The deterioration in the public health situation in the Eastern Mediterranean Region is of an unprecedented scale due to ongoing regional conflicts. Vaccine-preventable disease programmes require urgent attention in order to sustain the earlier success of major health initiatives such as polio eradication and measles elimination.
EASTERN MEDITERRANEAN HEALTH JOURNAL

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Editorial

Vaccine preventable diseases and immunization during humanitarian emergencies: challenges and lessons learned from the Eastern Mediterranean Region

N. Teleb 1 and R. Hajjeh 2

The last few years have seen the WHO Eastern Mediterranean Region suffer from multiple wars and conflicts leading to humanitarian emergencies of unprecedented magnitude. In addition to the many lives lost and affected, the conflicts have significantly impacted the infrastructure needed for delivery of healthcare services (1). Approximately 30 million people have fled their countries; the refugee population in Jordan has doubled and even tripled in Lebanon (2). The population displacement and resettlement, overcrowding, poverty, poor sanitation, and malnutrition due to food shortages have increased morbidity and mortality from various diseases, notably communicable diseases.

Control of vaccine-preventable diseases (VPDs) is especially vulnerable to disruption of health-care systems due to the need for continuous implementation and monitoring (3). The Syrian Arab Republic had a very strong immunization program prior to its current conflict, with more than 90 percent of children routinely vaccinated and the last polio case reported in 1999. However, diphtheria-tetanus-pertussis (DTP3) coverage in the country dropped to 41% in 2015; in 2013, less than two years after the start of conflict, the country experienced a polio outbreak that paralyzed 35 children. To contain it, more than 25 million doses of oral polio vaccine were administered. In 2014, other VPDs resurfaced in the Syrian Arab Republic, including measles and pertussis. Both Jordan and Lebanon faced large outbreaks of measles due to the influx of Syrian refugees. In Lebanon alone, the measles incidence increased from 2.1 to 41 cases/million population in 2012 and 2013 respectively (3).

The Region has earlier demonstrated significant progress in measles control, with reported measles cases decreasing from 89,478 in 1998 to 10,072 in 2010 (77%) (4). However, with the political turmoil and significant decrease in donor funding, regional progress slowed and measles cases doubled to reach 20,898 cases in 2015. The regional average of DTP3 coverage gradually declined from 86% in 2010 to 80% in 2015 (WHO/UNICEF estimates). In 2015, 3.8 million infants missed their third DTP dose in the Region – more than 90% of these infants are in conflict-affected countries (EMRO, unpublished data).

Immunization activities during conflict

Remarkable efforts were devoted to maintaining immunization programs and reaching every child with life-saving vaccines, even under active war and life-threatening situations. During 2011–2016, more than 248 million children aged 6 months to 15 years were reached by measles-containing vaccines in conflict-affected countries as well as countries hosting refugees in the Region (5).

While concerted partners’ support was a key factor for accessing required resources, governments’ commitment and allocation of national resources was critical. Most importantly, the devotion of health workers and their relentless efforts to reach children in hard to reach areas, and the demand from communities for vaccines, were major success elements. The examples of Yemen and the Syrian Arab Republic best illustrate how concerted efforts at multiple levels are critical to sustain immunization coverage and prevent outbreaks of VPDs.

Yemen

More than two million people in Yemen were displaced due to conflict and many health facilities destroyed (one third of health facilities and one fourth of vaccine stores). However, pentavalent vaccine (DTP-HepB-Hib) coverage dropped only slightly from 87% in 2010 to 84% in 2015 (6). To maintain coverage, outreach activities were conducted in the remote areas (24,000 and 30,000 sessions in 2014 and 2015 respectively), in addition to three rounds of polio national immunization days (NIDs) each year, thus sustaining the polio-free status. Yemen also smoothly introduced two new vaccines (measles–rubella [MR] and inactivated polio vaccine [IPV]), while sustaining other new vaccines (Hib, rotavirus and pneumococcal vaccines). These achievements

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were possible through concerted efforts spearheaded by WHO, effective coordination among partners through weekly meetings attended by all key stakeholders, active utilization of the Health Cluster forum to advocate for immunization, establishing a functional immunization Operational Control Room at central and governorate levels, and the devotion of frontline immunization workers. The effective uses of resources, especially Global Alliance for Vaccines and Immunization (GAVI) support, and distribution of roles and responsibilities among different partners, were instrumental.

Syrian Arab Republic

When the conflict in the Syrian Arab Republic began in 2012, routine immunization stopped in areas outside recognized government control. During the short break in the conflict in February 2016, WHO and UNICEF in collaboration with the Syrian Ministry of Health and other supporting partners (Syria Arab Red Crescent, Syria Immunization Group, and local NGOs), as part of Accelerated Implementation of Routine Immunization initiative (AIRI), conducted multiple antigens vaccination campaigns in the hard-to-reach areas deprived of access to routine vaccines. Every child born since the start of the conflict was provided with three doses of pentavalent vaccine, 3 doses of oral polio vaccine, 2 doses of MR vaccine, and one dose of IPV. Despite the active war in the north of the Syrian Arab Republic, three campaigns were implemented – 1.9 million doses of pentavalent vaccine, more than 1.3 million doses of MR vaccine, more than 1.9 million of OPV and 168,405 doses of IPV (EMRO, unpublished data).

The constant support of the partners, led by WHO and UNICEF, and the high dedication of the local NGOs and health workers were behind the exceptional success in the areas that implemented the campaigns. Independent post-campaign monitoring, using card information or finger marking, proved that more than 90% of the children were reached — an incredible success in view of all the challenges.

Challenges

Multiple challenges were faced while supporting immunization activities in the Region during conflict. Many health facilities were destroyed and the functioning facilities faced major challenges with availability of fuel and electricity. Security concerns were major obstacles, affecting all planned activities, particularly outreach and mobile activities, and significantly increasing operational costs. Obviously, the active war in many areas made parents reluctant to take their children to health centres for vaccination. The resulting inadequate number of immunization staff who had fled conflict areas or were reassigned to other healthcare priority functions, was also a major difficulty. Lastly, in many countries, immunization activities were limited by the shortage of funds required for vaccine purchase and operational costs.

Policy level

The Strategic Advisory Group of Experts (SAGE) and the World Health Assembly requested in 2011 that WHO develops guidance on the delivery of immunization services in humanitarian emergency settings. In 2013, the final version of the framework entitled “Vaccination in acute humanitarian emergencies: a framework for decision making”, was released and disseminated (7). The document provides key decision-makers in countries and partner agencies with a systematic and comprehensive approach to decision-making on the use of vaccines in acute humanitarian emergencies, taking into account various factors including the epidemiologic risk assessment, vaccine characteristics, and contextual factors. In addition, it provides guidance on ethical concerns such as prioritization of interventions, equity, and informed consent. It is currently being updated to facilitate its use, based on input from various countries affected by conflict. In addition, a package of tools on vaccination in humanitarian emergencies is being prepared, in order to provide practical guidance for delivering vaccines and improving vaccination coverage during these situations, as well as overcoming barriers to timely supply affordable vaccines.

Conclusions

Sustaining immunization activities and preventing VPD outbreaks during conflicts is very difficult and requires massive and adequately coordinated efforts by all parties involved, including governments and other political parties, since the health of populations and children should transcend all political considerations. Although emergencies often lead to disruption of immunizations and other health services, their impact can be minimized if strong health systems are in place and appropriate preparedness measures are taken preemptively. Partners, whether technical, implementing or financial, play an even more important role in supporting public health programmes overall and immunization in particular during conflicts. Community engagement and demand for vaccines remains essential. Policy frameworks recently developed should serve as guidance for decision-making and implementation. The global community should recognize that the deterioration in the public health situation in the Eastern Mediterranean Region is of an unprecedented and dramatic scale. Communicable diseases, and VPDs in particular, require urgent attention. If adequate support, both financially and programmatically, is not consistently provided, the situation poses an immense threat to health security globally, and to the success of major health initiatives such as polio eradication and measles elimination.
References


ABSTRACT This study reviewed trends in the incidence of common communicable diseases among children under five years in Afghanistan between 2005 and 2013, a period of expansion of public health services. New visits to outpatient clinics constituted the denominator for calculating proportions. In 2013, almost three-quarters of all new visits of children to public health services were for an infectious disease, with respiratory infections the most common. Because of inconsistent data collection for some infections early in the period, the trend for infectious diseases as a whole cannot be estimated. However, there was a statistically significant downward trend in the proportion of new visits that were diagnosed as one of the 11 leading communicable diseases from 74.5% in 2005 to 62.1% in 2013 ($P < 0.001$). There was no difference in communicable disease patterns between provinces, but a higher per capita consultation rate was associated with a higher proportion of the leading infections ($P = 0.008$). Recent improvements in maternal health, hygiene, and preventive services may have had an impact in reducing the burden of infections.

Tendances de l'incidence des maladies infectieuses chez les enfants en Afghanistan à l'heure de l'élargissement des services de santé publique

RÉSUMÉ La présente étude a étudié les tendances de l’incidence des maladies transmissibles les plus répandues chez les enfants de moins de cinq ans en Afghanistan entre 2005 et 2013. Les premières consultations en soins ambulatoires ont constitué le dénominateur pour calculer les pourcentages. En 2013, presque trois quarts de toutes les premières consultations d’enfants dans les services de santé publique avaient pour cause une maladie infectieuse, les infections respiratoires étant les plus fréquentes. Du fait d’une collecte des données incohérente pour certaines infections au début de la période d’étude, les tendances pour les maladies infectieuses dans leur ensemble ne peuvent être estimées. Pour autant, une tendance à la baisse statistiquement significative a été observée en ce qui concerne le nombre de premières visites pour lesquelles le diagnostic établi était l’une des 11 maladies transmissibles les plus répandues (74,5 % en 2005 contre 62,1 % en 2013, soit $P < 0,0001$). Aucune différence en termes de caractéristiques des maladies transmissibles n’a été établie entre les provinces, mais un taux de consultation plus élevé par habitant a été associé avec un pourcentage plus élevé pour les infections principales ($P = 0,008$). Les récentes améliorations en matière de santé maternelle, d’hygiène et de services de prévention ont pu avoir une influence sur la réduction de la charge des infections.
Introduction

Afghanistan has suffered from instability and conflict for the past 40 years. Almost 36% of the population live below the poverty line (1) and access to public sector health facilities has historically been inadequate (2). In such a context, a high incidence of treatable diseases is to be expected. Children are particularly affected, not only because they are more vulnerable, but also because they constitute a large proportion of the Afghan population, of which 64% are under 24 years (2) and 17% under 5 years of age (3). The mortality rate for children under five years old is estimated to be 99 per 1000 live births, while the infant mortality rate is 71 per 1000 live births; with these rates, Afghanistan is 18th from last on the United Nations Children’s Fund (UNICEF) ranking of countries for child health (3). Children’s health is a sensitive reflection of the efficiency of the health services in a country.

In recent years, particularly since 2001, efforts have been made to expand public health services and increase access to them, as part of international cooperation to rebuild the country (4). Several studies have evaluated the association between these efforts and various health indicators, particularly in the areas of malnutrition, reproductive health, mortality and immunization, for both academic and planning purposes.

A less studied area is whether recent developments in Afghanistan have been associated with specific trends and characteristics of infectious diseases, particularly among children. While it is generally assumed that most diseases affecting children are communicable, precise numbers and trends have not been comprehensively studied, especially in relation to the recent expansion of public health services. A few sources, such as the Multiple Indicators Cluster Surveys (MICS) and the Afghanistan National Household Surveys, contain sections on infectious disease morbidity, but these are usually limited in scope. In the absence of systematic data, it is hard to calculate the prevalence of communicable diseases in the country.

The objective of this study was to assess trends in communicable diseases among children under five years of age, with particular attention to the most frequent infections, in light of recent efforts to invest in and expand public health services throughout the country. The results could provide some measure of the success of the efforts, as well as lessons for other similar undertakings.

Methods

The absence of a consistent health information system prior to 2004 makes the historical study of disease patterns among children difficult. Thus, we considered only reports on patterns, characteristics, and trends in communicable disease among children attending public health facilities from 2005 to 2013. During this period, public health facilities expanded considerably. We used data from facilities implementing the Basic Packages for Health Services (BPHS), which have been in place since 2002 (5). Nationally, nearly 80% of consultations for under-five-year-olds take place in these facilities (6). The number of such health facilities providing BPHS increased from 1075 in 2004 to over 2000 in 2014 (7).

In the absence of a national census, we used the totals for all “new visit” consultations for children in BPHS facilities as the denominator for calculating proportions; this method is also used in the Ministry of Public Health’s Diseases Early Warning System (MoPH–DEWS) (8). The data set is managed by the Health Management Information System (HMIS) Department of the Ministry, which defines a “new visit” as a visit at which “a patient [is] diagnosed with an episode of an illness for the first time”. Return visits for the same diagnosis within a predefined period were considered as re-attendance, and were excluded from our analysis. The diagnoses categorized as communicable diseases among children under five years of age in HMIS are listed in Box 1;

Box 1. Diseases categorized as communicable in HMIS records

1. Cold and cough (ARI)
2. ENT (ear, nose, and throat) infection
3. Pneumonia (infectious)
4. Acute bloody diarrhoea
5. Acute watery diarrhoea
6. Diarrhoea with dehydration
7. Viral hepatitis
8. Measles
9. Pertussis
10. Diphtheria
11. Tetanus (neonatal)
12. Malaria
13. Urinary tract infection (UTI) (all types)
14. Gastrointestinal tract worms
15. Skin infections
16. Eye infections
17. Severely ill (infections with severe symptoms, not classified in other categories)
classification is based on clinical manifestations.

We used data from 2013 to assess disease trends, seasonal fluctuations, and distribution by province. We then analysed trends in some key diseases between 2005 and the end of 2013. Data analyses were performed with STATA statistical software (v.12) and Excel (v.2013). Linear regression analysis was used to evaluate the significance of associations. Reports from the World Health Organization, UNICEF, the United States Agency for International Development, and the Afghanistan MoPH were consulted for comparison.

