had been subjected to violence by their husbands (65%) said that they preferred to remain silent.

In response to the situation of often severe psychological stress in the Gaza Strip and the West Bank, UNRWA launched a Community Mental Health Programme. The Programme offers counselling and support, and ensures the long-term strategic incorporation of psychosocial wellbeing of refugees into the Agency's healthcare package. Through a network of counsellors, established in UNRWA health centres and schools and in community based organizations, the programme seeks to help groups at risk to develop effective coping mechanisms and prevent further psychological deterioration.

During 2010, more than 4,000 people received counseling services or participated in support group activities in the West Bank. This represents double the number of clients benefitting from these services during 2009. Family violence, which may reflect the levels of stress and frustration among the population, has reached worrying proportions. Among the 6,029 patients assisted through UNRWA's community mental health services in Gaza during 2011, 27% of visits were related to family problems. Almost a quarter of the patients were children with bedwetting, a frequent symptom of psychological trauma. Depression, anxiety, fear and anger were also common reasons for seeking care. Tables 2 and 3 show the number of persons who received services from the community mental health programs in West Bank and Gaza.

Table 2. Community Mental Health Programme Activities in West Bank (2011)

	<i>Individual Counselling</i>	<i>Group Counselling</i>	<i>Family Counselling</i>	<i>Home Visits</i>	<i>Summer/ Winter Camps</i>	<i>Supportive Groups</i>	<i>Group Interventions</i>
Sessions	29,452	2,662	1,213	55	378	758	2,517
Beneficiaries	29,452	16,636	882	55	20,826	7,153	65,266

Table 3. Community Mental Health Programme Activities in Gaza (2011)

	<i>Individual Counselling</i>	<i>Group Counselling</i>	<i>Group Guidance (Awareness)</i>	<i>Home Visits</i>
Sessions	34,602	10,887	4,588	4,198
Beneficiaries	24,200	41,461	4,903	5,077

8 Sixty-fourth World Health Assembly, Agenda Item 15: Health conditions in the occupied Palestinian territory, including east Jerusalem, and in the occupied Syrian Golan. A64/INF.DOC./3, 12 May 2012.

9 Labour Force Survey; April – June 2010, Palestinian Central Bureau of Statistics, 2011.

10 Violence Survey in the Palestinian Society. Palestinian Central Bureau of Statistics, 2011.

UNRWA Health Services

UNRWA is deeply concerned about the above changes in the determinants of health. UNRWA has been the key primary health care service providers to Palestine refugees for over 60 years. These years have seen some remarkable health gains, particularly in relation to maternal and child health. However, the context in which the health program operates is changing, bringing with it a range of new challenges, particularly non-communicable diseases and mental health conditions.

Management of non-communicable diseases is complex, requiring lifestyle modifications and costly medications, as well as lifelong medical follow up. Moreover, the resource implications associated with high numbers of chronic patients on costly medications require appropriate health management information systems to monitor the efficiency of care. In response, UNRWA implemented two major health service reform initiatives: the Family Health Team approach and E-health.

Family Health Team Approach

The family health team offers comprehensive PHC services emphasizing care of the entire family. Families are registered with a team consisting of a doctor, a midwife and one or more nurses. This team is responsible for all the health care needs of the families registered with them. Patients see the same team each time they visit the health centre. The approach is person-centred rather than disease-centred, focusing on the comprehensive health needs of the patient and family over time. Strong patient-provider relationships and long-term continuity of care, particularly important in the management of the increasing number of non-communicable disease patients, are central elements of the approach. The notions of “my doctor” and “my patient,” hitherto unknown in UNRWA facilities, capture the essence of the new approach.

After an extensive consultation and preparation process, family health team pilots commenced in two health centres in the Gaza Strip and Lebanon during late 2011. Introduction of the approach required changes to the way the services were organized within the health centre. The physical arrangement and workflow of the facility were re-organized, teams were created, and roles and responsibilities of staff members were adapted to the approach. In order to effectively manage the change process, staff buy-in and community support are essential. Therefore all health centre staff members were included in the planning and preparation process. Careful preparation of the patients and the community through consultation and information campaigns were also crucial.

Preliminary assessments in the pilot health centres found a very positive response to the approach from both staff and patients. Equitable workload distribution, a consequence of the new teamwork structure, was one of the key positive factors perceived by all cadres of staff. Staff also stated improved professional satisfaction that resulted from having responsibility for the comprehensive health care of patients registered with them, as well as the opportunity to build relationships with patients over time. Patients appreciated having a “personal” doctor for their family and perceived the health centre to be more organized and less congested since introduction of the approach.

The early success of the pilots generated much enthusiasm in UNRWA. Field staff members are motivated to begin implementing the approach in their health centres. Consequently, the implementation of the family health team will be able to proceed much more rapidly than initially anticipated. During 2012, family health teams will be expanded to health centres in all five fields, building upon the lessons learned from the pilots.

E-Health

UNRWA's health service has for decades relied on a labour intensive system of hand-written patient records, prescriptions and registers. UNRWA recognized that an electronic system could strengthen both the quality and efficiency of health services, and developed UNRWA's E-health. This is an electronic medical record system for primary health care, with all patient records in electronic format, accessible from multiple service delivery points within the clinic, and able to generate aggregate reports for management use. Through E-health, information on all aspects of the patient's care, including both curative and preventive services, is easily available at any station a patient may need to visit.

By the end of 2011, E-health was operational in five UNRWA clinics in Jordan and had been introduced in 29 clinics in Lebanon. E-health has streamlined service delivery and data management in UNRWA clinics. After introducing a module, all clinical information is managed electronically. Routine service data are available through automated reporting functions, reducing the time spent on reporting tasks. E-health has also enhanced data analysis capacity. For example, using E-health, UNRWA was able to introduce an innovative system of cohort analysis for routinely monitoring the care of non-communicable diseases patients. Before the introduction of E-health, such analyses were feasible only for a limited sample of patients and even then required time-consuming hardcopy record reviews.

Building on the lessons learned so far, UNRWA aims to implement E-health in all of its 138 clinics. The various E-health modules are being integrated into a single comprehensive electronic medical record system, One-E-health. One-E-health, with its integrated modules, will serve as a vehicle for expanding the Family Health Team approach.

Public Attitudes and Perceptions of Mental Health in the Palestinian Community

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Key words: *Mental health, treatment, Palestinians, violence, perceptions*

Abstract

The study was conducted in late 2010 to probe the extent of detrimental psychological effects that Palestinians sustained due to the traumatic events that they experienced besides their everyday burden caused by several socioeconomic factors, geopolitical systems, and the heterogeneous nature of the Palestinian population of the West Bank. Current local citizens are a combination of the original inhabitants and the emerging Palestinian refugees right after the 1948 and 1967 wars. The study also seeks to uncover the impact of social stigma and sub-cultural inclinations on acceptance towards mentally ill patients and mental health services. In this study we also explored local Palestinian people's attitudes towards many variables including psychotherapy, treatment methods for psychiatric patients, and public assessment and perceptions of these services.

A stratified cluster sample was employed to a randomly selected group of 600 adults residing in 60 residential areas in various parts of the West Bank, the so called northern governorates.

The measuring tool consisted of three main parts:

1. *Demographic details* including age, gender, income, social status and other related areas of concern. These data were acquired through a specially tailored questionnaire.
2. *Impressions and attitudes towards perceiving psychiatric patients*, dealing with psychological problems/disturbance and evaluation of some existing services. This was achieved by a well-grounded questionnaire based on a pilot study, desk study and available resources in this regard.
3. *The epidemiology of current psychiatric disorders* relying heavily on standardized inventories such as the SCL 90, the BDI, and the PTSDI, an inventory based heavily on the diagnostic criteria of the DSM-IV.

Data were collected, filtered, analyzed and recognized according to scientific research standards. The study therefore is a quantitative study and the first of its kind in the Palestinian community to the best of our knowledge.

Results reflected several significant findings. PTSD, depression, and psychotic features of a paranoid ideation were among the alarming findings. It was also clear that certain contradictions still stand concerning what people think and how they perceive issues related to mental health and their real practice, acceptance and public awareness.

Special Introduction to the Treatment and Rehabilitation Centre for Victims of Torture

The Treatment and Rehabilitation Center for Victims of Torture (TRC) is a Palestinian non-governmental, nonprofit organization active in the area of mental health provision and in defending human rights. TRC's developmental mandate is to arrive at a Palestinian society well established, health-oriented and free of torture and organized violence. For the realization of these objectives, TRC strives to increase community awareness of primary mental health issues and human rights, and to disseminate knowledge on the topics of mental health, torture and organized

violence, such as suffering of ex-detainees, wounded individuals, families of martyrs/bereaved families, victims of the Separation Wall and the occupation's road blocks, victims of the violence implemented by settlers, and others. In addition, TRC offers victims of torture and organized violence and their families in Palestinian society a complementary set of psychosocial and rehabilitation services. Those who benefit from the service programs can take advantage of a wide range of treatments, rehabilitation, capacity-building, awareness-raising, and voluntary medical visits to the homes of individuals who are unable to reach TRC's several branches. Free medical services, medication and other needs, as well as vocational trainings, are provided to the beneficiaries to enable them to acquire skills that qualify them for the labour market, and to start their own income-generating projects.

The idea of having a rehabilitation centre for victims of torture and organized violence came to light in January of 1997 when TRC was founded. Mental health services provided to the Palestinian clinical population in general and for Palestinian victims of torture in particular are very poor and on many occasions even trigger aspects of their original trauma. The public health system in Palestine is underdeveloped and lacks essential aspects in the promotion of appropriate measures. Public mental health centres are even in a harder situation in terms of qualified staff members and quality of services. The accumulated experience in addressing the issues and needs of victims of torture and their families for the creation of a specialized professional centre paved the way to assist primary victims and their families (often considered as secondary victims or victims who suffer in silence) who shared the sufferings caused by experiencing traumatic events during the detention period. TRC is the only centre of its kind in the West Bank, in terms of its multi-functions and comprehensive services. TRC has branches in Jenin, Nablus, and Hebron in addition to its primary headquarters in Ramallah. A voluntary Board of Directors composed of independent Palestinian professionals and public figures is responsible for provision of oversight and decision-making with regard to TRC's policies, programs, and functions, as well as its personnel.

Introduction/ Study Background

At a time when most communities seek to develop and achieve a level of excellence in all types of service provision, mental health services remain subject to public rejection, sometimes due to ignorance or misunderstandings. Lack of awareness has rendered one segment of the community unable to perceive the state of abnormality that they experience and the importance of psychological assistance in overcoming it.

All societies in general and Arab and Palestinian societies in particular still suffer from the cultural heritage of social stigma attached to psychiatric disorders and mental health services. This has consequently led to hesitation or refraining from seeking treatment despite the multiple sources of stress complicated by an ongoing trauma.

Therefore, this study aims to determine the psychosocial disturbances which cause suffering among members of the community, and presents know-how of the tendencies, cultures and attitudes of people toward dealing with mental disorders and entailing problems. Further, the study aims to shed light on this devastating phenomenon and means of treatment for the advancement of a healthy society. Similar to other culturally-oriented societies, Palestinian society has its own peculiarity. However, decades of living under occupation has resulted in a society that is suffering from accumulated trauma. This has led to the creation of new ways of thinking and types of lifestyles to correspond to the ongoing pressure and feeling of insecurity, instability and inability to prosper in the future.

Social stigma of mental illness is a common problem faced by all societies, even in industrial ones like the United States of America and Europe. In many cases, stigma may result in a lack of understanding of the psychiatric disorder itself, which could result in deterioration of marital relationships or irrational fear of mental illness (Sherbini, 2009). Several irrational beliefs and sometimes superstitions were found to be linked to people's perception of psychiatric disorders. For example, some people reflected their fear of becoming mentally ill at the mere interaction with a mentally ill person. They even thought that mental illness might be contagious (Sehwal et al., 2004). Stigma decreases in society when psychiatric disorders are manifested in physical symptoms and increases when it is attributed to social crises or factors of a spiritual nature, such as possession by "demons," lack of faith, social suffering and weakness of will. In some societies, this attitude leads to the rejection of patients by their own communities and increases the possibility of exposing them to ill-treatment and abuse of several methods, such as beating or restraining them to remove the "demons or evil spirits" (Sherbini, 2001).