Results

Monthly data returns for 2013 reported 13 404 322 new visits of children less than five years old to BPHS facilities for all conditions. Of these, 9 678 477 (72%) were diagnosed as having a communicable disease (Table 1). Among all first visits for communicable disease, respiratory infection was the most frequent diagnosis, with 2 610 013 cases of acute respiratory infection (ARI) (27%) and 1 067 017 of pneumonia (11%). Diarrhoea, ear, nose and throat infection, urinary tract infection, and malaria were the next most frequently reported infectious diseases.

There were no statistically significant seasonal fluctuations in the overall proportion of diagnoses of communicable diseases in 2013, although respiratory infections peaked around December–March (winter), diarrhoea in June–August (summer), and malaria in June–September. The total number of first visits to outpatient departments of public health facilities by children under five years increased from 2 883 736 in 2005 to 13 404 322 in 2013 (Table 2), as a result of the expansion of the health infrastructure in Afghanistan during this period (7). From 2005 to 2010, there was an apparent downward trend in the proportion of first visits that were for communicable disease, which reversed after 2010 (Figure 1). This may reflect a change in the reporting forms in 2010 to include specific communicable diseases that had previously been recorded as “others”, e.g. eye infections, intestinal worms, skin diseases, and oral–dental infections. This inconsistent recording of data means that no statistically significant trend can be distinguished in the proportion of new visits classified as communicable diseases, over the period 2005–13 (Table 2).

There was, however, a statistically significant downward trend in the proportion of new visits that were classified as one of the infections for which there was continuous reporting, in particular the 11 leading infections (P < 0.001). Overall, the average decrease was around 1.8% per year (Table 3). Further breakdown of the data showed a reduction in the incidence of all these diseases, except ARI and measles (Table 3 and Figure 2). Malaria showed the most dramatic fall. Statistically similar patterns were seen in girls and boys.

Similar patterns of the leading infections were found in the different provinces, despite differences in climate and in socioeconomic and other characteristics. From 2008 to 2011 (9), higher consultation rates in provinces were positively correlated with higher proportions of visits for the leading communicable diseases (an average of 2.5% increase for each point increase in per capita consultation rate (P = 0.008)).

Discussion

Our results show that respiratory infections account for the biggest share of all new visits to public health facilities by children under five years. The finding is in line with previous studies (8,10); of 247 216 deaths reported among children under five in Afghanistan in 2008, 72 716 (29.4%) were attributed to pneumonia (11). Afghanistan is part of the list of those few countries that account for half of pneumonia-related deaths among children (11). However, despite continuing to be the most widespread disease among children, our analysis indicates a statistically significant reduction in the proportion of diagnoses of pneumonia between 2005

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Table 1 Communicable diseases diagnosed in children aged under 5 years at health facilities in Afghanistan, 2013

<table>
<thead>
<tr>
<th>Total number of new visits</th>
<th>13 404 322</th>
</tr>
</thead>
<tbody>
<tr>
<td>No. of diagnoses of communicable disease (% of all new visits)</td>
<td>9 678 447 (72.2%)</td>
</tr>
<tr>
<td>No. of diagnoses of specific infectious diseases (% of all infectious diseases)</td>
<td></td>
</tr>
<tr>
<td>ARI</td>
<td>2 610 013 (27.0%)</td>
</tr>
<tr>
<td>Diarrhoea</td>
<td>2 581 053 (26.7%)</td>
</tr>
<tr>
<td>ENT infection</td>
<td>1 708 129 (17.6%)</td>
</tr>
<tr>
<td>Pneumonia</td>
<td>1 067 017 (11.0%)</td>
</tr>
<tr>
<td>Urinary tract infection</td>
<td>224 727 (2.3%)</td>
</tr>
<tr>
<td>Malaria</td>
<td>43 347 (0.4%)</td>
</tr>
<tr>
<td>Other</td>
<td>1 444 161 (15.0%)</td>
</tr>
</tbody>
</table>

ARI = cold and cough
and 2013. There may be several possible explanations for why incidence rates are falling while mortality remain high for respiratory infections. It may be that many cases are not reported to the database that we used, but are accounted for through other means (remembering that there are considerable areas where there are still no regular services). Or it could be that, in the information system, children who die from pneumonia are categorized as severely ill patients, using the Integrated Management of Childhood Illnesses (IMCI) classification, and may be reported separately on an IMCI form (12). Therefore, while there may have been a modest reduction in pneumonia, as found also in another recent study (8), the apparent dramatic decrease in morbidity rates found here should be viewed with great caution.

In general, the findings indicate that almost three-quarters of all new visits of children to public health facilities are for communicable diseases. Reports from DEWS indicate that the proportion of communicable disease diagnoses in all outpatient departments in public sector facilities for all age groups is between 60% and 80% (8). This suggests that, whatever the trends, the burden of communicable diseases in Afghanistan is still very great.

Although no association was found between geographical location and burden of infections among children, we found that the higher the per capita consultation rate, the higher the proportion of diagnoses for the leading 11 communicable diseases among children. It is likely that, in rural provinces, consultation rates in the public sector facilities are higher, as there is a paucity of private clinics in these areas. It may also be that larger family sizes in rural areas create a higher demand for paediatric care. A report in 2014 found a higher risk of death from infectious causes among children in remote rural areas, consistent with our analysis (13). It is interesting that no difference was observed in the proportion of infections among boys and girls, contrary to popular perception that boys are more vulnerable.

The incidence of the leading infectious diseases appears to be declining. Similarly, the DEWS reported a reduction in communicable diseases among the general population from 2007 to 2013, comparing their annual reports in

<table>
<thead>
<tr>
<th>Year</th>
<th>Communicable disease</th>
<th>Other conditions</th>
<th>Total new consultations</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>2005</td>
<td>2,168,226 (75.2%)</td>
<td>715,510 (24.8%)</td>
<td>2,883,736</td>
<td>–</td>
</tr>
<tr>
<td>2006</td>
<td>3,137,87 (74.7%)</td>
<td>1,059,956 (25.3%)</td>
<td>4,197,342</td>
<td>–</td>
</tr>
<tr>
<td>2007</td>
<td>3,737,258 (74.1%)</td>
<td>1,305,145 (25.9%)</td>
<td>5,042,403</td>
<td>–</td>
</tr>
<tr>
<td>2008</td>
<td>5,077,243 (71.2%)</td>
<td>2,056,401 (28.8%)</td>
<td>7,133,644</td>
<td>–</td>
</tr>
<tr>
<td>2009</td>
<td>6,041,342 (69.3%)</td>
<td>2,678,126 (30.7%)</td>
<td>8,719,468</td>
<td>0.1171</td>
</tr>
<tr>
<td>2010</td>
<td>6,629,445 (67.9%)</td>
<td>3,133,727 (32.1%)</td>
<td>9,763,501</td>
<td>–</td>
</tr>
<tr>
<td>2011</td>
<td>7,900,573 (70.1%)</td>
<td>3,375,465 (29.9%)</td>
<td>11,275,038</td>
<td>–</td>
</tr>
<tr>
<td>2012</td>
<td>8,675,290 (72.8%)</td>
<td>3,238,986 (27.2%)</td>
<td>11,914,276</td>
<td>–</td>
</tr>
<tr>
<td>2013</td>
<td>9,678,447 (72.2%)</td>
<td>3,725,875 (27.8%)</td>
<td>13,404,322</td>
<td>–</td>
</tr>
<tr>
<td>Total</td>
<td>53,045,540 (71.4%)</td>
<td>21,289,190 (28.6%)</td>
<td>74,334,730</td>
<td>N/A</td>
</tr>
<tr>
<td>Boys</td>
<td>27,428,378 (71.8%)</td>
<td>10,748,401 (28.2%)</td>
<td>38,175,279</td>
<td>0.157</td>
</tr>
<tr>
<td>Girls</td>
<td>25,617,162 (70.8%)</td>
<td>10,540,789 (29.2%)</td>
<td>36,156,416</td>
<td>–</td>
</tr>
</tbody>
</table>

Table 2 Diagnoses in children under 5 years attending health facilities in Afghanistan, 2005–2013

P value is for annual trend.
Table 3  Incidence of 11 leading communicable diseases among children under 5 years making a new visit to a BPHS facility, 2005-2013

<table>
<thead>
<tr>
<th>Year</th>
<th>2005</th>
<th>2006</th>
<th>2007</th>
<th>2008</th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
<th>2012</th>
<th>2013</th>
<th>Trend</th>
<th>P value(^1)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total no. of new visits</td>
<td>2,883,736</td>
<td>4,197,342</td>
<td>5,042,403</td>
<td>7,133,644</td>
<td>8,719,468</td>
<td>9,763,501</td>
<td>11,276,038</td>
<td>11,914,276</td>
<td>13,404,322</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>11 leading communicable diseases, no. (% of all new visits)</td>
<td>2,150,777</td>
<td>3,111,946</td>
<td>3,712,426</td>
<td>5,041,490</td>
<td>6,002,353</td>
<td>6,587,977</td>
<td>7,404,865</td>
<td>7,488,711</td>
<td>8,255,859</td>
<td>-1.8%</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>All other cases</td>
<td>732,959</td>
<td>1,085,396</td>
<td>1,329,977</td>
<td>2,092,154</td>
<td>2,717,115</td>
<td>3,175,524</td>
<td>3,871,173</td>
<td>4,425,565</td>
<td>5,148,463</td>
<td>N/A</td>
<td>N/A</td>
</tr>
</tbody>
</table>

**Disease incidence, no. of cases (incidence per 100,000 new attendees under 5 years)**

<table>
<thead>
<tr>
<th>Disease</th>
<th>2005</th>
<th>2006</th>
<th>2007</th>
<th>2008</th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
<th>2012</th>
<th>2013</th>
<th>Trend</th>
<th>P value(^1)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diarrhoea</td>
<td>764,631</td>
<td>1,064,029</td>
<td>1,217,259</td>
<td>1,705,819</td>
<td>2,099,186</td>
<td>2,347,957</td>
<td>2,285,600</td>
<td>2,581,053</td>
<td>N/A</td>
<td>-0.953</td>
<td>0.006</td>
</tr>
<tr>
<td>ARI</td>
<td>529,676</td>
<td>804,398</td>
<td>982,439</td>
<td>1,217,259</td>
<td>1,705,819</td>
<td>2,099,186</td>
<td>2,347,957</td>
<td>2,285,600</td>
<td>N/A</td>
<td>+4.23</td>
<td>0.318</td>
</tr>
<tr>
<td>Diphtheria</td>
<td>110</td>
<td>54</td>
<td>34</td>
<td>93</td>
<td>124</td>
<td>62</td>
<td>31</td>
<td>396</td>
<td>180</td>
<td>-0.13</td>
<td>0.775</td>
</tr>
<tr>
<td>ENT infection</td>
<td>377,970</td>
<td>566,723</td>
<td>695,447</td>
<td>954,228</td>
<td>1,472,699</td>
<td>1,543,689</td>
<td>1,708,129</td>
<td>N/A</td>
<td>N/A</td>
<td>-8.23</td>
<td>0.096</td>
</tr>
<tr>
<td>Malaria</td>
<td>64,941</td>
<td>76,609</td>
<td>83,311</td>
<td>88,263</td>
<td>82,690</td>
<td>83,574</td>
<td>83,144</td>
<td>43,347</td>
<td>N/A</td>
<td>-253</td>
<td>0.004</td>
</tr>
<tr>
<td>Measles</td>
<td>1,166</td>
<td>2,692</td>
<td>2,734</td>
<td>2,704</td>
<td>2,704</td>
<td>2,704</td>
<td>2,704</td>
<td>2,704</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Pertussis</td>
<td>1,888</td>
<td>2,607</td>
<td>2,607</td>
<td>2,607</td>
<td>2,607</td>
<td>2,607</td>
<td>2,607</td>
<td>2,607</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Pneumonia</td>
<td>3,499,248</td>
<td>5,232,959</td>
<td>6,255,955</td>
<td>7,455,200</td>
<td>9,765,887</td>
<td>10,486,929</td>
<td>10,348,481</td>
<td>10,576,017</td>
<td>N/A</td>
<td>-5.673</td>
<td>0.008</td>
</tr>
<tr>
<td>Suspected tuberculosis</td>
<td>670,992</td>
<td>763,062</td>
<td>692,018</td>
<td>911,071</td>
<td>1,202,299</td>
<td>1,678,826</td>
<td>1,518,818</td>
<td>1,508,818</td>
<td>N/A</td>
<td>-183</td>
<td>0.007</td>
</tr>
<tr>
<td>Urinary tract infection</td>
<td>524,464</td>
<td>78,086</td>
<td>91,696</td>
<td>127,036</td>
<td>155,773</td>
<td>177,321</td>
<td>194,956</td>
<td>195,373</td>
<td>224,727</td>
<td>-273</td>
<td>0.009</td>
</tr>
<tr>
<td>Viral hepatitis</td>
<td>1,992,000</td>
<td>4,902,000</td>
<td>3,880,000</td>
<td>4,975,000</td>
<td>4,164,000</td>
<td>6,443,000</td>
<td>5,003,000</td>
<td>5,446,000</td>
<td>7,022,000</td>
<td>-5.53</td>
<td>0.032</td>
</tr>
</tbody>
</table>

\(^1\)P value for trend.
\(^2\)Percentage decrease per year.
\(^3\)Average annual change in incidence among new attendees.

ARI = cold and cough; BPHS = basic packages for health services; ENT = ear, nose, throat infection
this period based on assessment of a wider datasets. Another study reported that the proportion of disability-adjusted life years (DALYs) attributable to communicable and neonatal diseases was 48.9% in 2010, a reduction of 20% from 1990 (14). Thus, as suggested by these other sources, there may be a real downward trend in some important childhood infections, if not in all.

It is plausible that efforts to improve the public sector health services in Afghanistan since 2002 have contributed to the reduction in pneumonia and other communicable diseases in the country (15). These investments, aimed at improving service delivery, especially for women and children (16), have produced results that may be associated with reduced childhood morbidity, including: a reduction of almost three-quarters in the maternal mortality rate (17), which is attributed to better antenatal and postnatal care (18); an increase of 4000% in the number of births attended by a skilled birth attendant (7); and improved family planning services (19). Another relevant development may be the improvements in water supply, sanitation and hygiene. The MICS survey in 2010–11 found that 57% of the population had access to clean water and hygiene, a substantial improvement compared with the early 2000s (20). According to field studies, better access to clean water is the reason for the reduced incidence of diarrhoea and typhoid (8). A study in Wardak province demonstrated that a water and hygiene intervention resulted in a 40% reduction in diarrhoea-related illness (21). Improved water and sanitation may also be associated with the reduction in outbreaks of viral hepatitis, which is mostly transmitted through contaminated food and water (22). Other contributory factors could be the wider implementation of preventive measures and control programmes, such as vaccination campaigns and distribution of insecticide-treated nets (ITNs), which are credited with reducing the incidence of poliomyelitis and malaria, respectively (8). In some parts of Afghanistan, up to 75% of the population uses ITNs (23).

We found some reports of circumstances that could potentially or actually hinder efforts to reduce the burden of childhood infections. These include

Figure 2. Trends in diagnoses of 11 leading infections (incidence per 100 000 new visits) among children under 5 years attending health facilities, 2005-2013
inadequate vaccine coverage. In the case of measles, the coverage was reported by different sources to be as low as 44% in the second quarter of 2012 (24), 62% in 2011 (3) and 56.7% in 2010/11 (20). Continued insecurity and a low level of education among women, particularly in rural areas (8), may have hampered vaccination efforts. Such low coverage in a context of high birth rates can only mean frequent outbreaks, which may also have distorted the trends in measles and poliomyelitis in our analysis.

The high rate of malnutrition among children (25), a consequence of food insecurity (26), poor economy, extreme weather conditions, and ongoing conflict, may further contribute to mortality rates. The interaction between malnutrition and childhood infections (27), which results in a vicious cycle of more infections, makes it harder to tackle the burden of infections. While the fertility rate in Afghanistan is falling, the birth rate is still high compared with other countries in the region, at 39–48 per 1000 population (28). With high fertility rates, it is harder to reduce the burden of some infections, e.g. measles, as has been observed in other regions of the world (29). Furthermore, a shortage of qualified health professionals adds to the challenge (2).

Limitations of results

Our main source of information for this study was reports to the HMIS, which started collecting data in 2003. The data are not collected under the rigorous conditions typically applied to designed studies. The majority of cases are diagnosed and reported on the basis of clinical manifestations; thus, incorrect classification, resulting in over- or under-reporting, is an occasional problem (30).

Another limiting factor is the difficulty of establishing reference points and denominators for morbidity rates, because of the lack of national census data. For this reason, we chose to use proportions rather than rates, and children attending outpatient departments as the denominator, rather than those in the general population. This might not reflect health service use by some parts of the population, e.g. those who prefer to use the private sector, which is not regulated and does not contribute data to the national system (31). It is possible that higher-earning groups have lower incidence rates of disease.

Conclusion

While children are still affected by a high burden of infectious diseases, the picture is gradually improving for at least a few key communicable diseases. Although it is hard to attribute the observed results to specific factors, recent progress in maternal health, access to clean water and hygiene, and wider implementation of control programmes – all as a result of recent public health programmes – may have been associated with the reduction in infectious diseases among children. However, if the momentum is to be sustained, policy-makers and health planners need to address remaining challenges, through continued investment in quality health services and infrastructure, especially in areas such as vaccine coverage, food security, awareness of hygiene and nutrition, training of health personnel, and programme monitoring.

Acknowledgements

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Self-reported versus proxy reported quality of life for breast cancer patients in the Islamic Republic of Iran

F. Najafi, S. Nedjat, K. Zendehdel, M. Mirzania and A. Montazeri

ABSTRACT Since quality of life (QoL) is subjective, self-reported QoL is the main source of assessment; however, in some situations the patient cannot evaluate his/her own status. In this cross-sectional study, 148 patients with breast cancer referred to the Cancer Institute of the Islamic Republic of Iran and their caregivers were selected through the consecutive sampling method. Five oncologists from this centre also evaluated the QoL of these patients. The European Organization for Research and Treatment of Cancer Quality of Life Questionnaire was completed by these 3 groups and the results compared. The patient–caregiver intra-class correlation coefficient (ICC) for all 15 QLQ.C30 domains was moderate to good (ICC = 0.41–0.76). Agreements between QoL scores of patients and those of oncologists were moderate to good, except in the 4 domains. In the patient–caregiver comparison there was 55% exact agreement, and for the patient–physician comparison agreement was 45%. The findings can be used in the patients’ decision-making process and care planning when patients with breast cancer are unable to self-report the QoL.

Qualité de vie auto-évaluée et évaluée par un tiers pour des patients atteints d’un cancer du sein en République islamique d’Iran

RÉSUMÉ La qualité de vie étant de nature subjective, l’auto-évaluation constitue l’instrument de choix pour la mesure de celle-ci. Pour autant, dans certaines circonstances, le patient n’est pas capable d’évaluer sa situation. Au cours de cette étude transversale, 148 patients adressés à l’Institut du Cancer de République islamique d’Iran pour un cancer du sein ont été sélectionnés avec leurs aidants à l’aide d’une méthode d’échantillonnage consécutif. Cinq oncologues travaillant dans ce centre ont également évalué la qualité de vie de ces patients. Le questionnaire Qualité de vie (QLQ) de l’Organisation européenne pour la Recherche et le Traitement du Cancer a été rempli par ces trois groupes et les résultats ont fait l’objet d’une comparaison. Le coefficient intra-classe (CIC) patient-aidant pour les 15 domaines du QLQ-C30 allait de modéré à bon (CIC= 0.41-0.76). La concordance entre les scores des patients portant sur la qualité de vie et ceux des oncologues étaient compris entre « modéré » et « bon », excepté dans quatre domaines. La comparaison patient-aidant donnait une concordance exacte dans 55 %, et la comparaison patient-médecin une concordance de 45 %. Les résultats peuvent être utilisés au cours du processus de décision clinique et de planification des soins quand les patients atteints d’un cancer du sein ne sont pas en mesure d’évaluer eux-mêmes leur niveau de qualité de vie.

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Introduction

Quality of life (QoL) is considered an important outcome in both health research and cancer research. It has been measured to evaluate the effects of various curative and palliative treatments, to assess the function of patients in different domains and as a criterion for clinical decision-making (1–5). The World Health Organization defines QoL as “an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (6,7).

Since QoL, a subjective concept, shows the person’s perception of his own health status and other aspects of life, it should be self-reported. In other words, the patient is the main source of QoL assessments (3,8,9). However, there are situations in which the patient is not able or does not want to properly respond to the QoL questions. For instance, in patients with cognitive or mental disorders or in patients with serious diseases like cancer where conducting the interviews is not physically or mentally feasible, proxy-reported QoL has been suggested (5,8,10–12). Patients with breast cancer who participate in QoL studies may not be able or may not wish to provide sufficient and valid information for self-reported QoL assessment. In these cases, the proxies that are in direct contact with the patient can be considered potential substitutes for self-evaluation (12,13). The main question is how close these evaluations are to the patient’s self-reported evaluation (3,10,14–16). Caregivers and health care providers are considered main candidates for the role of proxy. There are contradictory findings about QoL assessments by physicians: some studies show good patient–physician agreement (9,14,17), while others do not (3,18). On the other hand, caregivers such as a partners, parents or children may provide a more valid evaluation of the patient’s QoL since they have a longer and closer contact with, and more understanding of, the patient (8,10–22).

The characteristics of both patient and proxy, e.g., sex, age, education, the relationship between them and the contact frequency can affect agreement (8,15,21,23). This investigation, therefore, was designed to establish whether physicians or caregivers could be valid proxies for the self-assessment of QoL. As QoL is a culture-dependent concept and has different definitions in different countries, information obtained from other parts of the world cannot be used for our Region. To the best of our knowledge, there is no evidence from the Islamic Republic of Iran and the Eastern Mediterranean Region showing that agreement between self-reporting and proxy-reporting of QoL for breast cancer patients and their characteristics has been assessed.

The objective of our study was to determine whether QoL assessments by proxies (caregivers and physicians) are in agreement with self-reported QoL for breast cancer patients. The correlations between the scores obtained by the proxies and the patients themselves were calculated. The absolute level and direction of differences between the ratings was estimated. We also aimed to explore the association between patient and proxy demographic characteristics and agreement.

Methods

Study population and sampling

The study was conducted from June to December 2014. The study population comprised patients who had been referred to the medical oncology clinic of the Cancer Institute of the Islamic Republic of Iran and had been diagnosed by pathology tests as having breast cancer at least 2 months previously. The inclusion criteria were lack of any mental disorders which could interfere with answering the questionnaires, knowing Farsi, and not being involved in any other study. Patients should have completed at least 2 chemotherapy sessions because of the acute changes to QoL during the first 2 sessions. It should be noted that chemotherapy was conducted on more than 96% of the patients of the Cancer Institute; only those with very small tumours did not undergo chemotherapy. Thus, because of the availability of the chemotherapy patients, they were considered the study population. A consecutive sampling method was applied, i.e. every patient meeting the inclusion criteria was selected till the required sample size was achieved. The sample size was calculated as 148 pairs of patients–caregivers using the common statistical formula

\[
n = \frac{2\sigma^2(Z_{1-\alpha/2} + Z_{1-\beta})^2}{d^2}
\]

where \(d = 7\), \(\sigma = 21\) and \(\beta = 0.80\), with type I error of 5%. We considered in-home caregivers who were the patients’ family members or relatives in this study, not the facility-based caregivers. The caregivers were asked to fill out the questionnaires independently. Each patient’s oncologist was also requested to complete the questionnaires independently.

Study tools

The QoL was evaluated using the Farsi language third version of the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30) (24).

This questionnaire consisted of 30 items (28 4-point items and 2 7-point items on visual analogue scales) on 5 functional scales (physical, role, cognitive, emotional, social), 3 symptom scales (fatigue, nausea and vomiting, pain), 6 single items (dyspnoea, insomnia, appetite loss, constipation, diarrhoea, financial difficulties) and a global health status/QoL scale. In line
with EORTC guidelines, all scales and single items were scored 0–100. On the functional and global QoL scales, higher scores indicate better QoL, while on the symptom scales higher scores show a higher level of problems and symptoms (25).

**Demographic questionnaire**

The patients’ demographic variables covered age, marital status, education and self-reported social status (5-point Likert scale). Disease stage was obtained from the patients’ files.

The caregivers’ demographic information included age, sex, education, relationship with patient and the number of hours per day spent caring for the patient.

The caregivers and physicians were asked to review the patient’s situation and answer the QLQ-C30 whose questions had been changed to third-person to evaluate the patient’s QoL.

**Statistical methods**

The statistical analysis was conducted using SPSS, version 20, and STATA, version 12.

The descriptive analysis of the data was done to obtain the mean and standard deviation (SD) of the questionnaire scales in the 3 study groups.

To determine level of agreement between the study groups, intra-class correlation coefficients (ICCs) for patient–caregiver and patient–physician were estimated (26). An ICC ≤ 0.40 was considered poor, 0.41–0.60 moderate, 0.61–0.80 good and 0.81–1.00 excellent agreement (5,27).

The mean absolute patient–proxy differences for 15 QLQ-C30 measures was calculated, not considering the direction of differences. The mean for directional differences was also calculated, presenting the bias in proxy scores. Significant differences from zero in directional mean scores were determined by paired t-tests and interpreted as systematic bias in proxy QoL evaluations (5,28–30). We also determined 95% confidence intervals (CI 95%).

The directional mean scores were standardized by dividing them by their SD. They were interpreted as the Cohen’s d effect (0.2 = small, 0.5 = moderate and 0.8 = large bias) (31).

The magnitude of the exact response agreement and differences of more than one response category (large patient-proxy discrepancies) were calculated for each question: if the 3 raters chose exactly the same response category for each question, complete agreement was reported (3).

The association between patient-proxy agreements and characteristics was assessed using simple and multiple linear regression. Absolute and directional differences in global health status/QoL scores were considered dependent variables while the patient’s and proxy’s characteristics were considered independent variables. All variables

### Table 1 Characteristics of patients and caregivers (n = 148)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Caregivers</th>
<th>Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>79</td>
<td>148</td>
</tr>
<tr>
<td>Male</td>
<td>69</td>
<td>0.0</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Illiterate</td>
<td>6</td>
<td>35</td>
</tr>
<tr>
<td>Primary school</td>
<td>25</td>
<td>68</td>
</tr>
<tr>
<td>Secondary school</td>
<td>94</td>
<td>39</td>
</tr>
<tr>
<td>University level</td>
<td>23</td>
<td>6</td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
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<td></td>
</tr>
<tr>
<td>Married</td>
<td>104</td>
<td>113</td>
</tr>
<tr>
<td>Single</td>
<td>39</td>
<td>10</td>
</tr>
<tr>
<td>Divorced</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Widowed</td>
<td>2</td>
<td>22</td>
</tr>
<tr>
<td><strong>Disease stage</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Local</td>
<td>-</td>
<td>64</td>
</tr>
<tr>
<td>Local/regional</td>
<td>-</td>
<td>56</td>
</tr>
<tr>
<td>Advanced</td>
<td>-</td>
<td>10</td>
</tr>
<tr>
<td><strong>Relationship to patient</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>57</td>
<td>38.5</td>
</tr>
<tr>
<td>Child or parent</td>
<td>53</td>
<td>35.8</td>
</tr>
<tr>
<td>Brother or sister</td>
<td>24</td>
<td>16.2</td>
</tr>
<tr>
<td>Other relative</td>
<td>14</td>
<td>9.5</td>
</tr>
<tr>
<td><strong>Living situation</strong></td>
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<td></td>
</tr>
<tr>
<td>Same household</td>
<td>96</td>
<td>64.9</td>
</tr>
<tr>
<td>Not same household</td>
<td>52</td>
<td>35.1</td>
</tr>
<tr>
<td><strong>Subjective socioeconomic status</strong></td>
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</tr>
<tr>
<td>Poorest</td>
<td>-</td>
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</tr>
<tr>
<td>Poor</td>
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<td>50</td>
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<td>-</td>
<td>77</td>
</tr>
<tr>
<td>Rich</td>
<td>-</td>
<td>15</td>
</tr>
<tr>
<td>Richest</td>
<td>-</td>
<td>2</td>
</tr>
</tbody>
</table>

*No. varies owing to missing data.
with P-value < 0.2 in the simple linear regression analysis were included in the regression model simultaneously (32). Variables with P < 0.05 were considered statistically significant.