In a comparative study on people's perceptions and the need for mental services, Middle East university graduates in four Arab countries (Kuwait, Egypt, Palestine, and Palestinians of the 1948 region) were studied. The study addressed cultural beliefs about mental health and explored gender differences in terms of faith. (Al Krenawi et al., 2009). The study was conducted on 716 graduates, 61% female and 39% male.

This study revealed cultural differences related to ideals held in the four communities studied on parallel; 95% of Kuwaitis, which was more than the others, tend to believe that mental health is related to religious doctrines or as a punishment from God, while 87% of Palestinians, 83% of Egyptians and 67% of Palestinians in the 1948 area turn to prayer. Aboriginal Palestinians, or the so-called the Israeli Arabs in Israel, believe in the importance of mental health, more than Palestinians of the occupied Palestinian territories (Al Krenawi et al., 2009).

In terms of gender, some differences were also noticed; 57% of women indicated that they tend to pray and use various religious healing rituals for recovery in comparison to 43% of men who do the same. The study also showed that the more education they had and the greater circle of social relations, the greater the recognition of the need for psychiatric treatment.

Numerous studies have confirmed the high rate of psychiatric disorders that exist worldwide, particularly in areas of conflict and war, as evident in Palestine. A study to assess the state of mental health in the West Bank (Sehwail & Rasras, 2004) showed that 21.4% of Palestinians suffered from post-traumatic stress disorder (PTSD), while 38.1% endured some of its symptoms. Another study on the psychological effects of torture demonstrated that 31% of Palestinian ex-detainees in Israeli jails had experienced PTSD, whereas 38.1% of those arrested after September 1999 had experienced it. It was also found that 42.5% of children and 50% of female prisoners are affected by the same disorder (Sehwail et al., 2007). Finally, other limited scale studies showed that 11% of Palestinians suffer from severe depression as compared to 15% who experience moderate to severe depression.

To overview the Palestinian social context, it is essential to note that the ongoing political conflict is profoundly complicated and unpredictable; as this current traumatic pain in the life of Palestinians is huge and demands crises intervention, psychotherapy and trauma containment have become inevitable. The Palestinian people, in general, are collectively traumatized and are being subjected to systematic torture and organized violence which should make a difference in bereaved families' reactions to their loss; there is a collective consciousness of their ongoing pain. The Palestinian people in general are gradually losing their sense of security and faith in the peace process, due to a lack of political progress. In the end, these traumatic events occur in an atmosphere of peace expectations, although not as promising as it used to be, which eventually creates a higher degree of frustration and disappointment as it is simply unpredictable.

We have assessed a group of 37 bereaved family members on a period length of 3 weeks to 2 months since their losses. They were re-assessed at about 6 months since the initial loss and after another 6 months as well (across one year). The main aim of the study was to understand the prevalence of the dysfunctional grief among the affected families and the main factors responsible for their grief. We realized that the sense of powerlessness, hopelessness and deep-seated feelings of oppression were among the most crucial factors leading to complicated grief reactions (Rasras et al., 2004).

Hypotheses/Objectives

The psychiatric patient is usually blamed for his general weakness and/or for his weak religious faith, as mental illness is generally attributed to a state of going out of proportion and misfortune resulting from envy (the "evil eye"), in addition to other superstitious explanations. However, psychiatric disorders are obviously not a result of the psychiatric patient's own choice, but are disorders whose biological and social dimensions have an impact on their developmental tasks and milestones. They are widespread in the human community, so the recognition of their existence is correlated to culture, social environment and inter-personal relationships, economic status and emotional maturity. In addition, multiple scientific theories ascribe them to genetic and hormonal imbalance. In addition to that, further studies refer to organic changes in the brain and some brain parts' volumes due to deep-seated, long term and/or recurrent traumatisation (Vander Kolk, 1988, 1994).

The objectives of this study are to assess the magnitude of psychological effects resulting from the traumatic events Palestinians experience on an ongoing basis, attitudes towards available services, the impact of social stigma, the support provided to psychiatric patients, the level of awareness of coping with psychiatric disorders and the need for mental health services. These factors and others are better scrutinized and accomplished by surveying the most predominant psychiatric disorders in Palestinian society.

Our major hypothesis states that society's negative view of psychological disturbance and psychiatric patients (mental health issues) affects demands by people to receive mental health services. This is composed of a number of sub-hypotheses: that psychological disturbances/ psychiatric disorders exist widely in the Palestinian society, however, people are not fully aware of their existence; that a negative view is held of mental health services; and that there is a statistically significant relationship between a number of factors and several issues addressed in mental health. These relationships include

variables of gender, age, employment, education, severity of PTSD and degree of depression, existence of psychological disturbance and seeking therapy, belief in the causes of psychological disturbance and the orientation to receive mental health services, and finally to know whether statistically significant relationships exist between confidence in the treatment of psychiatric patients and the demand for such services.

Materials/Methods

The study was conducted on a random sample of 600 adults over 18 years of age, living in 60 diverse residential communities of the West Bank. It was drawn according to stratified multi-stage cluster sample selection criteria, where the West Bank was divided into districts and each one was given a percentage representing its proportion from the total population. Then, 10 houses were randomly selected in each community and an adult of each house was interviewed, requesting the respondent's position either by acceptance or rejection of statements.

An attached letter to the survey included an introduction of research objectives, assuring full confidentiality of participants and offering TRC's services of crisis intervention, if needed, due to potential emotions stimulated by research procedures, to ensure the participants' well-being.

Measurement Tools

The measurement tool was prepared carefully by the research team and a questionnaire was divided as follows:

- Part I. A set of questions in a well composed questionnaire measuring demographic information of the sample, such as age, gender, education, and marital status.
- Part II. A measure of people's attitudes, impressions and values pertaining dealing with mental health issues.
- Part III. Detection of PTSD, largely based on the Diagnostic and Statistical Manual IV TR criteria (American Psychiatric Association, 2000). Adoption of the scale of the Beck Depression Inventory 1979 to detect depression and its severity. Detection of indicators of nine psychological disorders based on the SCL90.

Results

The study showed that the majority (85%) of respondents (study sample) believed that psychological problems/psychiatric disorders are a phenomenon that exists in Palestinian society, while 92% considered that anyone is at risk of suffering from psychological problems or illnesses during one's lifespan. In addition, 17% of respondents admitted suffering from psychological problems or illnesses (19% males and 16% females). However, only 35% of them sought a professional, whether a psychiatrist, psychologist, or mental health institution, for treatment or assistance, and 23% indicated that one of their relatives had suffered from psychological problems as well.

The questionnaire proposed a range of causes for psychological disturbance, and respondents were requested to express their views on each stated cause. Results were organized, ranging from the most important to the least important, as perceived by respondents:

- 83% due to the shocking and mass violent practices of the Israeli occupation against them
- 76% due to living under psychosocial stresses related to life burden
- 64% believed that committing sins caused God's punishment by making them psychologically disturbed or mentally ill
- 44% attributed that to living with a psychiatric patient
- 42% due to hereditary/genetic factors
- 32% to being possessed by "evil spirits"

Findings showed negative feelings towards mental illness and individuals suffering from psychological problems, as detailed:

- 79% felt upset and saddened when thinking of people who have psychological problems or psychiatric disorders living in their neighbourhoods.
- 79% felt sad and afraid of suffering from psychological problems in the light of the surrounding stressful life burden.
- 44% (both genders) disagreed to marry a spouse who suffers from psychological problems or psychiatric disorders.
- 32% felt embarrassed because they had a mentally ill relative.
- 28% felt embarrassed to talk to mentally ill persons.
- 19% believed that mentally ill patients are dangerous and must be removed from society (taken to a remote area).

The study showed that respondents positively assess mental health centres and their staff, an outcome which contradicts society's negative public views of psychological disturbance and the mentally ill. Although members of the community acknowledge, and their conviction is, that mental health centres and psychologists/psychiatrists have a high capacity to address mental illness, only a small percentage of people with mental illness really seek professional assistance/help, in terms of psychiatric services, psychotherapy or counselling. In addition, although the majority of respondents demonstrated willingness to go to mental health centres, it appears that when persons suffer from mental disorders, they are hindered by the community's negative perception to really do so.

Some findings indicate the following:

- A strong majority (89%) said mental health centres ought to receive more financial support.
- Although 75% said they would not hesitate to go to mental health centres if they need such services, and 80% said they would advise acquaintances to do so if they suffer from mental illness, only 35% out of the 17% of those who declared having suffered from mental illness went to psychiatrists or mental health centres.
- Three-fourths (73%) believed it would be better to deal with psychiatric patients in specialized and separated mental health centres and to have them return to their homes afterwards (once they were relieved or recovered).
- Half (51%) felt it was necessary to have mental health services in residential areas, but 50% believed such centres should be far from residential areas and in a quiet remote area.

Results showed that community members believe that the best recovery from psychiatric disorders can be attained as follows:

- 93% believed mentally ill persons can be treated if taken to a psychotherapist/psychiatrist and/or to a mental health centre.
- 92% agreed that religious commitment/rituals help prevent the onset of mental illness, and 87% agreed that family support has a similar effect.
- 90% affirmed that reading the Holy Koran can cure mental illness and bring about healing and recovery.
- 64% believed mentally ill patients can be better cured/treated by taking them to holy places.
- 49% asserted that marriage can help mentally ill patients or help ease their suffering.
- 17% believed the mentally ill can be treated by going to soothsayers or traditional healers.
- 11% believe that mental illness/psychiatric disorders are irreversible and incurable.

Of the study sample, 22% suffered from PTSD, while 19% suffered from acute stress disorder as their symptoms diminished within the first few days to four weeks. The former were sub-classified as follows: 8% manifested acute type (symptoms continue for a period of no longer than 3 months), 10% chronic type (symptoms continued over a period of more than 3-6 months) and 4% delayed type (symptoms onset did not appear clearly before 6 months).

The study showed significant difference between males and females in the severity of PTSD, where the average for females in the sample (46%) was higher than that for males (36%). A significant difference between the employed and unemployed was also noticed, where the unemployed individuals (47% of the study sample) had a higher degree of suffering from the disorder than those who were employed (34%). There was a significant relationship between ages (the greater the age, the higher the average of suffering from posttraumatic stress disorder), the monthly income (when the income was lower, suffering from PTSD increased), and level of education (suffering from PTSD increased for persons with less education).

Based on the BDI scoring system, 18% of the sample was found to suffer from moderate to severe depression, while 10% experienced severe depression. Females were found to be more affected by depression than males. Unemployed persons, regardless of gender, were also more affected than those who worked. In addition, severity of symptoms was directly proportional to age, low income and level of education; the higher the age, the lower the income and level of education, the more profound the depressive symptoms. SCL90 (the symptom checklist 90) revealed that 12% of the sample suffered from psychotic features, mainly of a paranoid ideation, as compared to 10% who suffered from or demonstrated hostility and psychosomatic symptoms.

These findings reflect the public's confusion and lack of proper awareness, which in turn causes discrimination against psychiatric patients and disrespect for their rights, aggravating the magnitude of psychological problems and impeding recovery. Findings show that females were found to be more affected by PTSD and other subscales than males. In addition, age, low income and low level of education were directly proportional to the severity of illness.

The dictates of our culture do not encourage people to talk about their pain, especially among men where it is even much less permissive. Emotional release or catharsis are not very much welcomed in Eastern cultures. This cultural message is well learned by people and they often try to behave accordingly; this has probably participated in the promotion of complicated grief.

The ongoing occupation by Israel continues to inflict multi-facets of violence upon the Palestinian society. Unfortunately, as the Palestinian society is continuously exposed to a systematic practice of violence, the use of force became an alternative to dialogue and to more peaceful solutions. We observed that not only has the phenomenon of violence increased each year, but that it is slowly changing from a phenomenon to a social culture as well. Thereby violence extends to new sectors of society, as for example school violence, domestic violence, verbal assaults, and political motivated violence. The continuing traumatic stress in the life of the Palestinians is maintaining a state of insecurity and catastrophic expectation as well as a sense of unpredictability and severe oppression.