**Ethical considerations**

Participation in the study was completely voluntary. The objective of the study was explained to respondents and they were informed that their decision about taking part in the study did not have any effect on their treatment by the medical team member, and also that their responses would be kept confidential. The project was reviewed and approved by Tehran University of Medical Sciences ethics committee (Project number: 9111111013).

**Results**

Of 168 patients approached, 155 consented to participate in the study (92% response rate). The reasons for refusing to participate were lack of time or interest. Seven caregivers did not agree to take part. All 5 oncologists also took part in the study. Thus, the final analysis was conducted on 148 patient/proxy pairs.

The characteristics of patients and caregivers are presented in Table 1. More than 90% of caregivers were family members, with about 65% living in the same household as the patient. The mean age of patients was 47.6 (SD 10.1) years and for caregivers it was 37.6 (SD 10.2) years. The average duration of schooling for patients was 5.9 (SD 4.7) years and for caregivers it was 10.8 (SD 3.9) years. The mean time since diagnosis was 17.2 (SD 1.4) months. The mean duration of in-home care was 16.3 (SD 8.3) hours.

Table 2 shows the mean QLQ-C30 scores for patients from their own and from the proxies’ point of view. The factor with the highest mean score on the symptom scale was financial difficulties according to all 3 groups. On the functional scale, cognitive functioning gave the highest score in the viewpoint of patients and physicians while the caregivers scored role functioning highest. Patients scored global health status lower than the physicians and caregivers.

The correspondence between patients’ and proxies’ scores is shown in Table 3. The patient–caregiver agreement was not classed as weak on any of the scales (ICC < 0.40), while on the cognitive function, role function, insomnia and diarrhoea scales, the patient–physician agreement was weak.

For patient–caregiver, the mean absolute difference ranged from 9.96 to 21.40; for patient–physician this was 15.59 to 24.55 (Table 3). The mean patient–caregiver directional difference ranged from −5.01 to 6.53 and for patient–physician it was between −7.16 and 7.21.

The caregivers reported statistically significantly lower levels of QoL for patients for cognitive function, social function and fatigue compared with the patients’ reports, while the patients’ emotional function QoL was significantly higher from the caregivers’ point of view.

The differences in the QoL reports of patients and physicians were statistically significant on 11 scales, with the emotional function and global health status/QoL of the patients significantly better in the physicians’ viewpoint (Table 3).

Patient–proxy Cohen’s d-values ranged from small to moderate (Table 3).

We used 4144 comparisons (28 questions × 148 cases) to calculate the “exact response category” and “large patient–proxy discrepancies”. The exact response agreement, i.e. the proportion of cases for which 2 raters had chosen exactly the same response category, was 55.0% (2291) for patient–caregiver and 45.0% (1870) for patient–physician reports. Complete agreement (i.e. 3 raters choosing exactly the same response category) was 27.5% (1143). Large patient–caregiver discrepancy was seen in 6.5% (271) of cases; this discrepancy was 10.1% (419) for patient–physician.

**Association between patient-proxy agreement and patients’ and proxies’ characteristics**

None of the variables had a significant association with the patient–caregiver agreement on the Global Health Status/QoL in the simple linear regression analysis (Table 4). In the multiple linear regression, the only significant variable was patients’ age. i.e. older age was associated with a greater absolute difference.

In both simple and multiple linear regression, the longer the duration of schooling, the lower the directional difference (Table 4).

**Patient–physician agreement on the Global Health Status/QoL score**

In the simple linear regression analysis, directional difference was statistically significantly greater with older age of the patient. None of the variables was significantly associated with absolute difference in the simple and multiple linear regression (Table 4).

**Discussion**

This study compared the QoL rating of patients with breast cancer receiving chemotherapy with that estimated by caregivers and physicians using the EORTC QLQ. We found that the none of the ICCs between the patients and caregivers were ≤ 0.40 (weak agreement) on all scales (ICC range: 0.41–0.76). In a study on cancer patients in the Netherlands using the same questionnaire, the ICC range was 0.46–0.73 and the lowest agreement was reported for insomnia (5). The greatest absolute difference in our study was 21.4 on the insomnia scale, which was in accordance with the findings of the Netherlands study (5). The severity of pain, dyspnoea and nausea compared with
the severity of sleep problems could be
the reason for the better agreement.

In the patient–physician rating,
agreements were generally moderate.
The only 2 scales with good patient–
physician agreement were fatigue and
constipation. These were in line with
the findings of Blazeby et al. in a study
conducted in the United Kingdom on
52 oesophageal cancer patients (33).
In that study, there was weak patient–phy-
sician agreement on certain scales, in-
cluding insomnia, cognitive functional,
and diarrhoea; the strongest agreement
was seen for the pain scale, similar to our
findings. In accordance with some other
studies, patient–physician agreement
for the symptom scales was greater than
for the functional scales (33, 34). The
physicians appear to pay more atten-
tion to clinical problems and the com-
lications caused by treatment, while
patients' daily activities, concentration
and entertainment, covered in the role
and cognitive functional scales, do not
appear to have so much importance
to them. Cognitive function and role
function are the personal experiences
of patients, which physicians cannot
observe routinely. Since all our patients
were non-hospitalized, physicians could
not observe them long enough. Since
caregivers can see and feel the pa-
tients' daily activities and problems, they
have non-clinical viewpoints, and hence
different kinds of agreements.

Directional differences show
that the caregivers reported a worse
situation for the patients in the physical,
role functional, emotional and global
health scales, considering the negative
directional differences. The highest di-
rectional difference was −5.01 for the
emotional scale. These are in line with
the findings of Sneeuw et al. in the Neth-
erlands (5).

On the emotional scale, the physi-
cians overestimated the patients' QoL
status, while on the 9 other scales they
underestimated the status. Generally in
our study and in other research (5),
most differences were seen in the more
Table 2
Descriptive statistics, 95% CI, and paired t-test results of patient and proxy EORTC QLQ-C30 scores (range 0 to 100) (n = 148)

<table>
<thead>
<tr>
<th>Scale</th>
<th>No. of items</th>
<th>Patient score</th>
<th>Caregiver score</th>
<th>Physician score</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Functional</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical</td>
<td>5</td>
<td>68.51 (19.60)</td>
<td>65.33–71.70</td>
<td>70.27 (19.77)</td>
</tr>
<tr>
<td>Role</td>
<td>2</td>
<td>71.17 (27.05)</td>
<td>66.78–75.56</td>
<td>72.86 (23.43)</td>
</tr>
<tr>
<td>Emotional</td>
<td>4</td>
<td>42.90 (25.52)</td>
<td>38.76–47.05</td>
<td>47.91 (24.06)*</td>
</tr>
<tr>
<td>Cognitive</td>
<td>2</td>
<td>74.43 (23.28)</td>
<td>70.66–78.22</td>
<td>68.24 (23.43)*</td>
</tr>
<tr>
<td>Social</td>
<td>2</td>
<td>55.74 (26.13)</td>
<td>51.49–59.99</td>
<td>52.02 (27.27)*</td>
</tr>
<tr>
<td>Global health status/QoL</td>
<td>2</td>
<td>43.86 (23.57)</td>
<td>40.03–47.69</td>
<td>45.49 (22.30)</td>
</tr>
<tr>
<td><strong>Symptom</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fatigue</td>
<td>3</td>
<td>52.77 (24.79)</td>
<td>48.75–56.80</td>
<td>46.24 (23.18)*</td>
</tr>
<tr>
<td>Nausea &amp; vomiting</td>
<td>2</td>
<td>34.68 (27.86)</td>
<td>30.16–39.21</td>
<td>34.00 (27.75)</td>
</tr>
<tr>
<td>Pain</td>
<td>2</td>
<td>42.34 (25.67)</td>
<td>38.17–46.51</td>
<td>41.89 (22.79)</td>
</tr>
<tr>
<td>Dyspnoea</td>
<td>1</td>
<td>41.21 (32.61)</td>
<td>35.91–46.51</td>
<td>37.83 (28.47)</td>
</tr>
<tr>
<td>Insomnia</td>
<td>1</td>
<td>47.29 (30.86)</td>
<td>42.28–52.31</td>
<td>45.27 (28.57)</td>
</tr>
<tr>
<td>Appetite loss</td>
<td>1</td>
<td>43.91 (30.62)</td>
<td>43.92–38.94</td>
<td>40.99 (27.79)</td>
</tr>
<tr>
<td>Constipation</td>
<td>1</td>
<td>20.49 (27.90)</td>
<td>15.96–25.03</td>
<td>16.89 (24.12)</td>
</tr>
<tr>
<td>Financial difficulties</td>
<td>1</td>
<td>64.18 (30.88)</td>
<td>59.17–69.21</td>
<td>63.06 (30.15)</td>
</tr>
</tbody>
</table>

SD = standard deviation; CI = confidence interval.

(*) P < 0.05.
Table 3 Patient-proxy agreement on the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30) (n = 148)

<table>
<thead>
<tr>
<th>Scale/item</th>
<th>Correlation</th>
<th>Absolute difference</th>
<th>Directional difference</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Patient &amp; caregiver</td>
<td>Patient &amp; physician</td>
<td>Mean (SD)</td>
</tr>
<tr>
<td><strong>Functional scale</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical</td>
<td>0.76</td>
<td>0.76</td>
<td>0.59</td>
</tr>
<tr>
<td>Role</td>
<td>0.70</td>
<td>0.71</td>
<td>0.26</td>
</tr>
<tr>
<td>Emotional</td>
<td>0.61</td>
<td>0.60</td>
<td>0.54</td>
</tr>
<tr>
<td>Cognitive</td>
<td>0.47</td>
<td>0.45</td>
<td>0.41</td>
</tr>
<tr>
<td>Social</td>
<td>0.66</td>
<td>0.65</td>
<td>0.55</td>
</tr>
<tr>
<td>Global health status/QoL</td>
<td>0.75</td>
<td>0.75</td>
<td>0.62</td>
</tr>
<tr>
<td><strong>Symptom scale/item</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fatigue</td>
<td>0.64</td>
<td>0.61</td>
<td>0.64</td>
</tr>
<tr>
<td>Nausea and vomiting</td>
<td>0.74</td>
<td>0.74</td>
<td>0.62</td>
</tr>
<tr>
<td>Pain</td>
<td>0.56</td>
<td>0.56</td>
<td>0.63</td>
</tr>
<tr>
<td>Dyspnoea</td>
<td>0.60</td>
<td>0.72</td>
<td>0.60</td>
</tr>
<tr>
<td>Insomnia</td>
<td>0.42</td>
<td>0.41</td>
<td>0.38</td>
</tr>
<tr>
<td>Appetite loss</td>
<td>0.62</td>
<td>0.62</td>
<td>0.49</td>
</tr>
<tr>
<td>Constipation</td>
<td>0.62</td>
<td>0.60</td>
<td>0.62</td>
</tr>
<tr>
<td>Diarrhoea</td>
<td>0.60</td>
<td>0.60</td>
<td>0.37</td>
</tr>
<tr>
<td>Financial difficulties</td>
<td>0.50</td>
<td>0.50</td>
<td>0.47</td>
</tr>
</tbody>
</table>

Cl = confidence interval; SD = standard deviation; r = Pearson correlation; ICC = intra-class correlation coefficient; d = standardized difference (mean difference/standard deviation of difference).

*P < 0.05.

Study limitations:

One of the study limitations was that only patients who participated in our study. Although in practice we did need not participate in our study. All patients who were considered the same as QoL.

It is important to point out that there is no gold standard for QoL estimation, therefore we cannot always consider the best by proxies and subjective health. However, it was assessed as closer to the objective health as was assessed as closer to the objective health and was considered the same as QoL.

Large patient-proxy discrepancies were seen for 6.8% of patients-proxy. This discrepancy is lower than the finding of Sneeuw et al. using the Dartmouth COOP Functional Health Assessment charts/WONCA (3) who reported 17% and 18% respectively.

The different study tools are in line with the Iranian culture. In conclusion, our findings of Sneeuw et al. (5) there was no significant association between patient-proxy differences and demographic variables.
The caregiver’s burden and health status are important variables which were not assessed in our study although they can affect the associations we measured.

Considering the greatest patient-proxy discrepancy was on the emotional scale, it was suggested that patients with a wide range of mental health considerations be included in future studies. In addition, since our study population comprised patients who were referred to the medical oncology clinic of the Cancer Institute, the results should be generalized with caution.

From our findings it appears that home caregivers can be considered a more authentic source of information for patients’ QoL. Caution should be used in the interpretations of physicians’ reports on patients’ QoL, especially in the cognitive and role functional domains. Our findings could be used in the patient decision-making process, research and care planning when patients with breast cancer are unable to self-report.

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**Competing interests:** None declared.

## References


Messaging standard requirements for electronic health records in Islamic Republic of Iran: a Delphi study

M. Ahmadi 1, S. Foozonkhah 2, L. Shahmoradi 3 and A.D. Mahmodabadi 1

ABSTRACT The present descriptive-comparative study was conducted to give an overview of the messaging standards that are necessary for interoperable electronic health records (EHRs). We designed a preliminary model after data collection and compared the messaging standards of Health Level Seven (HL7) and the International Organization for Standardization (ISO). The data were assessed with the Delphi technique. A comprehensive model for the messaging standards of EHRs in the Islamic Republic of Iran was presented in three pivots: structural characteristics (standard for all EHRs, XML-based and object-oriented messages, and dual model); model specifications (reference model, archetypes and classes of reference model), and general features (distinct ontology, mapping with other standards, and using reference archetypes for exchanging documents).

In conclusion, we gave an overview of messaging standards for the interoperability of EHRs and experts selected ISO13606 as a suitable standard for the Islamic Republic of Iran.

Critères des normes de messagerie pour les dossiers de santé électroniques en République islamique d'Iran : une étude selon la méthode de Delphes


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Introduction

Electronic health records (EHRs) can be processed by computer and stored and exchanged securely by authorized users. Development and use of messaging standards for EHRs are needed for information exchange (1–4), and the absence of standards and lack of coordination between systems have made healthcare data sharing difficult (5–8). Lack of standards also hinders the widespread use of EHRs and integrated systems in healthcare services in the Islamic Republic of Iran. So, selecting appropriate standards is a priority for the development of national EHRs (9,10).

Syntactic interoperability guarantees exchange of the data structure but does not ensure that the meaning will be interpreted identically by all parties. HTML and XML are good examples of syntactic standards. Semantic interoperability guarantees that the meaning of a structure is unambiguously exchanged between people (8). Agreement on a standardized set of domain-specific conceptual models and agreement on standardized terminology associated with controlled vocabulary are two basic requisites for semantic interoperability. Currently, there are different health informatics standards that define domain models, such as HL7 version 3 Reference Information Model (RIM) and ISO EN 13606 “Health Informatics – EHR communication” (1,11).

Since the 1980s, many countries have tried to implement e-health and then EHRs. This has had a significant influence on the development of EHR standards by the two main international e-health standard development organizations: HL7 (Health Level 7) and ISO (International Organization for Standardization). HL7 is based in the United States of America and is accredited by the American National Standards Institute (ANSI). HL7 operates in the healthcare field and covers the Americas, some European and Asian countries, and Australia. The purpose of HL7 is to provide standards for data exchange between different types of healthcare computer applications (12–14). HL7 is formed of health care and information professionals who establish standards for exchange, management and integration of healthcare information (1). HL7 version 3 uses an object-oriented development methodology and an RIM to create messages; it also uses XML-based messages, a message development structure with an emphasis on semantic interaction, and interactive models (15–17). In addition to the reference model, HL7 version 3 uses a template to describe specific patterns for description and interpretation by humans rather than machines. Four types of models are used in HL7: case, information, interaction and message design models (15,18). Clinical Document Architecture (CDA) is one of the HL7 standards that has been created for presenting and machine processing of clinical documents (19).

The ISO Technical Committee, ISO/TC 215, is an international standard body that deals with health informatics (20). The EN 13606 (Health Informatics – Electronic Health Record Communication) standard is a European norm from the European Committee for Standardization (CEN) that is also approved as an international ISO standard. It is designed to achieve semantic interoperability for EHR communication and ISO is now responsible for development of the EN 13606 standard. The standard defines architecture for communicating part or all of EHRs. ISO 13606 has two major ontologisms (21,22) and five parts (reference model, archetype interchanges specification, reference archetypes and term lists, security, and interface specification) (6,16,21,23).

The features of the HL7 and ISO13606 messaging standards are shown in Table 1. The strengths of HL7 version 3 have been investigated in six pivots: interoperability, RIM, simplicity, object orientation, dual model and use of XML. Its weaknesses are also presented in three pivots: structural problems, difficulties in use, and relationship with other standards (1,12,13,20–24). The strengths of ISO13606 include simplicity, archetype, dual model, reference model, object orientation and linkage or mapping with other terminology. The lack of relationship between Parts 1–5 is one of the weaknesses of this standard. No more weaknesses have been mentioned in other studies because of the lack of long-term use of the standard (1,22,25,28).

The responsibility for implementing EHRs in the Islamic Republic of Iran lies with the Statistic and Information Technology Office in the Ministry of Health and Medical Education that works on EHR infrastructure, standards and requirements. Furthermore, the Corresponding Technical Committee 215 of ISO has been established in the Ministry. Its mission is the implementation of e-health by preparation of national and international standards in health informatics.

Considering the importance of messaging standards for achieving EHRs and the recent decision by the Iran Ministry of Health and Medical Education to develop EHRs for individuals, this study investigated the EHR messaging standards and proposed an appropriate model for the Islamic Republic of Iran.

Methods

This descriptive–comparative study was conducted in the Islamic Republic of Iran between 2011 and 2012 in the following 3 phases.

Phase I: literature review

We reviewed books, journals, reports and websites and identified HL7 (http://www.hl7.org) and ISO (http://www.ISO.org) as organizations that have messaging standards for EHRs. Other organizations do not have messaging standards specific for EHRs.
Phase II: model design

After Phase I, to design a preliminary study pattern, we surveyed messaging standards criteria based on three major pivots (structural features, model specification and general features).

Phase III: testing questionnaire reliability and validity of proposed model

To design the proposed model, we used the Delphi technique. A questionnaire was designed. For each item in every pivot, three options were considered: I agree, I disagree, and no idea. Pivot priority was considered in model specification. To assess the validity of the questionnaire, it was administered to several academic professionals, medical record specialists and health information administrator. After 10 days, the same individuals were asked to complete the questionnaire for a second time. The data collection method was approved by the specialists.

After testing the reliability, the questionnaires were sent to 37 specialists, including university staff in health information management departments and experts in the EHR domain of the Ministry of Health and Medical Education who were familiar with EHR standards. The questionnaires were either sent by e-mail or delivered in person, and reminders were sent after a few days. Thirty-three participants completed the questionnaires. The questionnaires were received within 7 weeks and the data were collected and analysed.

We applied descriptive statistical methods for data analysis. For the first part of the questionnaire, the items in the model that were approved by < 50% of experts were excluded and those approved by ≥ 75% of the experts were adopted. The items approved by 50–74% of the experts and their recommended items based on other options were identified. These items were assessed in the second stage of the Delphi technique to achieve a consensus. In the second stage, questionnaires were sent to the same 37 experts, and 29 completed the questionnaires. The second part of the questionnaire related to the standard models and the questions were designed based on their priority. The frequency was calculated for each priority and then the means of the priorities were calculated. Calculated priorities ranged from 1 to 3, and in some cases from 1 to 6. The scores were multiplied by the response frequency and divided by the number of respondents. When analysing the results, the smaller the percentage, the greater the priority and vice versa. The final model design was based on the means of the priorities.

Table 1 Features of HL7 and ISO 13606 messaging standards

<table>
<thead>
<tr>
<th>Features of messaging standards of HER</th>
<th>ISO13606</th>
<th>HL7</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mission</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Defines rigorous and stable information architecture for communicating part or all of the HER</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Standards for the exchange, management, and integration of healthcare information</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Included parts</td>
<td></td>
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</tr>
<tr>
<td>Models</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Archetype</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Template</td>
<td>–</td>
<td>✓</td>
</tr>
<tr>
<td>Available model</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Information model</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Use case model, interaction model, message design model</td>
<td>–</td>
<td>✓</td>
</tr>
<tr>
<td>Core model</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Reference model</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Classes of reference model</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Act, roll, participation, entities, act relationship, roll link</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>HER – extract, folder, composition, section, entry, element, cluster, record component, audit-information, function role, attestation-information, link</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Development plan</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Message development framework and hierarchical message description</td>
<td>–</td>
<td>✓</td>
</tr>
<tr>
<td>Other criteria</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Ontology</td>
<td>✓</td>
<td>–</td>
</tr>
<tr>
<td>Dual model</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Architecture for documentation exchange</td>
<td>–</td>
<td>✓</td>
</tr>
<tr>
<td>Term lists</td>
<td>–</td>
<td>✓</td>
</tr>
<tr>
<td>Mapping with other standards</td>
<td>✓</td>
<td>–</td>
</tr>
<tr>
<td>Exchange language</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>XML</td>
<td>✓</td>
<td>✓</td>
</tr>
</tbody>
</table>

*Ontology is the structural frameworks for information that is transferred by means of systems, therefore, inevitably messaging standards use it.

HER = electronic health record.
Results

In the Delphi phases, about 56.5% and 43.5% of the specialists were women and men, respectively, and 52.2% were aged 25–34 years and the rest 35–54 years. About 43.5% of the participants had 3–9 years of work experience and 56.5% had > 10 years. For academic achievement, 17.4% had a master’s degree, 43% had a bachelor’s degree and 78.3% had a PhD. The field of study was health information management in 82.6% of the participants and health informatics and software engineering in 13%. A total of 65.2% were faculty members while about 34.8% were not.

According to the specialists’ views about appropriate messaging standards for EHRs, standards for exchange, management and integration of healthcare data were necessary. In other words, messaging standards were deemed necessary for all areas of health care. Reference models were most important for the essential and main parts of the messaging standards for EHRs. The emphasis was on the reference model and interactive model of EHRs. The use of terminology such as SNOMED (Systematized Nomenclature of Medicine), LOINC (Logical Observation Identifiers), and ICD-10 (International Statistical Classification of Diseases and Related Health Problems, 10th Revision), is considered suitable for the ontology of the EHRs (Table 2).

The experts’ emphasis on structural features required for EHRs was based on XML-based and object-oriented messages (Table 3).

To select an appropriate model for messaging standards and designing its classes, essential subclasses of each class were expressed and the priority of each one was determined by the experts (Table 4).

Discussion

A major healthcare challenge is to create interoperability between EHR systems that can be achieved with the selection of appropriate standards (10). Some comparative studies have shown that some organizations have a messaging standard like HL7 for the exchange, management and integration of healthcare information and ISO13606 defines rigorous and stable information architecture for communicating part or all of the EHRs of a single recipient of care (20, 25). The proposed model of Iranian experts emphasized the use of standards for exchange of data and information in all areas of health care.

Atalag et al. (1) and Jaffe (29) determined the structural features of standards for EHRs that included the use of RIM, messages based on XML, message development framework with an emphasis on interoperability, object orientation, interaction model, and displaying complex relationships. The Iranian experts also had an emphasis on XML-based and object-oriented messages. Although other studies have emphasized the information models, the experts in our study placed this feature as the second priority.

Wollersheim et al. have suggested that, to present the clinical documentation components, each messaging standard uses a number of models and the types of model in the 2 standards are different and based on different objectives (27). Among the existing models, experts emphasize the reference and interaction models. Wollersheim et al. have reported that the reference model provides a base for data definition and includes several classes that support legal requirements and record management functions (27). The model makes it possible to access further requirements of EHRs, which leads to the exchange of information between discrete systems.

Results of previous studies have revealed that ontology is used to share and reuse specific domains. As ontology is the structural framework for the transfer of information by systems, its use by messaging standards is inevitable (20, 26, 30). The Iranian experts emphasized the use of terminology such as SNOMED, LOINC and ICD10 for ontology. SNOMED and LOINC are not commonly used in the Islamic Republic of Iran; therefore, the experts emphasized the use of ICD10 for death and disease coding.

Several studies have indicated that the HL7 organization uses the necessary terminology when it exists in a specific area; otherwise, the technical committee will create it. With regard to

<table>
<thead>
<tr>
<th>General feature</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scope of standard</td>
<td>56.5</td>
</tr>
<tr>
<td>Essential and main parts</td>
<td>76.2</td>
</tr>
<tr>
<td>Essential models</td>
<td>53.0</td>
</tr>
<tr>
<td>Information model</td>
<td>71.4</td>
</tr>
<tr>
<td>Use case model</td>
<td>52.4</td>
</tr>
<tr>
<td>Interaction model</td>
<td>81.0</td>
</tr>
<tr>
<td>Use of current terminologies like SNOMED and LOINC</td>
<td>85.7</td>
</tr>
</tbody>
</table>

EHR = electron health record; LOINC = Logical Observation Identifiers; SNOMED = Systematized Nomenclature of Medicine.
Table 3  Experts’ opinion of the structural features of EHR messaging standards

<table>
<thead>
<tr>
<th>Structural features</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Use of reference information model</td>
<td>76.2</td>
</tr>
<tr>
<td>Message based on XML</td>
<td>85.7</td>
</tr>
<tr>
<td>Message development framework with emphasis on interoperability</td>
<td>61.9</td>
</tr>
<tr>
<td>Object oriented</td>
<td>85.7</td>
</tr>
</tbody>
</table>

Table 4  Experts’ opinion of essential subclasses for act, participation, entity, role, composition, section, entry, cluster, function role, and authentication in EHRs

<table>
<thead>
<tr>
<th>Essential EHR classes</th>
<th>Essential subclasses</th>
<th>Mean of priority</th>
</tr>
</thead>
<tbody>
<tr>
<td>Essential subclasses for act class</td>
<td>Observation</td>
<td>2.3</td>
</tr>
<tr>
<td></td>
<td>Procedures (medication or surgery)</td>
<td>1.8</td>
</tr>
<tr>
<td></td>
<td>Supply</td>
<td>3.0</td>
</tr>
<tr>
<td></td>
<td>Financial action</td>
<td>3.4</td>
</tr>
<tr>
<td></td>
<td>Management</td>
<td>3.3</td>
</tr>
<tr>
<td>Essential subclasses for participation class</td>
<td>Performer</td>
<td>1.5</td>
</tr>
<tr>
<td></td>
<td>Author</td>
<td>2.6</td>
</tr>
<tr>
<td></td>
<td>Subject</td>
<td>1.6</td>
</tr>
<tr>
<td>Essential subclasses for entity class</td>
<td>Physician, nurse, other care staff and non-care staff</td>
<td>1.4</td>
</tr>
<tr>
<td></td>
<td>Hospital or other healthcare organizations</td>
<td>2.0</td>
</tr>
<tr>
<td></td>
<td>Material and care devices</td>
<td>2.3</td>
</tr>
<tr>
<td>Essential subclasses for role class</td>
<td>Patient</td>
<td>2.6</td>
</tr>
<tr>
<td></td>
<td>Attending physician or surgeon</td>
<td>1.6</td>
</tr>
<tr>
<td></td>
<td>Nurse</td>
<td>2.1</td>
</tr>
<tr>
<td></td>
<td>Paraclinical staff</td>
<td>3.2</td>
</tr>
<tr>
<td></td>
<td>Financial staff</td>
<td>4.2</td>
</tr>
<tr>
<td>Essential subclasses for composition class</td>
<td>Clinical report, e.g., documentation of patient progress</td>
<td>1.1</td>
</tr>
<tr>
<td></td>
<td>Paraclinical report such as laboratory results</td>
<td>1.7</td>
</tr>
<tr>
<td></td>
<td>Health assessment</td>
<td>2.9</td>
</tr>
<tr>
<td>Essential subclasses for section class</td>
<td>Reason of encounter</td>
<td>1.1</td>
</tr>
<tr>
<td></td>
<td>Past history, family history</td>
<td>2.8</td>
</tr>
<tr>
<td></td>
<td>Allergy information</td>
<td>3.0</td>
</tr>
<tr>
<td></td>
<td>Laboratory result</td>
<td>2.7</td>
</tr>
<tr>
<td>Essential subclasses for entry class</td>
<td>Clinical signs, e.g., vital signs</td>
<td>2.0</td>
</tr>
<tr>
<td></td>
<td>Observation, test results</td>
<td>2.5</td>
</tr>
<tr>
<td></td>
<td>Prescribed drugs</td>
<td>2.7</td>
</tr>
<tr>
<td></td>
<td>Differential diagnosis</td>
<td>2.4</td>
</tr>
<tr>
<td>Essential subclasses for cluster class</td>
<td>Test results, e.g., electroencephalogram</td>
<td>2.0</td>
</tr>
<tr>
<td></td>
<td>Weighted differential diagnoses</td>
<td>1.8</td>
</tr>
<tr>
<td></td>
<td>Drug prescription organized as a time series</td>
<td>2.0</td>
</tr>
<tr>
<td>Essential subclasses for function role class</td>
<td>Function that was performed in the situation</td>
<td>1.2</td>
</tr>
<tr>
<td></td>
<td>Identity of the agent performing the function</td>
<td>1.9</td>
</tr>
<tr>
<td></td>
<td>The mode in which participation was made (e.g., in person, by telephone)</td>
<td>2.6</td>
</tr>
<tr>
<td></td>
<td>The type of service location, department</td>
<td>2.5</td>
</tr>
<tr>
<td>Essential subclasses for attestation information class</td>
<td>The date and time at which attestation occurred</td>
<td>2.1</td>
</tr>
<tr>
<td></td>
<td>The person who made this attestation</td>
<td>1.3</td>
</tr>
</tbody>
</table>