Discussion/Conclusions

The Palestinian community in the West Bank is composed of a heterogeneous structure; those who have ever been there and those who happen to be there as a large community emerging right after the Nakba (the Palestinian ordeal in 1948), the so-called "Palestinian refugees." In the light of that four health systems exist:

1. The public sector services are very poor equipped and very poorly staffed.
2. The services provided to refugees administered by the United Nations Relief and Works Agency for Palestine Refugees in the Near East (UNRWA) is also as poor as the former one, or can be evaluated on a comparative level at least.
3. The private sector is expensive for those who cannot afford. In addition to that well trained psychiatrists are very few indeed.
4. The non-governmental sector, which generally provides better and integrated services but of course cannot meet the huge demand in the society.

Statistical findings concerning symptoms and/or clinical diagnosis were often higher in intensity (severity) than comparable data in Western countries. In addition to physical/environmental and natural disasters, major life changes (good and bad), hassles/day-to-day aggravations, and personality-related factors, the Palestinian community has other crucial factors that contribute and lead to the suffocating, stress-generating atmosphere. Living under occupation which takes your life out of your personal control and makes you unable to plan, as almost everything is unpredictable and sometimes goes out of proportion, can never be perceived as a neutral stress, but rather a continuing traumatic stress that contaminates one's perception of oneself, the surrounding world and the future.

In addition to that, the social context is rich with trans-generational traumatisations related to the collective traumas that the Palestinians have passed through in the last decades. More than 7 million Palestinians are scattered all over the world as refugees or asylum seekers.

The socio-economic circumstances are not any better. More than one third of the community is redundant (jobless) and far below the poverty line. More than one fourth of the Palestinian community were jailed at least once in Israeli custody; most claim having been exposed to physical or psychological torture. The suffering of survivors of torture is rather complex and inter-related, entailing all aspects of the person's life, his family and the community at large. Such close to regular practices can cause sometimes irreversible damage to the victim's personality and belief system, his family and his community. These effects go far beyond the immediate space, to the remote horizons of the individual and his surroundings. He will no longer perceive his surrounding environment as safe and balanced to thrive fully and become self-actualized on a certain stage. The statistics are brought around to help understand the intra-socio-economic context of the Palestinian community.

Mental health illness and services in Palestinian society remain subject to public rejection or misunderstanding. Lack of proper awareness affects negatively seeking and receiving psychiatric interventions required to mitigate and hopefully overcome the mental disturbances and psychological illnesses. Moreover, a contradiction exists between the positive assessment of mental health centres and practitioners and the community's negative perception of mental health interrelated issues. This is evident in the small percentage of psychiatric patients who approach these services. Social stigmas and negative stereotyping have a profoundly deterring factor, causing only small portions of the mentally ill to demand appropriate treatment.

Mental illness is often perceived as a source of anxiety by Palestinian culture; subsequently, patients are socially rejected, leading them and their families to demand quick and magical remedies for resolving the problems at hand. Patients do not seek treatment when symptoms first appear, fearing society's negative perceptions. With 32% believing that psychiatric disorders are caused by "evil spirits and demons," patients prefer the help of the wise. Consequently, treatment is delayed until symptoms worsen and increase. Moreover, they seek in parallel psychotherapists and religious figures and practices.

Our findings reveal that a majority of respondents attribute the cause of psychological crises and pressures within the Palestinian community to the Israeli occupation; however, less than 6% of the random sample take actual steps to receive professional services. This attribution is grounded with reality testing, since the scale of suffering due to political trauma is enormous. More than 41% of Palestinian males have been in detention at least once, during which many were tortured, and nearly 25% of respondents were subjected to injury leading to trauma. These statistics are no more than hints related to the current situation while in fact the entire community is targeted with a mass traumatisations. Uprooting the olive tree is an example of targeting symbolic values and sources of living of the whole community.

Alarming figures of suffering from mental illness show a much higher percentage of Palestinians than the general worldwide rate, since 41% persons are affected by PTSD, whereas depression (ranging from moderate to severe) constitutes 28%, and psychosomatic complaints amount to 10%. Negative attitudes towards receiving psychiatric/psychological treatment are compromised, depending on the seriousness of the illness; for example 69% of those who experienced severe depression, and 24% of those who had mild depression, approached such services.

Negative attitudes decrease with age, i.e. the younger people are the less likely to reject these services. Also, the type of illness plays a role; patients with psychotic disorders are more prevalent towards receiving services because their illness is apparent to others and cannot be denied or hidden. Their family members had to bring them to such services.

These indicators illustrate the effect of social stigmas and negative stereotyping since those who should receive the service far outnumber those who actually make use of it. The issue of shame and social attitudes towards mentally illness and psychiatric patients is very obvious; 79% of respondents feel frustrated when thinking of people with mental illness, while a third feel embarrassed for having a relative with mental illness, or for conversing with a psychiatric patient. Additionally, nearly half of those asked (both genders) would not get engaged or married to a person who has a history of mental illness.

In many cases, mental illness is expressed through physical complaints such as headaches, stomach aches or pain in joints and limbs which can be on many occasions indicative of psychosomatic disorders. Furthermore, general physicians lack the knowledge and experience required to recognize these symptoms and establish their origin before they escalate. Therefore mental disorders are hardly identified if identified at all in primary health centres.

In view of the above, it is imperative to raise community awareness of the real cause(s), true nature, and medical and/or psychological treatments of psychiatric disorders. Despite access to knowledge and current scientific progress, a number of factors collectively continue to delay necessary solutions to these problems: lack of a rational and realistic approach

to mental illness, false cross-generational transmitted beliefs, unsatisfactory available services, lack of highly qualified professionals, and very high demands due to the particular objective traumatic reality of living constantly under the brutality of Israeli occupation. Effective public education campaigns to transform communities' negative perceptions, increase significantly the number and quality of psychiatric clinics/psychological centres, and provide local and affordable services are some of the remedies to this harsh reality, rather than leaving psychiatric patients untreated, thus aggravating their status to advanced stages.

However, awareness campaigns should take the following points into consideration:

- To develop quality services rather than being satisfied with quantitative services. In other words such services should aim at establishing real community mental health that encompasses appropriate services.
- To head for audiovisual and print media to produce programs promoting comprehensive public awareness of mental health.
- To develop therapeutic models of a multidisciplinary nature that include psychiatrists, psychologists and social workers among other specialists who contribute to the qualitative integration of the provided services.
- To conduct comprehensive periodic studies to survey the mental health scene and monitor its positive and negative orientation, for the purpose of monitoring the social phenomena that may cause harm to mental health.
- To provide focussed capacity building programs for the staff of mental health institutions and centres in order to persuade people of the efficiency of the provided services so that they prefer them over non-scientific methods of therapy and adjustment.
- To rehabilitate psychiatric patients to become efficient members of society, able to contribute to the cycle of economic development, as a means of alleviating the burden weighing down on the state, the family and the psychiatric patient.

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Public Health Genomics: Closing the Gap between Gene Discovery and Global Health

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In this presentation, I discuss both the promise and the challenges of advances in human genomics in medicine and public health. With the completion of the human genome project and advances in genomics and related fields, a new era of genomic and personalized medicine is on the horizon. The promise of genomics is enhanced primary, secondary and tertiary prevention based on genomic information. To achieve this promise, the new discipline of “public health genomics” seeks to evaluate the use of emerging genomic information effectively and responsibly to improve population health. A translational research agenda is needed to fulfill the promise of genomic applications. I will give examples, with a focus on common chronic diseases, of emerging genomic tests and the use of family health history as tools to improve health and prevent disease in the United States and globally.

Care Coordination: A Key Role in Health Care

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The new millennium has provided the health care field with major challenges. The population has become older and sicker, with more people suffering from chronic illnesses than ever before. New medical technologies and scientific advancements in curing disease and in prolonging life have contributed to this shift. More emphasis in health care has been placed as a result on care and in particular on the palliative aspects of it. Shorter hospital stays and the provision of care in the home setting have become more the norm than the exception. As a result the coordination and management of care continues to receive major emphasis.

These developments are apt to create new positions in health care, develop new roles, and extend and change existing boundaries. Advanced Nurse Practitioners will be responsible for adjusting the boundaries for the development of future nursing practice. The provision of care by specialized, highly skilled nurses will not only ensure that quality care is provided in the hospital but also in nontraditional care settings such as the community, the home, outpatient clinics, and specially developed care centers. Trans-mural care provided by nurses will ensure the continuity and coordination of care between the hospital and the home.

During this lecture the importance and effectiveness of care coordination will be highlighted. Emphasis will be placed on providing evidence on the effectiveness of new expanded roles, on extending the boundaries of nurse professionals, and on establishing multidisciplinary partnerships in the care process.

Driving Quality and Healthcare Equity: Henry Ford Health System's Healthcare Equity Campaign

Kimberlydawn Wisdom

Henry Ford Health System

Background. Henry Ford Health System (HFHS) is a non-profit health care organization in the metro-Detroit region consisting of 5 hospitals, 25 medical centers, and over 23,000 employees. HFHS is in the process of completing a 3-year Healthcare Equity Campaign aimed at ensuring that healthcare equity is understood and practiced by all Henry Ford employees and at linking healthcare equity as a key, measurable aspect of clinical quality. The CEO of the health system serves as honorary chair with system vice presidents for Quality and Community Health serving as co-chairs. The first phase, launched in 2009, focused on raising awareness among employees about racial and ethnic disparities in health and health care; the second phase focused on promoting culturally competent communication and care; and the third and final phase is focusing on integrating changes into system policies and processes so they are sustainable over time.

Methods. In order to raise awareness about disparities among health system employees, a number of activities were implemented. A CME/CEU workshop and accompanying toolkit were developed to cultivate “ambassadors” to then spread awareness among their colleagues. The documentary, *Unnatural Causes*, was shown in “Brown Bag” lunch sessions, at departmental meetings, and at system events. An internal communications team developed and rolled out a comprehensive communications plan. Finally, an online awareness-raising course was developed for employees titled, “Healthcare Equity 101: Social Determinants of Health.” To promote culturally competent communication and care, two more workshops were created targeting clinicians and non-clinicians. Also various speakers were invited to HFHS to speak to this topic, and efforts to improve language access services and organizational health literacy are under way. Finally, opportunities to integrate changes into policies and processes are being identified and implemented.

Results. Over the past three years, 227 employees attended the awareness-raising CME/CEU workshop. The communications team developed over 20 pieces of information from articles to vodcast and toolkits. A total of 1,278 employees took the online course and 223 employees participated in a course related to cultural competence. Changes that have been integrated into policies and processes have included the collection of race, ethnicity, and primary language data from patients at the point of registration; adding education on healthcare equity into all Leadership Academy programs for current and future organization leaders; creating an “Equity Award” for submissions to the system’s annual Quality Expo; including a question related to equity in the regular Employee Engagement survey; and creating an equity page in the system’s annual quality report, among other changes.

Conclusions. The Healthcare Equity Campaign has accomplished a great deal in just three short years. Most of all, however, this process allowed the organization to grow capacity for this work, create a structure, develop tools, improve leadership awareness, and identify existing gaps in organizational cultural competence and equity. In other words, it has pointed us in the direction of where to go from here. We will continue toward this goal, transforming lives and communities through health and wellness...one person at a time!

Factors Contributing to Disparities in Disease Outcome

Adnan Munkarah

Henry Ford Health System

Over the past decade, studies have revealed that the race and gender of a patient have a significant impact on the treatment that a patient receives and his/her overall outcome. Many factors seem to come into play and contribute to those differences. Socioeconomic status, societal support and financial challenges are definite contributors to the disparities. Patients and their families may decide to forgo or delay care because of low income, lack of insurance or limited family support and means. As a result, their disease is diagnosed in more advanced stages and their life span is shortened.

Disparities in outcomes are not only due to restricted access to medical care. Other factors seem to play equally important roles. Cultural norms and expectations have not been well studied in health care in the past. Yet, they frequently impact how patients and their families perceive disease and accept treatment plans. In a society that is ethnically diverse, it is important that healthcare systems be aware of the diverse composition of the community they serve. Everyone involved in patient care has a role to play and should be educated on how to deal with patients' diversity, how to create a comfortable environment, and how to build trust. HFHS launched an initiative three years ago to address this issue.