EHR = electronic health record.
using ontology, the ISO13606 standard tries to maintain coordination with common terminology. In the context of ISO13606 standards, plans have been devised for homogenization with other standards such as HL7 and openEHR (6). A research by Karla has suggested that different standards have to be matched with each other to meet the broad need for healthcare (31), which was confirmed by the current study.

Our results also indicate that the 2 standards have specific methods for the exchange of clinical documents. HL7 uses a CDA standard and ISO13606 uses reference archetypes (1,6,20). Iranian experts put emphasis on reference archetype for the exchange of clinical documents.

The proposed model is presented in three main pivots of EHR messaging standards: structural characteristics (standards for all EHRs, XML-based and object-oriented messages, and dual model), model specifications (reference model, archetypes, and classes of reference model), and general features (separate ontology, mapping with other standards, and using reference archetypes for exchanging documents).

Other countries like Turkey, Egypt, Saudi Arabia, South Africa and Malaysia emphasize XML, reference models and interaction models as requirements for messaging standards. Previous studies – Other countries like Turkey, Egypt, Saudi Arabia, South Africa and Malaysia emphasize XML, reference models and interaction models as requirements for messaging standards. Previous studies have also mentioned the use of special standards for exchanging documents (32–35).

EHRs and their standards are important in the Islamic Republic of Iran; therefore, more research in this field must be conducted. According to the results of the current study and research experience, ISO 13606 is suitable for the situation in the Islamic Republic of Iran. Also, having a committee corresponding to ISO/TC 215 in the Iranian Ministry of Health and Medical Education provides an opportunity for better cooperation with ISO.

Considering the approach of the Ministry of Health and Medical Education towards the creation of an EHR for each Iranian, and the absence of customized messaging standards in the healthcare system, we recommend using the proposed model in an attempt to meet the requirements for messaging standards in the Islamic Republic of Iran (Figure 1).

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**Competing interests:** None declared.

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**Figure 1** Proposed model for requirements for messaging standards in the Islamic Republic of Iran.
References


Oral health status, knowledge and practice among pregnant women attending Omdurman maternity hospital, Sudan

H.M. El-Mahdi Ibrahim¹, A.M. Mudawi¹ and I.A. Ghandour²

ABSTRACT Good oral health is important in pregnancy but little is known about the oral health and knowledge and practices of pregnant Sudanese women. This cross-sectional study was conducted to address this gap. A sample of 420 pregnant women attending the prenatal clinic at Omdurman maternity hospital were interviewed and examined for caries and periodontal disease. The mean age of the women was 27.1 (SD 5.8) years, 52.4% had > primary school education and 7.1% were employed. Only 12% had a high level of oral health knowledge and 21.2% a positive attitude towards oral health. Most of the women (65.9%) had poor oral health practices; only 10.2% had visited a dentist during pregnancy. On clinical examination, 58.6% had healthy gums while 12.1% had bleeding gums and 22.9% had calculus. The mean decayed, missing and filled teeth value was 1.16 in the age group 16−19 years and 3.49 in age group ≥ 20 years. These findings suggest the need for oral health programmes as part of prenatal care for pregnant Sudanese women.

État de santé bucco-dentaire, connaissances et pratiques en la matière parmi des femmes enceintes à la maternité de l'hôpital d'Omdourman (Soudan)

RÉSUMÉ Une bonne santé bucco-dentaire est importante en période de grossesse, mais peu d’informations sont disponibles sur l’état de santé bucco-dentaire, les connaissances et les pratiques des femmes enceintes soudanaises en la matière. La présente étude transversale a été conduite afin de combler cette lacune. Un échantillon de 420 femmes enceintes de la clinique prénatale de la maternité de l’hôpital d’Omdourman ont été interrogées et examinées afin de déterminer si elles souffraient de caries et de parodontopathies. L’âge moyen des femmes étaient de 27,1 ans (ET 5,8) ; 52,4 % avaient suivi un enseignement primaire, et 7,1 % avaient un emploi. Seulement 12 % d’entre elles avaient une bonne connaissance de la santé bucco-dentaire, et 21,2 % démontraient une attitude positive en la matière. La majorité des femmes (65,9 %) avaient de mauvaises pratiques d’hygiène bucco-dentaire, et seulement 20 % s’étaient rendues chez un dentiste au cours de leur grossesse. À l’examen clinique, 58,6 % avaient des gencives saines, contre 12,1 % qui souffraient de saignements gingivaux et 22,9 % qui avaient du tartre dentaire. La moyenne de l’indice CAO (dent cariée, absente ou obturée) était de 1,16 pour le groupe d’âge des 16−19 ans, et de 3,49 pour le groupe d’âge des 20 ans et plus. Ces résultats laissent penser qu’il existe un besoin en programmes de santé bucco-dentaire dans le cadre des soins prénataux pour les femmes enceintes soudanaises.
Introduction

Pregnancy is a natural process characterized by physiological changes, including fluctuating hormones. These changes increase susceptibility to oral infections such as pregnancy gingivitis, periodontitis and oral pyogenic granuloma (1–4). Periodontal disease has been reported to be associated with other health problems such as cardiovascular disease, diabetes, low birth weight and preterm birth (5–7). In addition, certain cultural beliefs may impede proper nutrition and the ability of pregnant women to achieve good oral health (8). Unfortunately, it is widely observed that many women with obvious signs of oral disease do not visit a dentist before, during or after pregnancy (9). Some, fear that they or their fetus might be harmed by dental treatment, others consider poor oral health status during pregnancy as normal (10). Appropriate knowledge, attitude and behaviour of pregnant women could prevent oral problems and their complications during pregnancy (11).

A woman’s knowledge of and action on her own oral health are important for the oral health of her children (12). Children whose mothers have poor oral health are 5 times more likely to have oral health problems than children whose mothers have good oral health (13). Mothers are the main source of transmissible cariogenic bacteria to their children; it has been shown that Streptococcus mutans of mother and child are phenotypically and genotypically similar (14).

Pregnant women are readily accessible as most of them have regular antenatal check-ups. Furthermore, their key position in the family enables them to have a great influence over the behaviour of family members and they play a very important role in educating the young generation (15). Thus, educating pregnant women on oral health can be an effective way of conveying dental health education to the general public, starting at the individual level, then to the family and finally to the community level (16).

Pregnant women in Sudan generally have limited access to oral health education and no previous study in Sudan has assessed the oral health status, and knowledge, attitude and dental practices of pregnant women. The aim of this study therefore was to assess the oral health status, knowledge, attitude and practices among a sample of pregnant Sudanese women in order to obtain the base-line data needed to establish an oral health preventive programme during pregnancy.

Methods

Study design and setting

This was an observational, cross-sectional, hospital-based study conducted among pregnant women attending the prenatal outpatient clinic in Omdurman Maternity Hospital. This hospital was selected because it is the largest government maternity hospital in Sudan and a considerable number of pregnant women of different socioeconomic levels attend daily for examination and regular prenatal care. It has 12 wards for delivery (248 beds) and 5 delivery rooms (25 beds) with about 65 deliveries per day. In addition the hospital has an outpatient clinic and prenatal care with approximately 350 visits a day from pregnant women.

Sample size and selection

The minimum sample size was computed using the formula $n = \frac{z^2pq}{d^2}$, where $n =$ required sample size; $z = 1.96$ at 95% confidence interval; $p =$ anticipated prevalence of women with good oral health knowledge (set at 50%); $q = 1 - p$; $d =$ the desired precision (set at 0.05). Thus, the computed minimum sample size was 384 women. This was increased to account for attrition.

All patients available in the clinic when the researcher was present were approached and informed verbally about the study. The women were informed that non-participation would not affect their care. Those who agreed to participate were included in the study after signing a written informed consent form. Illiterate women had the form read to them and marked the form if they consented to participate. Those agreeing to participate were interviewed about their medical history and those who were suffering from any mental or physical disease were excluded.

After refusals and ineligibility to participate were excluded, 420 pregnant women from the prenatal clinic of Omdurman maternity hospital were enrolled in the study over a period of 8 weeks to reach the required sample size (June–July 2010).

Data collection

The research is composed of two parts; face-to-face interview and clinical examination.

Face-to-face interview

All the participants were interviewed by the first author and a questionnaire (of 32 questions) was completed. The questionnaire was adapted by the research team from standard questionnaires used in other studies (16–18). It was translated into Arabic by postgraduate students (Division of Preventive and Community Dentistry, University of Khartoum) and back translated into English by the staff of the Division of Preventive and Community Dentistry, University of Khartoum. This criterion validation step was supported by the research team’s expertise and collective judgement on the final refined version of the questionnaire. To assess reliability, the questionnaire was pilot-tested on a group of 35 women. This pilot process revealed the optimal time for questionnaire completion by participants, while the statistical analysis revealed a good agreement with kappa statistics result ranging from 0.75% to 100%.
The questionnaire had 5 parts: 1) Sociodemographic data (age, nationality, educational level, occupation, number of current pregnancy, average of family income, medical insurance); 2) Perceived oral health (current and last dental pain, gum problem); 3) Dental practice (tooth-brushing, other oral hygiene methods, dental visit before and during pregnancy); 4) Attitude before and during pregnancy (dental care behaviour during pregnancy, behaviour towards dental pain during pregnancy); 5) Knowledge about the cause of tooth decay, gum disease and how they can be prevented, and the source of knowledge.

The Registrar General’s classification of social classes groups for the United Kingdom (UK) was used in this study as it is widely used in medical research (19). This system of classification is based on occupation. It groups occupations into social classes according to their skill level and general social standing in the community. Unemployed women are allocated on the basis of their husband’s occupation (19).

After completing the interview, the knowledge, attitude and practice questions were evaluated and scored. For knowledge, the scoring system was: high knowledge = a score of 13−17, average knowledge = 7−12, and low = 0−6. For attitude, the scoring system was: positive attitude = a score of 6−12 and negative attitude = 0−5 score. Finally, for practices: good practices = a score of 19−27, average = 10−18, and bad = 0−9.

The relationships between these 3 main variables were examined.

Clinical examination
The second part of the research was the clinical examination which was performed by the first author. A full mouth examination was done for all the women who finished the interview using the Community Periodontal Index (CPI) and decayed, missed and filled teeth (DMFT) according to World Health Organization (WHO) criteria (20). For CPI the highest score of the clinical examination was taken for every subject. The DMFT were modified from the WHO descriptions based on age (21). The clinical status scores were compared with scores of knowledge, attitude and practice.

After examination, 5 women were randomly selected each day and asked to return before they left so as to be re-interviewed and re-examined for test–re-test purposes.

Data analysis

**STATA** software, version 8 was used for statistical analysis. Descriptive statistics were used for data classification; the chi-squared test was used to evaluate the differences between different categorical variables (knowledge and attitude; knowledge and practice; knowledge and oral health status; attitude and oral health status; and practice and oral health status). Statistical significance was set at $P < 0.05$.

Ethical clearance

Ethical approval for the study protocol was obtained from the Research Board, Faculty of Dentistry, University of Khartoum. An approval letter was also obtained from the Academic Department of the hospital to conduct the research and every patient participating in the study signed a written informed consent form. Code numbers were used instead of names to ensure anonymity and confidentiality.

Results

**Sociodemographic background**

The response rate was 89% (48 women declined to participate and 4 were ineligible according to our exclusion criteria). Table 1 shows the sociodemographic characteristics of the 420 pregnant women who were eligible and agreed to participate in this study. The age range of the participants was 16−44 years with a mean and standard deviation (SD) of 27.1 (SD 5.8) years. Of the 420 participants, 10.7% were illiterate, 36.9% had up to primary-school education, 30.2% had high-school education and 22.2% had higher education. The majority of the women (92.9%) were housewives and only 13.6% had medical insurance. According to the Registrar General’s classification of social classes (19), the largest proportion were from intermediate class II (27.4%) based on their husband’s occupation. For 30.5% of the women, this was their first pregnancy.

**Perceived oral health**

Almost a quarter of the 420 women (22.6%) felt that their current oral health was poor, 45% felt it was average, 18.6% good, 5.5% very good and 8.3% excellent. At the time of the interview, 151 (36%) of the women felt dental pain and 82 (19.5%) were found to have gingival/periodontal problems.

**Oral health knowledge**

With regard to oral health knowledge scores among the pregnant women, 82% had an average score indicating medium level of knowledge, 12% high scores and 6% low.

Table 2 shows the oral health knowledge of the participants. The majority of the women (88.1%) agreed that tooth-brushing prevents tooth decay, gum diseases and a bad smell. Only 2.6% thought that brushing is just a habit. Most of the women (69.5%) believed that the main cause of tooth decay was sugar and 31.9% thought that the cause was bacteria. Just over half (52.4%) of the women thought that tooth decay could be prevented by tooth cleaning and brushing, while 22.1% thought it could be prevented by avoidance of sweets and sugar. A majority of the women (58.3%) thought that the cause of gum disease was unclean teeth and food debris and 71.7% thought that gum disease could be prevented by tooth
cleaning and brushing while 17.9% did not know.

The main sources of oral health knowledge were: television (cited by 59.0% of the women), radio (51.9%), family (49.0%) and the dentist (42.4%).

**Oral health attitude**

With regard to oral health attitude among the pregnant women, 21% had a positive attitude, i.e. expressing a willingness to take care of their oral health and to change towards a better oral health care and showing an openness to new practices, ideas and concepts.

Only 20.0% of the sample planned to visit a dentist and 26.2% said that pregnancy affected their attitude towards oral health. Of these 110 women, 20.0% considered this change as bad, 23.6% as average, 33.6% as good, 13.6% as very good and 9.1% as excellent. About 89% of the 26.2% whose attitude had changed, changed their behaviour by brushing their teeth more frequently, 2% by visiting the dentist for a check-up and by 3% visiting the dentist when they felt pain; the other 6% exhibited other changes such as using mouth wash, decreasing sugar intake and drinking milk. However, 73.8% did not change their attitude during pregnancy.

**Oral health practices**

Evaluation of oral health practices among the pregnant women showed that 66% had bad oral practices and 34% average oral health practices; none of the women had good oral health practices.

Table 3 shows the oral health practices of the participants. The majority of the women (85.5%) reported that they brushed their teeth more than once a day, while 14.5% brushed once a day. Only 9.5% used other oral hygiene methods such as dental floss, toothpick, miswak and mouth wash. A small majority (58.1%) of the women reported that they had visited a dentist before pregnancy; their main reason was dental pain (84%). A large proportion of the women (42%) had never visited a dentist in their life. Only 10.2% of the pregnant women had visited a dentist during pregnancy; the main reason for the visit was toothache. Of the 377 women who had not visited the dentist during pregnancy, 62.1% did not do so because they did not think that they needed dental care, and 27.9% thought that they and their baby might be harmed by dental treatment.

**Relationships between sociodemographic characteristics, knowledge, attitude and practice**

The chi-squared test showed that there was a significant relationship between the age and attitude to oral health.
and oral health practice ($P = 0.044$). There was also a significant relationship between education and oral health knowledge ($P = 0.001$) and education and oral health practice ($P = 0.003$). Similarly, a significant relationship was found between current pregnancy and oral health practice ($P = 0.003$) (Table 4).

Pearson correlation indicated that there was no relationship between oral health knowledge and practice ($P = 0.8962$), oral health knowledge and attitude ($P = 0.6393$), and between oral health attitude and practice ($P = 0.1729$).

Clinical examinations

The clinical examination indicated that 246 (58.6%) of the study sample had healthy gum, 51 (12.1%) had bleeding, 96 (22.9%) had calculus, 8 (1.9%) had pockets and 19 (4.5%) were excluded (the index tooth was not found, e.g. it was unerupted or extracted).

Only 24.5% of the women were free from dental caries. The mean DMFT was 1.16 in the age group 16−19 years and 3.49 in age group ≥ 20 years.

The chi-squared test indicated that there was no statistically significant relationship between CPI and oral health knowledge ($P = 0.712$) and CPI and oral health attitude ($P = 0.203$), but there was a statistically significant relationship between CPI and oral health practice ($P = 0.003$) (Table 5).

The chi-square test showed that there was no statistically significant relationship between DMFT and oral health knowledge ($P = 0.249$), and DMFT and oral health attitude ($P = 0.065$); however there was a statistically significant relationship between DMFT and oral health practice ($P < 0.001$) (Table 5).

Discussion

Our study showed that the majority of our sample of pregnant Sudanese women (81.9%) had average oral health knowledge, but they were unaware of the relationship between oral health and pregnancy. Similarly, in Iowa, United States of America (USA) Hubashna et al. 2005 showed that women had limited knowledge of the possible relationship between oral health and pregnancy outcome ($18$). In addition, it has been reported that women are not aware that the health of their gums may also affect the health of their babies ($6$). It has

---

Table 2 Oral health knowledge among a sample of Sudanese pregnant women ($n = 420$)

<table>
<thead>
<tr>
<th>Variable</th>
<th>No.</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Advantages of tooth brushing</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prevents bad smell</td>
<td>370</td>
<td>88.1</td>
</tr>
<tr>
<td>Prevents tooth decay</td>
<td>356</td>
<td>84.8</td>
</tr>
<tr>
<td>Prevents gum disease</td>
<td>305</td>
<td>72.6</td>
</tr>
<tr>
<td>Only habit</td>
<td>11</td>
<td>2.6</td>
</tr>
<tr>
<td><strong>Causes of tooth decay</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sugar and carbohydrate consumption</td>
<td>292</td>
<td>69.5</td>
</tr>
<tr>
<td>Bacteria</td>
<td>134</td>
<td>31.9</td>
</tr>
<tr>
<td>Other</td>
<td>49</td>
<td>11.7</td>
</tr>
<tr>
<td><strong>Methods to prevent tooth decay</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tooth cleaning and brushing</td>
<td>220</td>
<td>52.4</td>
</tr>
<tr>
<td>Avoidance of sweets and sugar</td>
<td>93</td>
<td>22.1</td>
</tr>
<tr>
<td>Tooth brushing and mouth wash after meals and sweets</td>
<td>57</td>
<td>13.6</td>
</tr>
<tr>
<td>Tooth-brushing and regular check ups</td>
<td>4</td>
<td>1.0</td>
</tr>
<tr>
<td>I don’t know</td>
<td>43</td>
<td>10.2</td>
</tr>
<tr>
<td>Other</td>
<td>3</td>
<td>0.7</td>
</tr>
<tr>
<td><strong>Causes of gum disease</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Food debris and unclean teeth</td>
<td>245</td>
<td>58.3</td>
</tr>
<tr>
<td>Bacteria</td>
<td>158</td>
<td>37.6</td>
</tr>
<tr>
<td>I don’t know</td>
<td>52</td>
<td>12.4</td>
</tr>
<tr>
<td>Other</td>
<td>13</td>
<td>3.1</td>
</tr>
<tr>
<td><strong>Methods to prevent gum disease</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tooth cleaning and brushing</td>
<td>301</td>
<td>71.7</td>
</tr>
<tr>
<td>Tooth-brushing and mouth wash after meals</td>
<td>9</td>
<td>2.1</td>
</tr>
<tr>
<td>Tooth cleaning and regular check ups</td>
<td>15</td>
<td>3.6</td>
</tr>
<tr>
<td>Mouth wash</td>
<td>12</td>
<td>2.9</td>
</tr>
<tr>
<td>I don’t know</td>
<td>75</td>
<td>17.9</td>
</tr>
<tr>
<td>Other</td>
<td>8</td>
<td>1.9</td>
</tr>
<tr>
<td><strong>Source of knowledge</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Television</td>
<td>248</td>
<td>59.0</td>
</tr>
<tr>
<td>Radio</td>
<td>218</td>
<td>51.9</td>
</tr>
<tr>
<td>Family</td>
<td>206</td>
<td>49.0</td>
</tr>
<tr>
<td>Dentist</td>
<td>178</td>
<td>42.4</td>
</tr>
<tr>
<td>Magazine</td>
<td>158</td>
<td>37.6</td>
</tr>
<tr>
<td>Outdoor advertising (e.g. billboards)</td>
<td>144</td>
<td>34.3</td>
</tr>
<tr>
<td>My experience</td>
<td>54</td>
<td>12.9</td>
</tr>
<tr>
<td>School curriculum</td>
<td>24</td>
<td>5.7</td>
</tr>
<tr>
<td>From my study</td>
<td>1</td>
<td>0.2</td>
</tr>
</tbody>
</table>

Women could select more than one answer for each variable.
been shown that periodontal disease increases the risk of adverse pregnancy consequences (18).

Women in our study mainly acquired their oral health knowledge from television and radio. These media may be useful and suitable for the dissemination of oral health education messages in Sudan. This was in contrast to a study conducted in the UK where the main source of knowledge of mothers who were aware of dental care was the general practitioner (19) while in Kuwait, 65% of female students at a health science centre reported that they received tooth-brushing instructions from the dentist (22).

Most of our sample (78.8%), which had different age groups, educational levels and social classes, had a negative attitude to oral health during pregnancy. About 90% did not visit a dentist; of those, more than half did not feel they needed to, and a considerable proportion thought that dental treatment should be avoided during pregnancy as it might harm their baby or themselves. Likewise, a survey in the USA revealed that half of the women who reported oral problems did not seek care because they believed that poor oral health during pregnancy was routine and feared that dental treatment might harm their baby (10).

The majority of the studied sample had good tooth-brushing habits (brushing more than once a day), but only about 10% used adjunct oral hygiene methods. However, in a study in the UK, only 75% of the pregnant women brushed their teeth more than once a day and 51% used mouth wash (19). Likewise, in Australia the dental utilization rate of pregnant women was only about 30% (23). Also in a study in Kuwait a large proportion of the pregnant women had oral health problems; however, half of the women had not seen a dentist during pregnancy (22).

In our study, there was a statistically significant relationship between women’s educational level and oral health knowledge. Higher educated women had greater oral health knowledge than lower educated or uneducated women. While education increased knowledge, surprisingly, no statistically significant relationship was found between oral health knowledge and attitude, and also between oral health knowledge and practice. This may be due to fear, cultural factors and wrong beliefs. In

<table>
<thead>
<tr>
<th>Variable</th>
<th>No. %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tooth-brushing</td>
<td></td>
</tr>
<tr>
<td>More than once/day</td>
<td>359 85.5</td>
</tr>
<tr>
<td>Once/day</td>
<td>61 14.5</td>
</tr>
<tr>
<td>Other oral hygiene method</td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>380 90.5</td>
</tr>
<tr>
<td>Dental floss</td>
<td>6 1.4</td>
</tr>
<tr>
<td>Tooth picks</td>
<td>5 1.2</td>
</tr>
<tr>
<td>Mouth wash</td>
<td>7 1.7</td>
</tr>
<tr>
<td>Miswak</td>
<td>21 5.0</td>
</tr>
<tr>
<td>Other</td>
<td>1 0.2</td>
</tr>
<tr>
<td>Dentist visit before pregnancy</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>244 58.1</td>
</tr>
<tr>
<td>No</td>
<td>176 41.9</td>
</tr>
<tr>
<td>Reasons for visit before pregnancy (n = 244)</td>
<td></td>
</tr>
<tr>
<td>Check-up</td>
<td>5 2.0</td>
</tr>
<tr>
<td>Scaling</td>
<td>13 5.3</td>
</tr>
<tr>
<td>Toothache</td>
<td>205 84.0</td>
</tr>
<tr>
<td>Gum problem</td>
<td>20 8.2</td>
</tr>
<tr>
<td>Filling</td>
<td>14 5.7</td>
</tr>
<tr>
<td>Prosthesis</td>
<td>5 2.0</td>
</tr>
<tr>
<td>Last visit (n = 244)</td>
<td></td>
</tr>
<tr>
<td>&lt; 6 months ago</td>
<td>7 2.9</td>
</tr>
<tr>
<td>6–</td>
<td>74 30.3</td>
</tr>
<tr>
<td>1–</td>
<td>81 33.2</td>
</tr>
<tr>
<td>&gt; 2 years ago</td>
<td>82 33.6</td>
</tr>
<tr>
<td>Dentist visits during pregnancy</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>43 10.2</td>
</tr>
<tr>
<td>No</td>
<td>377 89.8</td>
</tr>
<tr>
<td>Reasons for visit during pregnancy (n = 43)</td>
<td></td>
</tr>
<tr>
<td>Check-up</td>
<td>2 4.7</td>
</tr>
<tr>
<td>Scaling</td>
<td>3 7.0</td>
</tr>
<tr>
<td>Toothache</td>
<td>37 86</td>
</tr>
<tr>
<td>Filling</td>
<td>1 2.3</td>
</tr>
<tr>
<td>Reasons for not visit dentist during pregnancy (n = 377)</td>
<td></td>
</tr>
<tr>
<td>Afraid of the dentist</td>
<td>2 0.5</td>
</tr>
<tr>
<td>No need</td>
<td>234 62.1</td>
</tr>
<tr>
<td>My baby or myself may be harmed</td>
<td>105 27.9</td>
</tr>
<tr>
<td>No time</td>
<td>27 7.2</td>
</tr>
<tr>
<td>Financial reasons</td>
<td>8 2.1</td>
</tr>
<tr>
<td>No dentist in my vicinity</td>
<td>1 0.3</td>
</tr>
</tbody>
</table>
Table 4 Association between sociodemographic characteristics of the pregnant women and their oral health knowledge, attitude and practice

<table>
<thead>
<tr>
<th>Variable</th>
<th>Knowledge</th>
<th>P-value</th>
<th>Attitude</th>
<th>Practice</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>0.762</td>
<td>0.045*</td>
<td>0.044*</td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td>0.001*</td>
<td>0.590</td>
<td>0.003*</td>
<td></td>
</tr>
<tr>
<td>Social class</td>
<td>0.775</td>
<td>0.904</td>
<td>0.242</td>
<td></td>
</tr>
<tr>
<td>Current job</td>
<td>0.094</td>
<td>0.398</td>
<td>0.182</td>
<td></td>
</tr>
<tr>
<td>Current pregnancy</td>
<td>0.732</td>
<td>0.642</td>
<td>0.003*</td>
<td></td>
</tr>
</tbody>
</table>

*Statistically significant at P < 0.05.