Biological differences may also contribute to the disparities seen in disease and treatment outcomes. Many examples emphasize this point. The prevalence of diabetes, cardiovascular disease and cancer differ around the world as well as among different ethnic groups within the same country. There is a differential response to similar treatments among races and between genders. In view of expected genetic variability, it is important to consider race and gender when planning research protocols and clinical trials. Advances in molecular and genetic technologies will help elucidate some of these differences.

The old theory of "one treatment fits all" is being replaced by a new approach of personalized medicine. Understanding ethnic and gender differences in disease is an important component of this personalization in treatment. Furthermore, improving equity in health care is essential to enhance the health status of our population.

Life Expectancy, All-Cause, and Cause-specific Mortality Among Arab Americans: Evidence from the Study on Arab-American Mortality

Abdulrahman M. El-Sayed

Features of the social experience of Arab Americans (AAs) differ from those of the majority population. These include experiences of immigration, discrimination, and acculturation, each shown to influence mortality risk. Therefore, there may be differences in the mortality of AAs compared to whites. We explored life expectancy and age-adjusted mortality risk relative to whites among AAs in Michigan, the state with the largest per capita population of AAs in the US. Data were collected about all deaths to AAs and whites in Michigan between 1990 and 2007, and year 2000 census data were collected for population denominators. We calculated life expectancy, age-adjusted all-cause, cause-specific and age-specific mortality rates stratified by ethnicity and gender among AAs and whites. Among AAs, life expectancies among men and women were 2.0 and 1.4 years lower than among white men and women, respectively. AA men had higher mortality than white men due to infectious diseases, cancer, diabetes, cardiac disease, cerebrovascular disease, and homicide. AA women had higher mortality than white women due to cancer, diabetes, cardiac disease, and cerebrovascular disease. Both AA men and women had lower mortality than white men and women due to chronic respiratory disease. Despite better education and higher income than whites, AAs have higher age-adjusted mortality risk than whites, particularly due to chronic diseases. Features specific to AA culture may explain some of these findings. Particular attention to chronic disease prevention among AAs may be warranted.

Place Matters: The Social Determinants for Infant Mortality

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More babies die before their first birthdays in Wayne County and the city of Detroit than in many parts of the United States and the world. Sadly, the infant mortality rate in this region has been extremely high for several decades. This is unacceptable. It inflicts tragedy on families and costs billions of dollars in medical care. In addition, the infant mortality rate—the number of babies per 1,000 live births who die within the first year of life—is an important indicator of a community's health. In addition to overall high infant mortality rates, racial disparities also exist. Black babies in Wayne County and Detroit are more than twice as likely to die before their first birthdays as white babies.

In Wayne County (excluding Detroit), the infant mortality rate is 11.9 deaths per 1,000 live births for black babies (the same as some Third World countries) and 5.9 deaths per 1,000 births for white babies (2008), according to the Michigan Department of Community Health. The rates in Detroit are even higher: 13.4 deaths per 1,000 births for black babies and 5.4 deaths per 1,000 births for white babies for the same year.

Addressing the social determinants of health which are the conditions in which people are born, grow, live, work and age is important to understand how these factors contribute to infant mortality rates. These circumstances are shaped by the distribution of money, power and resources at global, national and local levels, which are themselves influenced by policy choices. The social determinants of health are mostly responsible for health inequities—the unfair and avoidable differences in health status seen within and between countries.

These factors include where a girl or woman lives and goes to school, what she eats, how she's perceived and treated, whether she has a good job with equal pay, the quality of her relationships, and the extent to which she's affected by racism.

An “upstream” strategy is a radical departure from the traditional, “downstream” methods that have been tried for decades but have had limited and sporadic results. Traditional, downstream interventions may be too little, too late.

The Diabetes Forum

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Introduction. Type 2 diabetes mellitus is an emerging clinical and public health problem in Arab Americans. We have shown that the prevalence of diabetes—impaired fasting glucose (IFG) and/or impaired glucose tolerance (IGT)—are 18% and 23% in Arab Americans 20-75 years of age [1]. Clinical trials have demonstrated that diabetes can be delayed or prevented with lifestyle intervention in individuals with IGT and/or IFG. However, the translation of lifestyle interventions for the prevention of diabetes into clinical and public health practice in diverse communities is a challenge. Lifestyle modification entails substantial resources and an active use of behavioral principles and cultural elements.

Objectives. We conducted a study to examine the effectiveness of a community-based, culturally-specific, family-oriented, group lifestyle intervention in the Arab-American community [2]. A series of focus groups was conducted to explore cultural norms and barriers and promoters to participation in diabetes prevention activities. A committee of health care professionals and community members was charged with modification and cultural adaptation of the Diabetes Prevention Program (DPP) core curriculum. Emphasis was placed on healthy lifestyle choices with simple dietary modification of ethnic foods and preparation techniques. The lifestyle intervention was designed to achieve the following two goals: a $\geq 7\%$ loss in body weight and ≥ 150 minutes of physical activity. The adapted DPP core curriculum was delivered in weekly group sessions over a 12-week period. Follow-up was performed at week 24. An intent-to-treat analysis was utilized.

Results. A total of 71 individuals aged 47 ± 10 years was enrolled in the lifestyle intervention. By week 24, 44% of the participants had achieved at least a 7% reduction in body weight and 78% reached the physical activity goal of ≥ 150 -minutes/week. Body weight, body mass index, waist and hip circumferences were all significantly reduced from baseline. Marked reductions in daily energy and fat intakes were also noted. Using a two-sided Fisher Exact test, family support at the core curriculum sessions was significantly associated with achievement of the weight loss goal.

Conclusions. This trial demonstrates that a culturally specific group lifestyle intervention implemented in a community setting is feasible and may be effective in preventing diabetes in Arab Americans.

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An Overview of the Diabetes Epidemic in the Arab World

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As in many countries worldwide, there is an alarming rise in the incidence and prevalence of Type 2 diabetes in the majority of Arab countries. The following table summarizes the results of recent epidemiological studies on the prevalence of Type 2 diabetes in some of the Arab countries.

Prevalence of Type 2 Diabetes in Arab Countries

Country	% Prevalence	Age Group (in Years)	Author	Year
Qatar	16.7%	> 20	Zirii M	2007
Bahrain	26.4%	> 20	Zurba F	1996
Saudi Arabia	24.0%	> 30	Nozha	2004
Egypt	9.3%	> 20	Herman	1995
Jordan	17.1%	> 25	Ajlouni	2008
Lebanon	13.1%	> 30	Salti	1997
Oman	16.1%	30-64	Alwati	2000
Kuwait	14.8%	20-50	Abdallah	1999
Palestinian	12.1%	30-65	Abdul-Rahim	2001
Syria	16.9%	Not Available	Al-Bache	2006
Libya	14.0%	> 20	Kadiki	2001
UAE	25.0%	> 30	Malik	2006

According to the WHO and IDF, the above prevalence figures represent a substantial 2-3 fold increase in comparison to what existed 2-3 decades ago in some of these countries.

The risk factors for the rising prevalence of Type 2 diabetes appear to be multi-factorial. Most important are the following factors:

1. *Obesity secondary to a changing life style* (decreased physical exercise, increased intake of calorie-dense food). That is why the high prevalence figures tend to be highest in urban communities compared to rural or desert communities. In most of the epidemiological studies, there was a strong correlation between the prevalence of obesity and that of Type 2 diabetes.
2. *Impact of increasing life-span* with the well-known increasing prevalence of diabetes with advancing age. However, it should be noted that in contrast to the developed countries, the highest prevalence of diabetes is in the age group 45-64 years which are the productive years.
3. Although Type 2 diabetes is most probably polygenic and although specific genetic abnormalities are yet to be identified, the impact of consanguinity, which is high in the Arab countries, remains a potential risk factor.

An important concern on the diabetes and obesity epidemics is their known co-existing serious health problems, especially hypertension and dyslipidemia and their expected combined impact on cardiovascular and cerebro-vascular morbidity and mortality. Moreover, diabetes is becoming world-wide the leading cause of end-stage renal disease, adult onset blindness and non-traumatic leg amputations.

Thus it should be anticipated that these twin epidemics will pose a big burden and increasing cost on health care systems in the Arab countries. This concern should enhance efforts for early diagnosis and prevention. These efforts should focus on the following measures:

1. Highly focused campaigns to increase public awareness about the disease and how to prevent it.
2. Improved health care facilities to optimize early detection and effective long term treatment. This can best be achieved by teamwork involving not only physicians (both primary care and specialists) but also nutritionists, diabetes-nurse educators and social workers. It also involves the public sector as well as the private sector.
3. As in all chronic diseases, the key to success is to educate and empower patients so that they become strongly involved in optimizing their treatment.

Increase of Prevalence Rate of Diabetes Mellitus and Risk Factors in Arab Countries

N. Albache

Abstract

Epidemiological research involving many different populations over the world has demonstrated significant differences in the prevalence of diabetes mellitus (DM). As in other regions of the world, the 22 Arab countries, with a combined population of nearly 300 million divided mainly between the Mediterranean and Gulf areas, and consisting of mostly Arab-speaking Muslims, has witnessed dramatic changes in both lifestyle and food habits within the last few decades. These changes have been reflected in the significant increase of risk factors: consumption of high calories and high-fat food, sedentary life styles, obesity, and an increase of the prevalence of DM in over age 20 members of the population from 1.83% [3] (prior to 1980) to above 20% in some countries.

Prevalence of Diabetes

The prevalence of diabetes can be considered within two distinct periods, pre and post 1980. Prior to 1980, although there were only a few studies, they indicated that the prevalence of DM was low (1.8 – 3.3% of the population above 20 years of age). After 1980 prevalence rates began to rise as changes occurred in lifestyle commensurate with industrial changes in the region linked to the increased discovery of oil, and changes in dietary habits. In most countries of the Mediterranean basin, the prevalence of DM is around 10%: Syria 10.8% [1-2], Algeria 9.3% [3], Egypt 11.2% [4], and Tunisia 9.9% [5]. In the Gulf countries the prevalence is above 15%: Bahrain 15.4% [6], Qatar 16.7% [7], Saudi Arabia 23.7% [8], and Kuwait 16.4% [9]. This high prevalence of diabetes in Arab countries results in five of the top 10 countries with the highest prevalence rates for diabetes in the world [10] (United Arab Emirates, Saudi Arabia, Bahrain, Kuwait, and Oman). Thus, diabetes is a true epidemic and one of the most challenging health issues in this part of the world.

For Type 1 DM the incidence in the Arab countries is also variable. It is less than 10 per 100,000 in most countries [11] and only in a few countries is it above 15 per 100,000. But, although Type 1 DM constitutes 4-5% of the total diabetic population, there is no registry for Type 1 DM across countries.

Prevalence of IGT

There is a big difference from one country to another; the lowest rate is in Sudan (2.3%) [12] and it is higher in other countries: Bahrain (18.8%) [6] and Syria (23.8) [1].

Risk Factors

There is a real increase in risk factors, such as obesity; the prevalence of overweight and obese peoples reaches in some countries more than 50% of the population above 20 years of age (in Egypt 60% in males and 72.2 in females, in Syria 52.9% in males and 58.8% [2] in females, in Saudi Arabia 64% in males and 70% in females, in Jordan 65.5% in males and 77% in females) [13-14]. One of most important factors for this phenomenon is lifestyle modification: the spread of fast food with high caloric intake, consumption exceeding in most countries 3,000 kcal per day except for some like Yemen where the daily caloric consumption is around 2,000 kcal [15], foods rich in fat calories (87-103 g/day) [15], and clearly different from traditional nutrition. Traditional Mediterranean diets are considered as less diabetogenic than the Western fast foods [16]. Lack of exercise and sedentary life styles are common among Arab populations. Smoking cigarettes and water pipes, particularly among teenagers, is a risk factor. The prevalence of current smoking is 48% and 9% for males and females, and among high school adolescents is 16% and 7% for boys and girls in Syria [17].

How to Fight this Epidemic

In order to counter the epidemic in DM and obesity, we have to (1) to return to our local and healthy nutrition (rich in vegetables and olive oil) and conserve it where it still exists (in the rural areas), and (2) promote sports and diverse modes of physical activities, develop campaigns for quitting smoking, especially among teenagers, establish a national policy for primary prevention of obesity and DM, create appropriate educational programs adapted for local needs, and collect and exchange data, particularly regarding the complications of DM.

Conclusions

Diabetes prevalence has increased in the Arab countries in the last two decades, with big differences between the Mediterranean and Gulf regions. This is probably due to the increase of risk factors: obesity with high fat consumption, sedentary life styles, and smoking.

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Parity and Coronary Heart Disease Risk Factors among Palestinian Women Living in Two Refugee Camps in the West Bank: A Population based Cross-sectional Survey

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Background. Evidence from the USA and Europe suggests that women who have given birth many times have a 50-80% increased risk of developing coronary heart disease. The mechanisms underlying this association are unclear, but plausible biological pathways exist—e.g., changes in adiposity and blood glucose and lipid concentrations that are associated with pregnancy can persist after completion of reproductive years. Previous studies of the association between parity and coronary heart disease have been restricted by inclusion of few women who had given birth more than six times; the high parity of Palestinian women therefore provides an unusual and interesting opportunity for further study of this association, and might help to elucidate underlying mechanisms. We aimed to examine the relation between parity and risk factors for coronary heart disease in a sample of women with high parity.

Methods. We undertook a population-based cross-sectional survey of women in the Amaari and Kalandia refugee camps in the occupied Palestinian territory. On the basis of UN Relief and Works Agency registration records, we selected a random sample of 515 of all 587 women living in the two camps who were aged 40-65 years at the time of the study (March to May, 2001). We sent letters to these women explaining the purpose of the project and inviting them to participate. The 15 women who did not attend a clinical visit to have their blood drawn were excluded. In the remaining 500 participants, we measured lipids and lipoproteins (total, HDL, and LDL cholesterol, triglycerides) and fasting blood glucose concentrations and assessed obesity, diabetes, hypertension, and metabolic syndrome.

Findings. Mean parity that we assessed was 7.3 (SD 3.7, range 0-21). Of the 500 women, 355 (69%) were obese (body-mass index ≥ 30 kg/m²), 432 (84%) had central obesity (waist circumference ≥ 88 cm), and 266 (52%) had abdominal obesity (waist-to-hip ratio ≥ 0.85). Frequency of diabetes was 22% (115 women) and of hypertension was 43% (220 women). After adjustment for age, own education, husband's education, and marital status, regression analyses showed that every additional birth was associated with an increase in body-mass index of 0.30 kg/m² ($p < 0.0001$), a 0.58 cm rise in waist circumference ($p = 0.001$), and an increase of 0.036 mmol/L in triglyceride concentration ($p = 0.033$). Gravidity, but not parity, was significantly associated with fasting blood glucose concentration; after adjustment, each additional pregnancy was associated with an increase of 0.14 mmol/L (95% CI 0.05-0.23, $p = 0.002$). Overall, 289 (58%) women presented with metabolic syndrome, and these participants had significantly higher parity ($p = 0.003$) and gravidity ($p = 0.024$) than did women without metabolic syndrome. Every additional birth was associated with a 7% increase in prevalence of metabolic syndrome ($p = 0.042$). Parity was not significantly associated with systolic and diastolic blood pressure. Total, HDL, and LDL cholesterol were not significantly associated with parity.

Interpretation. In Palestinian women, high parity was significantly associated with obesity, triglyceride concentration, and increased risk of metabolic syndrome. Any of these risk factors, alone or in combination, could result in increased incidence of coronary heart disease.

Note. This original research was part of a completion of a PhD requirement for Najwa Rizkallah. Tom Marshall supervised the work and provided scientific guidance and statistical advice. Donna Kritz-Silverstein reviewed parts of the draft thesis and provided valuable comments throughout the process.

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International Perspectives on Nursing Education: A Panel Presentation for Nurse Educators

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The Arab American Nurses Association is pleased to present this special session on nursing education to dialogue with nurse educators in the Middle East regarding international standards and recent developments in nursing education. Panelists facilitated a discussion of the greatest challenges faced in terms of upgrading the status of and professional regard for nursing in their respective countries. Ideas will be shared and a position statement and action plan will be generated to guide efforts toward the global professionalization of nursing as a discipline. In addition to discussing various aspects of this topic, panel members will be available to respond to questions from the audience.

The Current Status of Nursing Education in Jordan

Recently, the nursing profession in Jordan started to enjoy more public respect and confidence. The last decade witnessed significant landmarks in capacity building in nursing education and service and in the improvement of nurses' image and status. Jordan is taking the lead in our region in recognizing nursing as an independent profession. His Majesty King Abdullah the Second has articulated a clear vision for the right of his people for quality health care services. HM realized that nursing is an integral part of the country's health system development.

Based upon this belief HM issued a decree in 2002 to establish the Jordanian Nursing Council. The aim of this council is to regulate the nursing profession through the development of bylaws and credentialing policies and strategies to protect the health, safety and welfare of the public.

Currently, the nursing profession in Jordan has the power to set national standards and mobilize resources to develop sustained reform and support development of all nursing programs. The development of nursing in Jordan will challenge nurses and leaders to identify both hazards and opportunities that stimulate their imagination and encourage their creativity.

Our goal for the future is a better educated nursing workforce that will be able to absorb rapid changes in medical science and technology. Opportunities for advancement should be given to all nurses through the development of a national clinical ladder by law, Nurse's act by law, and leadership development programs, thus acknowledging each nurse's education, practice and expertise. Technology and new knowledge will change the roles and responsibilities of health care professionals over the next decade, but the public's need for caring continues to be top priority. The caring professional of the future will play a critical role in improving the quality of health in Jordan.

Nurse Licensure in the United States

Meeting the global standards for initial education is the goal for the future of many countries and it is the task of each country to determine the best approach for implementing these standards. Education should be evidence based, progressive, and ensure competent practitioners. Nurse registration has many facets in different Middle Eastern countries depending on the age of the nursing profession in each country. The inspiring story of nurse licensure in the United States and how it relates to nursing education will be discussed. A dialogue regarding implementing a nurse licensure exam and its challenges will be initiated in this panel.

Arab American Cancer Disparities and the Potential for Cancer Prevention

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American Cancer Society

Disparities in cancer studies generally focus on the fact that the health of one population is not as good as that of another. Measures of health are generally cancer incidence rates, survival rates, and mortality rates. There is also concern about disparities in quality of life (emotional well-being, pain control, etc.). These are more difficult to measure objectively.

In the US populations are generally defined by race or ethnicity. The racial and ethnic categories used in the collection of Federal health statistics including federally funded cancer registry data are defined by the US Office of Management and Budget. These categories are often modified and published just prior to every decennial census. OMB is very open in admitting that the categories are sociopolitical and not based in science or anthropology. Current categories are non-Hispanic white, Hispanic, Black or African American, Native American or Alaskan Native, Asian, and Pacific Islander.

Arab Americans and Americans of North African origin are considered white or Caucasian in Federal health statistics. There is a movement to better collect and use sub-category data for Hispanics and Asians. Ironically the Arab American population is larger than the Cuban-American or Chinese American population.

There are other ways of categorizing populations. Area of geographic origin, ethnicity and socioeconomic status are more scientific as they relate to risk of cancer.

- *Area of geographic origin* involves family and shared genetics. Area of geographic origin is not collected in Federal health data and the only ethnic categorization collected by the US government is Hispanic.
- *Ethnicity* relates to culture and habits. The food one eats, how one views obtaining healthcare and the environment one lives in do effect risk of developing cancer, as well as the timing of a cancer diagnosis (early versus late), and the treatment one receives.
- *Socioeconomic status* includes education, income and health insurance status. A number of publications show that socioeconomically deprived populations have health disparities compared to the socioeconomically advantaged.

There is no rigorously collected Arab American cancer registry data, but several surveys have assessed mortality rate by Arab surname in the Detroit Metropolitan area. These surveys indicate that Arab American men and women do have substantial cancer incidence and mortality rates for the common cancers (lung, breast, colon, prostate). Rates are substantial even though they are slightly lower than those of whites and markedly lower than Blacks or African Americans.

The US National Cancer Institute and the Middle Eastern Cancer Consortium have published cancer registry data for Cyprus, Egypt, and Jordan. They found that cancer incidence and mortality rates vary widely between countries. They did note that cancer incidence and mortality rates in these Middle Eastern countries are generally lower than rates of white Americans with a few exceptions. Egyptians had higher incidence rates of non-Hodgkins lymphoma and cancers of the liver and bladder.

Studies of cultural change and daily habits show that many Arab Americans are acculturating. Indeed westernization is leading to increasing numbers of Arab Americans with bad diet high in calories, little physical activity, and increased weight gain. These are pressures increasing risk for a number of cancers. This pattern predicts for a rising Arab

American cancer incidence and mortality rate in the future. The triad of bad diet high in calories, little physical activity, and obesity have become the second leading cause of cancer in the US, surpassed only by tobacco usage. These data justify development of culturally appropriate programs to improve nutrition, increase physical activity and reduce obesity rates.

Surveys of Arab Americans in the Detroit area indicate that up to 40% of Arab American men smoke tobacco. This compares to an already too high smoking rate of 20 to 25 percent for Americans in general. As stated earlier, tobacco use is the leading cause of cancer in the US. These surveys predict a rise in Arab American lung cancer rates in the future and justify culturally appropriate smoking cessation programs in the Arab American community.

The data tell us that the cancer control messages for the Arab American population are the same as the messages for other American populations. Prevention efforts should focus on improving nutrition and physical activity and reducing smoking rates. Appropriate screening for the early detection of breast, colorectal and cervical cancer, combined with adequate treatment, also has the potential of reducing cancer mortality. Culturally appropriate ways of delivering these messages must be developed and implemented quickly to avoid or curtail a rise in incidence and mortality and the creation of disparities.

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Leveraging Resources to Downstage Breast Cancer: Case Studies from Arab Communities

S. Al Madhi

Background

Friends of Cancer Patients (FOCP) is a charitable organization that works under the umbrella of the Supreme Council for Family Affairs in the Emirates of Sharjah providing services across the United Arab Emirates (UAE). FOCP was established in late 1999 under the patronage of Her Highness Sheikh Jawaher Bint Mohammed Al-Qasimi, president of the Supreme Council for Family Affairs, and wife of the Ruler of Sharjah and Federal Supreme Council Member. FOCP objectives are to provide moral, financial, emotional, medical and practical support for those afflicted with cancer and raise awareness around cancer in the community.

Objectives

FOCP in its 10th year anniversary (in 2010) launched the “Kashef” initiative to promote early detection and screening of early detectable cancers. The first initiative of Kashef was the Pink Caravan campaign, which was launched in 2011 and had three main objectives:

1. Raising public awareness around breast cancer in the UAE, concentrating on reaching remote areas where there is no access to services.
2. Raising 15 million Dirham over 3 years through donations and fundraisers to buy a mobile breast cancer unit, complete with the latest equipment.
3. Advocating for a unified UAE cancer registry.

Methods and Results

The Pink Caravan campaign travels throughout the seven Emirates of UAE, accompanied by a 20 rider equestrian team, for 10 days every April. Each year the Pink Caravan travels a different journey and covers approximately 600 km across the desert. The Arabian horses attract wide attention and through the process stimulate conversation around breast cancer in a culturally conservative community. We have 5 medical teams, each consisting of 1 physician, 1 nurse, 1 health educator and 1 administrator accompanying a mobile mammography/ultrasound machine to offer free services to all. They split up between different venues in the same Emirate to reach a maximum audience. We initiated two rides, the first launched in April 2011 and the second in April 2012. To date the campaign has clinically exceeded 15,000 screens since 2011, mostly of indigent populations.

Conclusion

The Pink Caravan initiative is the first of its kind globally and it's a pan-UAE campaign. At the end of the three year campaign the Pink Caravan is hoping to measure how many screens were done, how many were found to be cancer positive and at what stage. This will make FOCP the only organization of its type in the UAE collecting robust data and keeping accurate statistics. There is currently no unified cancer registry in the country and FOCP has undertaken, though our data, to provide the baseline figures and financial aid needed to start this important process with the governmental health authorities.

The core operation of the Pink Caravan campaign is basically screening and fundraising activities. Leveraging resources is a fundamental element for these activities, not only to minimize cost but also to make sure we start where other initiatives finished; this can only be achieved by having an open and transparent agenda plus working to establish strategic partnerships with healthcare sectors and important stakeholders representing different segments in the community.

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www.focp.ae
www.pinkcaravan.ae

Eliminating Breast Cancer Disparities in Vulnerable Populations

LaToya Stewart

Susan G. Komen for the Cure®

Within the United States, breast cancer rates among women vary by race and ethnicity. Race is not considered a factor that might increase a woman's chance of getting breast cancer. However, the rates of developing and dying from the disease differ among ethnic groups. Immigrants in the United States usually have breast cancer rates similar to those in their home country. Over generations, however, the daughters and granddaughters of immigrants take on a risk similar to U.S. women.

This presentation will focus on Komen's commitment to ending breast cancer disparities through community-based grants, research grants, and International partnerships. This presentation is also designed as an instrument to increase awareness of Susan G. Komen for the Cure® and resources available to meet the unique breast cancer needs of underserved populations. The panelist will discuss the following topics: history of Susan G. Komen for the Cure®, breast cancer statistics with an emphasis on racial and ethnic differences, the Breast Cancer Continuum of Care, examples of Komen-funded community based projects and partnerships targeting Arab communities, and national and local resources for breast cancer survivors.

At the conclusion of this presentation the nurse participant will be able to:

1. Discuss the two most common risk factors associated with breast cancer.
2. Identify each phase of the breast cancer continuum of care.
3. Identify at least two educational and financial assistance resources that can be shared with under-insured and low income breast cancer survivors.

Relationships between Pain Characteristics and Acculturation in Arab American Patients with Cancer

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Introduction. Advances in cancer detection and therapy are extending the life expectancy of cancer patients. However, cancer pain continues to be a persistent, disturbing, and often incapacitating cancer symptom. Although cancer pain occurs in all populations, minorities are at greater risk for unrelieved pain. Pain in African American and Hispanic cancer patients has been evaluated, but no published data are available on the cancer pain experience of Arab Americans. Acculturation is an important predictor of many health-related behaviors, including pain experience and management.

Objectives. The purposes of this study are to: (1) describe the cancer pain experience (i.e., pain severity, pain interference with activities) of an outpatient sample of Arab American patients with cancer pain; (2) examine the relationships between two pain characteristics (intensity and interference) and demographic characteristics; (3) examine patient barriers to cancer pain management; and (4) evaluate the relationship between pain characteristics, patient barriers, and patient's level of acculturation.

Methods. A convenience sample of 200 cancer patients was recruited from an outpatient waiting room of a large urban cancer center in southeastern Michigan. Participants completed self-report questionnaires measuring their pain severity and pain interference (BPI), barriers to pain management (ABQ-II), acculturation levels (ASPAS), and demographic data. Lower levels of acculturation were related to older age and lower education levels.

Results. Significant relationships were found between patient barriers to cancer pain management and education, pain intensity, pain interference with activities, and acculturation. Acculturation was also significantly related to beliefs about fatalism (nothing can be done about cancer pain) and communication with health care providers.

Conclusions. Findings of this study evaluate the status of Arab American cancer patients' pain, contribute to understanding the relationship between pain and acculturation in Arab American cancer patients, and allow for cross-cultural comparisons.

The Cancer Pain Experience of Jordanian and Arab American Patients: A Comparative Study

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Introduction. Incidence of cancer will increase, with predicted estimates of 60% in the US over the next two decades. Because pain is a common and distressing symptom experienced by cancer patients, understanding the cancer pain experience should be a global priority. A recent NIH panel noted that there are insufficient data to guide therapy for those of diverse cultures. No studies have explored the multidimensional cancer pain experience among Arab and Arab American patients, or compared the differences between these populations.

Objectives. The purpose of this descriptive comparative study is to describe the cancer pain experience and attitudinal barriers to cancer pain management of Arab patients in America and Jordan. A cross-sectional design was used. A convenience sample of 300 cancer patients was recruited from oncology outpatient units of two regional comprehensive cancer centers in Jordan (n = 150) and the US (n = 150).

Methods. Participants completed self-report questionnaires measuring their pain severity and pain interference (BPI), barriers to cancer pain management (BQ-II), and demographic data.

Results. Arab Americans experienced significantly higher levels of pain and more barriers to pain management. Multiple regression analysis was employed to explore which models best described worst pain and pain interference.

Conclusions. The findings from this study reflect the cultural diversity within Jordan and the US, and allowed comparison of the role of culture in the pain experience. Differences in pain intensity between the two groups may be related to the significant differences between the Arab Americans' and Jordanians' attitude towards pain control. Arab Americans' imprecise understanding about analgesics and pain protocols due to language barriers may have led to inappropriate pain control. An understanding of the part played by cultural factors in the pain experience of cancer patients is essential to help health professionals tailor pain control programs to cultural differences.

Breast Cancer Screening in Syria: A Pilot Project

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Syrian Society against Cancer

The Terry Fox Committee in Aleppo

Introduction

In recent years breast cancer has become widely recognized as a critical issue in health care all over the world. Although breast cancer cannot be prevented, women can help reduce their risk by early detection. Based on medical statistics and cancer registry, international medical societies have developed breast cancer screening programs in several countries.

In Syria there are no screening programs (some random tentative trials) and no breast cancer registry. The reasons are multi-factorial. The incidence of breast cancer is increasing dramatically, with a remarkable number of cases in women under the age of 40.

A study was initiated at the request of the Syrian society against cancer and the Terry Fox committee in Aleppo (a Canadian foundation for cancer research) in order to benefit from the money raised from the annual Terry Fox Run, to launch a pilot project for breast cancer screening in Aleppo.

Objectives

- To enable the methodology of early detection
- To launch a breast cancer register and a research program to study the multiple risk factors of Syrian women
- To get accurate statistics about breast cancer rate and incidence compared with age
- To share the obtained experiences between partners and political authorities
- To initiate political discussion about the early detection of breast cancer

Methodology

- We designed a preliminary protocol, written, defined and detailed based on the French screening program.
- We prepared a mammography unit response to physio-technical norms based on the European guidelines for quality assurance for mammography screening.
- We put in place a plan to have an active participation from the target group (awareness campaign, brochures, authority approval and encouragement).
- Our target group was 1,500 school teachers aged 35-70 years invited (by phone calls) for free annual mammogram for ten years.

Results

- The program started on June 2008; the first six months were experimental.
- We launched an awareness campaign for teachers in many levels: schools visits, workshops, meetings with syndicate authorities, TV and radio interviews.
- 1,500 asymptomatic patients were examined; annual free mammogram is planned for all of them for 10 years.
- Ultrasound and control in 6 months (if needed) are free of charge; biopsy, surgery and treatment are at special prices.
- 90% of first and second year patients returned for free annual screening.
- 12 cases of subclinical breast cancer emerged.
- 1 case of clinical breast cancer (misdiagnosed 3 years ago in another center).
- 2 cases of Atypia, 1 case of phylloid tumor.
- Young patient's rate (< 40) is 0 till now.
- Questionnaires, reports, and second reading system based on latest BI-RADS edition are all registered on software specially designed for the project.
- Decisions are taken by a multidisciplinary team depending on the ACR recommendations.
- Permanent evaluation is considered.

Regional Collaboration in Tobacco Control Research and Prevention

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Tobacco consumption (TC) is very high in the East Mediterranean Region. The prevalence of smoking among adult men ranges between 12% and 60%, with a steady spreading of water-pipe smoking among the youth and women. Multi-sector collaborations and strategic partnerships using a regional tobacco coalition are an effective way to advance policy. Several successful examples of collaborations in TC research have been achieved in the last decade in the region. Such cooperation promotes the transfer of technical, scientific and legal expertise and technology to establish and strengthen national tobacco control strategies, plans and programs.

FCA-EMRO, TFI/WHO, Global Bridges, the Union, and many others are prominent initiatives in the region that have been established to create a strong platform for developing tobacco control research, prevention, advocacy and treatment.

Prevalence of Marlboro Smokers Among Youth in Middle East Countries

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This study analyzed data from 118,743 adolescents completing 30 different Global Youth Tobacco Surveys conducted in 15 different Middle Eastern countries between 1999 and 2007 to determine the proportion of young smokers in these countries who usually smoked Marlboro, other cigarette brands, or no usual brand smoked. Marlboro was the most prevalent brand smoked in seven of the 15 Middle Eastern countries examined, the second most common brand smoked in four Middle Eastern countries, and the third most common in eight of the countries. Marlboro smokers were found to exhibit stronger commitment to smoking, to smoke more frequently, to have more close friends who smoke, to score higher on beliefs that smoking is attractive, and to score lower on the belief that smoking is harmful in comparison to other brand smokers. Understanding youth smokers' brand preferences and choices is advantageous because it provides insight into what influences young people to start and continue to smoke, and subsequently may inform smoking prevention and control strategy development. This information can be incorporated into targeted mass media campaigns and other interventions to counter advertising and marketing messages.

Suicide Risk Among Arab-Americans

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Introduction. Arab-American (AA) populations in the US are exposed to discrimination and acculturative stress—two factors that have been associated with higher suicide risk. However, socially-oriented norms, such as communalism and a collective social orientation, affective expressiveness, strong family bonds, and positive ethnic group identity among ethnic minority groups have been cited as important mechanisms through which ethnic minorities may be protected against suicide. Here we explored suicide rates and their determinants among AAs in Michigan, the state with the largest proportion of AAs in the US.

Materials and methods. ICD-9/10 underlying cause of death codes were used to identify suicide deaths from among all deaths in Michigan between 1990 and 2007. Data from the 2000 US Census were collected for population denominators. Age-adjusted suicide rates among AAs and non-Arab whites were calculated by gender using the direct method of standardization. We also stratified by residence inside or outside of Wayne County, MI, the county with the largest AA population in the state.

Results. Suicide rates were 22.61 per 100,000 per year among men and 4.89 per 100,000 per year among women in Michigan from 1990 to 2007. AA men had a 55% lower suicide rate and AA women had a 33% lower rate than non-Arab white men and women, respectively. The suicide rate among AA men in Wayne County was 33% lower than among AA men in all other counties, while the rate among AA women in Wayne County was 38% higher than among AA women in all other counties. Among non-Arab whites, the suicide rate in Wayne County was higher compared to all other counties among both men (9%) and women (13%).

Conclusions. Suicide rates were higher among non-Arab white men and women compared to AA men and women in both contexts. Arab ethnicity may protect against suicide in both sexes, but more so among men. Ethnic enclaves such as Wayne County maintain a cultural distinction from their surroundings, and AAs in this context may be more likely to adhere to traditional cultural practices than their counterparts in other localities. Arab cultural practices may influence suicidality differently among AA men and women. This study is the first, of which we are aware, to consider suicide risk among Arab-Americans; more studies about suicidality among Arab populations in other contexts are needed.

Mental Health Concerns of Arab American Women in the United States

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ACCESS

The number of Arab immigrants and refugees is increasing tremendously due to the political, religious, and ethnic instability in several Arab countries. Arabs migrating to the United States have constituted an important population requiring consideration for services, especially mental health. The Arab American Institute estimates that at least 3.5 million Americans are of Arab descent. Despite the large Arab American population, little is understood about the mental health of Arab American women. Refugees experience unique traumas that build up over time and persist during the transition from their country of origin to the host country. Immigrants in general and women in specific carry with them to the new environment experiences of hostility, violence, racism, discrimination, and isolation (Kulwicki, Khalifa, & Moore, 2008). The most common stressors are due to the policies that aim at preventing their presence in the host country, thus limiting their access to healthcare, education, and work (Steel et al., 2006). The resettlement period from the Arab world to a Western country is extremely critical because it exacerbates existing symptoms of post-traumatic stress disorder (PTSD) in addition to increasing them (Al-Saffar, Borga, Edman & Hällström, 2003). Thus, it is an area of concern for researchers and healthcare providers. Understanding the mental health needs of immigrant and refugee women is a critical step toward developing appropriate health services for this population. Hence, the purpose of this study was to explore the mental health concerns of Arab American immigrant and refugee women in the US.

In a study on 312 Arab American women from the metropolitan area of Detroit, Michigan, posttraumatic stress, anxiety, and depression were assessed. The women had a mean age of 36.12 (SD = 10.81) years, and the majority were married (religious and civil: $n = 221$, 70.8%; religious only: $n = 33$, 10.6%) and had been living in the United States for an average of 15.37 (SD = 8.53) years. The majority were originally from Lebanon ($n = 136$, 43%) followed by Iraq ($n = 120$, 38.5%) and moved to the United States due to war or the political situation ($n = 129$, 49.4%) and marriage ($n = 72$, 27.6 %). Posttraumatic stress disorder (PTSD) was one of the most prevalent mental health conditions faced by these women. Results revealed that the prevalence of PTSD in Arab American women was 39%, which is higher than the national rate of 9.7%. This is due to their exposure to traumatic events such as war, loss of family members, torture, or accidents in their native countries. Analysis of variance (ANOVA) to identify the difference in PTSD scores among the different countries of origin was significant ($F(6) = 2.20$, $p = .05$) where the Palestinian and Iraqi immigrants and refugees had higher PTSD scores. Our findings show that the main predictors of PTSD were whether the women were physically injured during the traumatic event and feeling helpless during the event. Women with PTSD are found to have significantly increased levels of psychological distress, anxiety, and depression. These women reported to be emotionally distressed (26.1%), anxious (30.7%), and depressed (30%).

In conclusion, Arab American women require culturally specific attention to their mental health needs based on their experiences. This is an essential concern for healthcare professionals to promote the wellbeing of these women.

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The Role of the Bilingual Counselor in Mental Health Services in New South Wales, Australia

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Australia is one of the most multicultural countries in the world with one of four Australians born overseas. Arabic is one of the top 5 languages spoken in the State of New South Wales (NSW). In the recent years there has been an increase in the knowledge regarding the patterns of utilization of mental health services amongst people from diverse cultural background including Arabic speakers.

Arabic speaking people in Australia with mental health concerns tend to underutilize these services. Those who do seek help are likely to be experiencing acute stages of illness or require an involuntary admission. They are usually reluctant to access mainstream mental health services for a number of reasons which may include: the lack of accurate information or understanding of mental illness and the type of treatments available for them; confidentiality and stigma issues; communication difficulties; nondisclosure of symptoms (or willingness to report only somatic ones).

The Bilingual Mental Health program was established in 1998 and more than 30 positions were created across the State of NSW, covering 16 languages groups including several Arabic speaking clinicians. The role of bilingual mental health counselor has proven to be an integral part of NSW mental health services in Australia. The bilingual counselor's role in mental health involves the provision of individual counseling, co-therapy, cultural consultancy, group work, community education and development; family assessment and education; and psychological and rehabilitation assessments.

In recent years, more evidence indicating that this specific mental health program, where the patients are matched with service providers according to their cultural and linguistic backgrounds, has been highly successful. The results indicate: reduction in treatment drop out, significant improvements in clinical outcomes, fewer psychiatric emergency presentations, increased cultural sensitivities and awareness among mainstream staff, and increase in access to mainstream community mental health amongst people from diverse cultural backgrounds.

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Immigration and Psychological Impact: Three Waves of (US) Iraqi Immigrants

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Introduction. Acculturation, or the process by which individuals or groups transition from one or more cultures into another, can be a complex and often stressful process. In many cases the reason for immigration can contribute, both positively and negatively, to levels of acculturative stress. Immigrants from Iraq over the past several decades have shifted in terms of prevalence, reason for and ease of immigration, and pre- and post-migration trauma among individuals and groups. There is a need to examine the impacts of immigration and acculturative stress in order to determine how best to provide services to address those impacts.

Objectives or hypotheses. We examined the psychological byproducts of acculturative stress by measuring post-traumatic stress disorder (PTSD), anxiety, depression/dysthymia, and panic among three distinct waves of immigrants from Iraq, hypothesizing that (1) there would be a difference in the frequency of PTSD, depression, dysthymia, anxiety, and panic among the three groups; (2) that the post-1990 group would yield the highest scores on all the measures; and (3) that the 1980-1990 group would yield higher scores than the pre-1980 group.

Materials and methods. A sample of 350 participants was recruited within a metropolitan area in the Midwestern US. Participants agreed to take a large-scale survey instrument encompassing distinct measures of PTSD (PTSD Checklist), as well as depression, dysthymia, panic, and anxiety (Primary Care Evaluation of Mental Disorders). We first computed scale scores for PTSD and then examined Pearson correlations regarding the extent to which scores were related within the participant group. We then performed a MANOVA to examine group differences, followed by ANOVAs for each outcome measure.

Results. The hypotheses that the groups would differ in their overall frequencies on variables of PTSD, anxiety, panic, depression, and dysthymia were supported. Further, the hypotheses that the frequencies would be differentially progressive statistically for the outcome measures also were supported. Finally, the hypothesis that mean scores would be differentially progressive by immigration group was also supported.

Conclusions. It is clear that there are differences in psychological symptomatology among groups of Iraqi immigrants. For practitioners, it is critical to recognize stages of acculturative stress. These should be explored through an “adaptation” approach, a developmental process through which the clinician can help the client navigate. Finally, mental health and medical clinicians must be familiar with relevant immigration laws. They need to be willing to initiate legislative advocacy on behalf of their client populations as well.

A Region in Turmoil

Impact of a Changing Political Climate on Public Health in the Arab Region

Iman Nuwayhid

American University of Beirut

May Darwish-Yassine

Michigan Public Health Institute

The Arab world is undergoing unique transformative changes that potentially have profound implications for public health and health systems (Bile 2011; Jabbour 2012; Lancet 2011; Rashad 2011). The popular demands for human rights; dignity; accountability; better governance; and participation pose new opportunities and challenges for public health practice in the region (Jabbour et al 2006).

In the midst of these citizen revolts, the first ever book on 'Public Health in the Arab World' (<http://www.aub.edu.lb/fhs/phaw/Pages/index.aspx>) was published by Cambridge University Press (Jabbour et al., 2012). With over 500 pages and 38 chapters, this book is the largest volume on public health in the region. The book represents the fruit of an international effort led by the Faculty of Health Sciences at the American University of Beirut (AUB) which brought together a community of 81 authors working together over three years.

During the 6th ACCESS conference (<http://dearborn.patch.com/listings/arab-community-center-for-economic-social-services-on-Health-of-Arab-Communities>), a panel of active health professionals from select Arab countries, where prominent political changes were recently experienced, presented key data and findings from the book with a focus on the social and political determinants of health. The panel, moderated by Professor Iman Nuwayhid, Dean of the Faculty of Health Sciences at AUB, Lebanon, included:

Bothaina Attal, MD, Assistant Professor of Public Health and Reproductive Health, Community Medicine Department, Faculty of Medicine and Health Sciences, San'a University, Yemen

Fouad Fouad, MD, Coordinator, Syrian Center for Tobacco Studies, Aleppo, Syria

Samer Jabbour, MD, MPH, Associate Professor of Public Health Practice, Faculty of Health Sciences, American University of Beirut, Beirut, Lebanon

Belgacem Sabri, MD, Public Health Practitioner and Former Director, Division of Health Systems and Services Development, World Health Organization Regional Office for the Eastern Mediterranean, Tunis, Tunisia

Hani Serag, MD, Associate Coordinator, Global Secretariat, People's Health Movement, Cairo, Egypt

The panel addressed the recent changes in their countries underscoring the centrality of people's demands for a better life and more freedom to individual and population health. They also warned of the risks to health gains and public health systems due to the ongoing violence in some of these countries, especially in Syria. In spite of the variations in dynamics within each of the countries, the panelists and the engaged audience recognized common themes along a spectrum.

The panel discussed ways of strengthening health systems and meeting public health needs during and following the current events in the Arab world. The role of institutions and institutional development was recognized as crucial in shaping public health and enacting adequate and effective responses to current and future challenges. In addition, the importance of robust research in multiple areas leading to opportunities for action and involvement by organizations concerned with research on health as well as human rights and dignity was emphasized. The importance of ongoing and enhanced support of international funding agencies, such as the NIH (US) and IDRC (Canada), and the Arab communities in North America for collaborative research, capacity building, and implementation projects in the Arab World was emphasized.

This lively session generated more questions than answers and was depictive of the great uncertainty under which people in many Arab countries are living every day. These changes and uncertainties provide public health researchers and practitioners with an opportunity to understand and respond to questions such as:

- How central is health to the Arab uprisings?
- What is the role of public health professionals in upholding and protecting people's demand for freedom, justice and dignity?
- What options exist for a new public health vision in the transformed Arab World?
- What role can public health professionals play in peace building and conflict resolution?
- How prepared are health professionals and health care systems for long-term population displacements and violence?
- What are the long-term impacts of ongoing violence on health systems in the region? Can national health systems be understood outside the context of the region and the displacement of people across borders?
- How can institutional (and not simply individual) capacity building contribute to strengthening of research for health and public health action in the region?

The numerous and critical issues and topics that were raised deserve their own dedicated conference. The aforementioned book production, as well as the collaborative organization of this particular session, and the passion and thoughtfulness of the panelists are proof of the resilience, perseverance, conviction, and hope of the people of the Arab World and Arab communities abroad, and are a clear indication of the tremendous scientific talent that exists in the Arab region. The commitment to work collaboratively to find solutions and build scientifically rigorous systems and institutions that share the common goal of population wellness in more just and equitable societies rang loud and clear.

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The Case of Tunisia

Sabri Belgacim

The rosy image marketed by the old regime depicting Tunisia as a model for the Arab World of a fast growing economy and a progressive society was tarnished following the self-immolation of Mr. Mohamed Bouazizi in the city of Sidi Bouzid. The whole world discovered the harsh reality of dictatorship, deprivation, social polarization and unacceptable social and economic inequalities. Despite good achievements in health and social protection, trend analysis has shown that the right to health has gradually eroded since the mid-eighties following macroeconomic structural adjustment reforms and active privatization policies. Families are shouldering an increasing burden of health care financing which has reached almost 50% of total health care expenditures and 5% of them face catastrophic expenditures leading to 3% being pushed into poverty annually. In view of increasing unemployment and poverty, nearly 10% have lost all forms of health insurance.

Active privatization policies have resulted in an important increase of private health care infrastructure attracting qualified health workers from a failing public system. Increasing user fees in government health facilities while competent health workers and medicines were not available have pushed insured patients to seek health care privately. The two tiered health care delivery system resulting in one for the rich who can afford it and another for the poor confined to an insufficiently funded government sector was and is still a manifestation of the erosion of right to health.

Health professionals, organized in unions and civil society organizations, have played an active role during uprisings and have provided necessary support to wounded demonstrators in health facilities and field hospitals. They have volunteered to help Libyan refugees and other displaced populations following political unrest in Libya. They have also denounced on several occasions the increasing regional disparities in relation to distribution of health professionals, health facilities, health care coverage and health outcomes.

Following the end of dictatorship and the first free and transparent election, several societal organizations active in the field of human rights and health began contributing to the democratic transition. A new organization aimed at defending the right to health in the new constitution was established and has initiated advocacy work to promote the right to health in the constitution.

Several meetings with related associations took place between civil society organizations to structure their advocacy for the right to health through media and public gatherings. The association defending the right to health is coordinating with the main workers' union, which has prepared a draft constitution promoting all social and economic rights including health. Plans are being developed to address the various inequities in the Tunisian health system and to protect the right to health as part of some planned policy reforms.

Civil society organizations defending the right to health are planning to network with similar organizations in the Arab World and particularly in countries going through a democratic transition following the Arab Spring. Efforts should be coordinated in sharing experiences related to advocacy work on right to health and in empowering populations at various levels. Collaboration with academic institutions could also help document country experiences and share learned lessons.

There is a need to network inside the WHO region, to partner with active groups and institutions working in public health and to foster collaboration with Arab American communities in the field of public health. ACCESS could play an important role in facilitating such collaboration with the Tunisian public health community and with other CSOs in the Arab World.

The Case of Yemen

Bothaina Attal

Yemen is one of the countries that witnessed a mass population uprising against a 33-year old regime. The revolution extended almost all through the year 2011. Yemen is one of the least developed countries in the Arab world, with a poor HDI (154) and 35% of the population under the poverty line. The development indicators draw a grim picture; high population growth (3.2%), high maternal mortality (365/100,000 live births), and high levels of malnutrition (58% stunted children). The health system is weak, with a poor budget (5.2% of the government expenditure), suffering gaps in human resources, governance, and coverage and quality of the care, leaving it weakly responsive to crises. Before the 2011 events, Yemen had suffered eight rounds of civil war in the north, civil unrest in the south and natural disasters in the East.

The donor support and government spending acutely dropped, increasing the burden on already strained health and social services. The health system is under-funded and faces repeated emergencies and an increasing burden of non-communicable diseases. Similar to the other parts of the government, corruption is a major concern. Information, referral, and logistic systems are weak. However, human resources is a major concern because of shortage, maldistribution and retention. Coverage of public health services is limited and the private sector is expanding and widely unregulated. Civil societies working in health are still limited in number and capacity while the private sector is expanding and widely unregulated.

The direct effect of the 2011 events included internal population displacement in the affected areas. The social and health services were interrupted. Access to food, water, sanitation and basic health care services were limited. These were reflected on the increasing levels of child malnutrition, observed violence and reported maternal deaths.

Currently, the country is passing through a 2-year transitional period. The national security and restructuring of the army are top priorities. The country is receiving financial aid from regional and international entities. This period is detrimental to the equity of health and social justice. The presentation looks at the challenges and opportunities facing the improvement of public health of the population within the current drive for change, national dialogue and competing priorities.

Tobacco Control: *The Ron Davis Symposium*

Chaired by:

Virginia Hill Rice

Wayne State University

The symposium began with a presentation about the state of Michigan two years after the passage of the Ron Davis Smoke Free Air Law. Mr. Orlando Todd, from the Michigan Department of Community Health, gave an overview about the public support, compliance, and economic impact of the law. Mr. Orlando presented data from research studies showing the positive trend in compliance of both food establishments and work sites in the state. Compliance parameters measured included a visibly posted “No smoking” sign, removal of ashtrays and other smoking paraphernalia, and whether or not smoking is observed in the establishment. Furthermore, Mr. Orlando presented data from recent studies showing no significant negative economic effects associated with smoking bans; while the Tobacco Quit Line received a 66% increase in calls since the law took effect.

Mr. Farid Shamo, also with the Michigan Department of Community Health, gave an overview about the health impact of the Ron Davis Smoke Free Air Law. Samples from 13 cities representing the 6 major regions in Michigan showed a 92% decrease in fine particle (PM 2.5) pollution. In another study, the state measured the levels of exposure to tobacco smoke in non-smoking bar employees. In this study, three parameters were measured. First, cotinine, a byproduct of nicotine metabolism in blood, was used as a biomarker to measure exposure to secondhand smoking. Second, NNAL, another biomarker found in the blood of people exposed to tobacco smoke was also measure. Finally, self-reported respiratory symptoms were also recorded. The study found marked decrease in all three parameters compared to pre-law records.

Next, Dr. Wasim Maziak MD, PhD, Professor and Chair, Department of Epidemiology at Florida International University, and Director of the Syrian Center for Tobacco Studies, gave a presentation about the tobacco epidemic and control in the Arab World. In his presentation, Dr. Maziak focused on the health effects of water pipe (also known as hookah or shisha). Because of the lack of research studies, there is a lack of evidence to inform policy. Dr. Maziak hopes to shed more light on the health consequences of water pipe smoking. With cigarette smoking reaching about 50% among men in Syria, water pipe smoking is creating a second epidemic, especially among youth. The danger of water pipe smoking is amplified because there is 1.7 times more nicotine in water pipe compared to cigarettes, and an astounding 46 times more tar compared to cigarettes. Furthermore, water pipe smokers are more likely to switch to cigarette smoking. Dr. Maziak remarked that while there are some laws limiting water pipe use in Syria, there is a lack of enforcement. Dr. Maziak identified these findings as opportunities for further research on water pipe.

Finally, Dr. John C. Ruckdeschel, Medical Director at the Oncology Clinical Program, Intermountain Healthcare, Utah, talked about how relapse prevention is harder than initial cessation. Cigarette smoking prevalence remains high, varying between 62% among men in Jordan, and 26% among men in Bahrain; the smoking prevalence remains markedly lower among women, either because of cultural norms or due to under-reporting issues. The reason why people smoke is that nicotine, the addictive component in cigarettes, causes increased tolerance, withdrawal, and compulsive use. The most troubling aspect of nicotine in cigarettes is that the rate of relapse is comparable to heroin, making it a challenge to successfully quit. Therefore, Dr. Ruckdeschel proposed an approach to tobacco control involving cessation assistance, prevention, and policy. One of the treatment challenges is the high rate of relapse in “high risk” situations, that is situations previously associated with smoking. Some of the cues which trigger the craving for smoking in these “high risk” situations include stressful times at work, time following a meal, and post coital. The treatment implication provided was extinction therapy (i.e. cue exposure therapy), in which the care provider aims to get rid of a conditioned reflex using a method described as “Enhanced cue-exposure therapy”. Dr. Ruckdeschel concluded his talk by presenting some statistics about quitting and stating “plain old ignorance is still our biggest enemy”.

ACCESS Community Health and Research Center Hookah Forum

Ann Najar

Marriam Ismail

Laura de la Rambelje

ACCESS Community Health and Research Center

On September 26, 2013, inspired by the deliberations on the health effects of tobacco smoking during the **6th International Conference on Health Issues in Arab Communities**, ACCESS Community Health and Research Center conducted a Hookah forum at its conference center. Twenty three attendees representing faith and community leaders in the Arab and Chaldean Community were among the attendees. Dr. Adnan Hammad, Senior Director of the ACCESS Community Health and Research Center opened with remarks about ACCESS's commitment to combating the use of tobacco and hookah, and his hope that the meeting would result in outcomes for the group to take into the community. The forum, which included a health presentation and a community discussion, resulted in a number of concrete recommendations that are in the process of implementation.



Attendees

Dr. Adnan Hammad
 Sheikh Hassan Habhab
 Fouad Berry
 Father Andrew Seba
 Father Rudy Zoma
 Father Pierre Konja
 Dr. Aly M. Lela
 Dr. Farid Shamo
 Ann Najar
 Marriam Ismail
 David Ponsart
 Kamran Salari
 Noha Khalafawi
 Ola Saad
 Nijmi Hamood
 Benoit K. Nyobe
 Laura de la Rambelje
 Jihad Najda
 Wali Altahif
 Masoud Al-Awamlieh
 Dr. Hakeem Lumumba
 Mona Farroukh

Health Presentation

Dr. Basim Dubaybo, Associate Chairman of the Department of Internal Medicine at Wayne State University School of Medicine, and member of the ACCESS Board of Directors, gave a detailed presentation on the health effects of tobacco smoking. He outlined the various risks of smoking on various organs of the body, with special emphasis on the heart, the respiratory system, and the various cancers associated with smoking. He emphasized the negative effects of exposure to children and young women, pointing out the dangers of passive smoking and noting that, contrary to popular belief, and based on scientific studies across the United States and the Arab World, as well as findings of the Center for Disease Control and Prevention, **hookah smoking is far more dangerous than cigarette smoking**. Dr. Dubaybo defined the dangers present in two forms of passive smoking: second-hand smoking and the recently described third-hand smoking in which individuals are exposed to tobacco related chemicals that deposit on clothes, furniture and walls and cause harm well after smoking had ceased. He also noted that quitting smoking at any time could improve quality of life afterward; the earlier you quit, the better your quality of life for a longer period of time. Dr. Dubaybo noted other impacts of tobacco use: increased sexual dysfunction and higher rates of infertility, particularly among men. For women who use hookah, they face an increased risk of heart attack, bladder cancer, and breast cancer (which is more common in premenopausal women). Hookah increases the risk of low birth weight in babies, asthma in children, and COPD and lung cancer in adults.

Community Discussion

Dr. Hammad then facilitated a dialogue among attendees. He opened the discussion by pointing out that the smoking rate among Arab and Chaldean Americans is 35% in Michigan, a statistic which is surpassed only by Native Americans. According to Wayne State University, hookah use among youth is approximately 62%, and dual use of hookah and cigarettes is about 80%. One of the problems the community must face is that parents see hookah session with their kids as a positive experience.

Other attendees noted concerns including:

- Risk of tobacco and hookah use as a gateway drug.
- Underage usage and the law – cafes are allowing teenagers to use hookah and permit toddlers to be in the lounges with their parents. Also the issue of hookah lounges possibly breaking the law or operating outside the law – do not want the community to get the reputation for flouting the law.
- Taking care to avoid demonizing smokers – tobacco addiction is an illness.
- Need to educate youth and families – this is a problem that is happening at home as well.
- Need to debunk idea that hookah is cool
- Concern that youth believe they're invincible – how to reach them, how to convince them that they need to be concerned with immediate quality of life.
- Immigration, trauma, and mental health

Attendees then identified resources that are available, and other ideas that could be enacted to bring about positive change:

Currently Available: 1-800-QUIT-NOW, hospital and community resources (i.e. in-person tobacco dependence treatment through Freedom from Smoking from American Lung Association)

Recommendations and Implementation

- Make dependence treatment (cessation) more widely available in the community
- Educate youth at community centers, churches
- Dr. Hammad recommended the group form a coalition on hookah and other tobacco products for the Arab and Chaldean American community to meet four times per year with faith-based organizations, community organizations, parents, schools, and youth. The coalition could educate legislators and community leaders, and fight for hookah to be taxed and regulated. Dr. Hammad stated ACCESS would happily host the coalition and would issue invitations to all to join the coalition.
- These Recommendations, including the establishment of the coalition, will be further discussed by the Michigan Muslim Council of Southeast Michigan to raise awareness and secure support for these efforts.

The Chair's Perspective ***Lessons from an International Forum:*** ***Closing Remarks***

May Darwish-Yassine

Michigan Public Health Institute

Scientific Chair, 6th International Conference on Health Issues in Arab Communities

Studies of immigrants to the US show that the effect of original social and cultural influences persist long after immigration and have a profound effect on health status and health related behaviors of immigrant communities.

The three-day conference was designed to enhance our understanding of social determinants of health as they apply to Arab communities in home countries and countries of immigration.

The Arab region is widely variable in socio-economic circumstances in which people are born; grow up, live, work, and age, as well as the systems put in place to deal with illness. We founded our program on our belief that understanding these determinants would help national health professionals to better intervene for reducing inequities in health, a goal currently sought by public health and health care professionals.

We aimed at offering, to the extent that time permits, a comprehensive consideration of emerging scientific topics closely related to chronic diseases that are increasingly becoming the prominent conditions of concern. Lead experts offered information on: 1) application of genetic discoveries to public health interventions for preventing disease and providing quality health care and challenges in delivering competent risk specific care from practical and ethical points of view; 2) the Patient- Centered Medical Home as a model for improving access to care, reducing health care cost, providing coordination of services, and monitoring the quality of health care; and 3) Impact of a Changing Political Climate on Public Health in the Arab Region.

The conference convened 565 attendees, representing 15 countries and 13 states. A lively exchange occurred within each of the sessions beginning with a first full day symposium on mental health issues and followed by a number of seminars presenting research and information on successful programs that were implemented locally, nationally and internationally to alleviate the burden that tobacco addiction; cancer; cardiovascular disease; diabetes; and other illnesses pose on Arab communities globally.

In an era of limited resources and increasing public health needs within hard-to-reach and underserved populations, it is imperative that specialists from various disciplines coordinate efforts and exchange information on best practices for efficient use of resources and optimal outcomes. We hope that this conference has provided a platform to cultivate partnerships and instigate new research initiatives.

Our quest for good quality data pertaining to Arab communities in home countries and countries of immigration is not new; this is the sixth in a series of conferences that have advocated for and leveraged an unprecedented volume of research specific to the Arab communities and looked at culturally specific determinants of health and health care. There continues to be a great need for population-based data and systematic research which would dissipate misconceptions and false inferences due to scarcity of information. Let us take it upon ourselves as health care professionals, scientists, and public health leaders to always demand knowledge founded in impartial and scientific observations.

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