Table 5 Association between oral clinical examination and oral health knowledge, attitude and practice of the pregnant women

<table>
<thead>
<tr>
<th>Variable</th>
<th>Knowledge</th>
<th>P-value</th>
<th>Attitude</th>
<th>Practice</th>
</tr>
</thead>
<tbody>
<tr>
<td>CPI</td>
<td>0.712</td>
<td>0.203</td>
<td>0.003*</td>
<td></td>
</tr>
<tr>
<td>DMFT</td>
<td>0.249</td>
<td>0.065</td>
<td>0.000*</td>
<td></td>
</tr>
</tbody>
</table>

*P-value statistically significant at P < 0.05.
CPI = community periodontal index; DMFT = decayed, missed and filled teeth.

of antenatal care from maternity care centres, they do not receive instructions concerning oral health care during pregnancy. A pregnant woman’s knowledge and actions concerning her oral health are critical to the oral health of her children and play a vital role in childhood caries prevention (27), and some countries have adopted a strategy of maternal oral health promotion through antenatal care providers (28).

Our study showed that the oral health status of the pregnant women was at a middling level but that the majority had negative attitudes towards oral health and had poor oral health practice. Oral health knowledge therefore needs to be enhanced and oral health preventive programmes should be developed for pregnant women. These would encourage good oral practice and a positive attitude toward oral health and lead to better oral health status. Pregnant women should be a priority group for oral health education and this should be an integral part of antenatal or postnatal care programmes.

This study was conducted among a sample of pregnant women from one maternity hospital. As such the sample cannot be considered to be representative of all pregnant women in Sudan and the results cannot be generalized to a wider population. Nonetheless, our study points to the need for preventive programmes, including oral health education during prenatal care, to increase awareness of oral health among pregnant women and improve oral health practice.

Acknowledgements

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Factors affecting breastfeeding practices among working women in Pakistan

J.A. Soomro 1, Z.N. Shaikh 2, S.A. Bijarani 1 and T.B. Saheer 3

ABSTRACT In urban areas of Pakistan, women’s return to work after giving birth has frequently been found to be a main contributor to the early termination of breastfeeding. This study aimed to assess workplace breastfeeding support provided to working mothers in Pakistan. In a cross-sectional survey in 2014, mothers and employers from a representative sample of 297 workplaces were interviewed using a pre-tested questionnaire. Mothers from 36 (12.1%) sites reported receiving breastfeeding breaks, and 86% of the mothers had received 3 months paid maternity leave. Provision of a lighter job and information about breastfeeding options on return to work were reported from 15% and 5% of the workplaces, respectively. Only two sites had designated breastfeeding corners. Significantly different results were found between types of employer (government or private) and type of organization (national or multinational) with regard to breastfeeding breaks, breastfeeding corners, lighter jobs and paid maternity leave. Public and multinational companies were slightly better than private and national ones in providing breastfeeding facilities.

Facteurs affectant les pratiques d’allaitement parmi les femmes actives au Pakistan

RÉSUMÉ Dans les zones urbaines du Pakistan, le retour des femmes au travail après un accouchement contribue très souvent à l’arrêt précoce de l’allaitement. La présente étude avait pour objectif d’évaluer les conditions favorables à l’allaitement au travail pour les mères actives au Pakistan. Au cours d’une étude transversale réalisée en 2014, des mères et des employeurs issus d’un échantillon représentatif de 297 lieux de travail ont été interrogés sur la base d’une questionnaire préalablement testé. Les mères travaillant sur 36 lieux de travail (12,1%) ont rapporté que des pauses étaient aménagées pour qu’elles puissent allaiter, et 86 % des mères ont bénéficié d’un congé maternité payé de 3 mois. La possibilité d’un travail allégé et la mise à disposition d’informations sur les options existantes pour l’allaitement après un retour au travail étaient rapportées dans 15 % et 5 % des lieux de travail respectivement. Seuls deux lieux de travail disposaient d’un espace dédié à l’allaitement. Des résultats significativement différents ont été obtenus selon les types d’employeurs (gouvernement ou privé) et d’organisations (nationales ou multinationales) concernant les pauses aménagées pour l’allaitement, les espaces mis à disposition à cette fin, un travail allégé et les congés maternités payés. Les entreprises publiques et multinationales se sont révélées légèrement meilleures que les entreprises privées et nationales dans la mise à disposition d’un environnement propice à l’allaitement.

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Introduction

Breastfeeding is an important measure in safeguarding children’s health and survival (1). In Pakistan it is estimated that 78 out of every 1000 live-born children die before their first birthday (2). According to the United Nations Children’s Fund (UNICEF), 16% of infant deaths could be prevented by breastfeeding from birth (2). From 1983 to 2008, the percentage of women in Pakistan who breastfed for up to one year declined from 96% to 31% (3). Workplace barriers have been reported as one of the major reasons for early cessation of breastfeeding by working mothers (3–6). Returning to work has frequently been found to be a main contributor to the early termination of breastfeeding (7,8). Many mothers who return to work stop or reduce breastfeeding because they do not have enough time or an appropriate place to breastfeed or express and store their breast milk (7–9). Studies indicate that mothers who have easy access to their baby during the working day, or who can express breast milk at work, breastfeed their babies for longer than those who do not have such access (9,10). A supportive environment, such as paid maternity leave, part-time work engagements, facilities for expressing and storing breast milk at work, breastfeeding breaks and national legislation on breastfeeding support at work have resulted in a higher prevalence and longer duration of breastfeeding (7,10).

For employers, the benefits of providing a working environment favourable to breastfeeding outweigh the costs. If breastfeeding is supported in the workplace, women are more likely to return to work earlier after giving birth, which contributes to women preserving their job skills, as well as reducing staff turnover (11–13). A survey in Hong Kong Special Administrative Region of China showed that 26% of workplaces had allocated a separate room for breastfeeding, and only 11% of hospitals allowed employees to take breaks as needed to use a breast pump (14).

Several studies have reported the importance of national legislation in supporting breastfeeding practices at work (10,13,14). One study noted that ‘policies can validate the employees’ right to provide their milk for their children, even when individual supervisors or co-workers are less than supportive’ (14). In Pakistan, the lack of legislation (other than that providing for three months’ paid maternity leave) in support of working mothers breastfeeding at work may be a contributing factor to the non-adherence of employers to international guidelines (3).

A qualitative study in Pakistan reported workplace barriers as one of the main reasons for early cessation of breastfeeding among working mothers (15). However, there has been little research into workplace breastfeeding facilities. The current study examines the status of the available breastfeeding facilities in Pakistan with a view to obtaining insights that could be useful to decision-makers.

Methods

Study design and sampling

A cross-sectional survey was conducted in 2014 on 297 workplaces, randomly selected from 2983 registered sites in Karachi, Pakistan. Karachi has a population of around 23.5 million, making it the largest city of Pakistan (16). The population of the city includes almost every socioeconomic class and ethnic group living in Pakistan. Additionally, it is home to Pakistan’s major business activities and a hub of higher education (16). All workplace sites registered with appropriate government authorities, i.e. hospitals, banks, factories and schools, were considered as the relevant study population (17–20).

At each selected site, one employer and one mother were interviewed. The employer was a manager or officer representing the workplace unit. Mothers were included if they were 3–24 months postpartum, had initiated breastfeeding prior to the survey, and at the time of the interview had returned to the job they had before giving birth. The mothers were selected purposively.

It was assumed that some employers in the randomly selected sample (n = 296) would refuse to take part in the study. Therefore, 7% extra workplaces were included in the initial sample. A final sample of 297 sites was achieved; ten sites were found not to be eligible, while eight employers refused to participate in the study. Female research assistants were trained to invite participants for the interview, to conduct the interview and to complete the questionnaire. The participants were given a sheet that contained information about the survey and contact details of the principal investigator. The research assistants were trained to explain the nature of the research, why the participant had been chosen, and her or his right to refuse to participate or to withdraw from the survey at any time.

The study was approved by the institutional review board of the Dow University of Health Sciences, Pakistan, and the South-Eastern Regional Ethical Committee of Oslo, Norway.

Data collection

The structured questionnaire was designed in English and Urdu based on guidelines of the World Alliance for Breastfeeding (21). The questionnaire was pretested in eight workplace sites, with equal representation of public and private enterprises. Subsequently, some changes were made to the survey’s language and style to improve its comprehensibility.

The questionnaire comprised two sections. The first section enquired about sociodemographic characteristics of the workplace: site level (national
versus multinational), job site (bank, school, hospital or factory) and type of employer (government, private, self-employed). Because the study focused on assessing workplace breastfeeding facilities, identifying information for the workplace, such as the name and address of the site, and personal details of the employer and the mother were not collected to avoid potential ethical issues.

The second section enquired about breastfeeding facilities, such as whether there were breastfeeding breaks, a breastfeeding corner, a place to store breast milk, a crèche or nursery at the workplace, paid maternity leave, possibility of moving to a lighter job, and options to facilitate breastfeeding (part-time work, extension of maternity leave or change of shift). Responses were yes or no. Mothers and employers were considered the persons in a workplace most likely to know about the availability of breastfeeding facilities. The employers and mothers from each site were interviewed using the same questionnaire, to enhance the confidence of the quality of our findings.

**Statistical analysis**

The data were analysed on Stata version 13 and SPSS version 22. All the variables were categorical. Descriptive statistics were computed by running frequencies and cross-tabulations on SPSS to obtain percentages and confidence intervals. Differences were considered statistically significant when $P < 0.05$. Charts were also developed using graph and chart builder.

Stata version 13 was used to compare proportions. Differences in proportions of breastfeeding facilities, with 95% confidence intervals (CI), were examined by type of respondent (mother or employer) type of employer (government or private) and site level (national or multinational). For the comparison by type of employer and site level, we used the mothers’ responses.

**Results**

A total of 594 participants from 297 sites completed the questionnaire. Table 1 shows the characteristics of the sample. The largest groups in the sample were banks (42%), private employers (75%) and national-level sites (76%). Figure 1 shows the availability of breastfeeding facilities at work according to the mothers (n = 297). Paid maternity leave was provided in most of the workplaces (86%). Only 15% of the sites provided mothers with a lighter or safer job while they were lactating. It was observed that most of the job assignments for female employees were fixed, with the exception of banks and schools; no other site had the possibility to relocate mothers to a site closer to their home to make breastfeeding easier. In 12% of the sites, at least one hour of paid breastfeeding breaks was offered during a work shift of 6–8 hours. Only two workplaces had a crèche on site providing child care and had designated a breastfeeding corner; none of the sites had a designated facility for storage of breast milk for later use.

The same questionnaire was used with the mothers and the employers, so that responses from the two different groups could be compared (Table 2). Altogether, 96% of the employers claimed that the mothers were provided breastfeeding breaks, compared with 12% of the mothers. The difference in
Table 1 General characteristics of the sample

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>297</td>
<td>100</td>
</tr>
<tr>
<td><strong>Type of business</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bank</td>
<td>123</td>
<td>42</td>
</tr>
<tr>
<td>School</td>
<td>87</td>
<td>29</td>
</tr>
<tr>
<td>Factory</td>
<td>66</td>
<td>22</td>
</tr>
<tr>
<td>Hospital</td>
<td>21</td>
<td>7</td>
</tr>
<tr>
<td><strong>Interviewees</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td>297</td>
<td>50</td>
</tr>
<tr>
<td>Employer</td>
<td>297</td>
<td>50</td>
</tr>
<tr>
<td><strong>Type of employer</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Private</td>
<td>222</td>
<td>75</td>
</tr>
<tr>
<td>Government</td>
<td>75</td>
<td>25</td>
</tr>
<tr>
<td><strong>Site level</strong></td>
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</tr>
<tr>
<td>National</td>
<td>226</td>
<td>76</td>
</tr>
<tr>
<td>Multinational</td>
<td>71</td>
<td>24</td>
</tr>
</tbody>
</table>

proportions between employers and mothers was statistically significant. Similarly, employers overestimated non-physical breastfeeding facilities compared with mothers, such as paid maternity leave (100% vs 86%), availability of lighter jobs (45% vs 15%), and provision of breastfeeding options for mothers on their return to work, e.g. part-time work, extension of maternity leave, or change of shift (21% vs 5%). However, no significant difference was observed between the two groups in their responses regarding physical breastfeeding facilities, such as a breast milk pump, jobsite crèche for child care, and availability of a place for storing breast milk (refrigerator).

The status of breastfeeding facilities in the public and private sectors was compared, using the responses of the mothers only. More public workplaces than private ones were reported to provide at least three months paid maternity leave (99% vs 81%). This difference was statistically significant (P < 0.001). Similarly, breastfeeding breaks of at least one hour in a shift of 6–8 hours were also more common in the public sector (23% vs 9%) (P < 0.001). Only the mothers in the private sector (7%) reported having breastfeeding options for their return to work (part-time work, change in shift, maternity leave extension). A breastfeeding corner was provided by 1% of the government sites and none of the private sites. However, this difference was not statistically significant. No workplace had a designated place or refrigerator to store mothers’ milk. A breast milk pump and jobsite crèche or nursery for child care was provided by 1.3% of the government facilities and 0.5% of the private companies; the difference was not statistically significant.

Table 3 shows the differences in proportions of workplace breastfeeding facilities between multinational and national sites. The multinational sites provided more breastfeeding facilities than the national sites and the difference was statistically significant (P < 0.001). The facilities included: breastfeeding breaks of at least one hour per shift (25% vs 8%); at least three months paid maternity leave (100% vs 81%); provision of lighter job or transfer to a safer workplace during lactation (38% vs 8%); provision of appropriate options to support breastfeeding at work (17% vs 2%). Most of the multinational sites offered more than three months paid leave. Surprisingly, none of the facilities had allocated a place, such as a refrigerator, for working mothers to store breast milk for their babies.

Discussion

To the best of our knowledge, this is the first quantitative study in Pakistan exclusively focusing on assessment of workplace breastfeeding facilities with a large random sample. Information was obtained from two sources, mothers and their employers, using the same type of questionnaire in order to increase confidence in the findings. Our study revealed that the workplaces generally had few breastfeeding facilities. The two groups of respondents gave significantly different answers regarding non-physical facilities, such as breastfeeding breaks, maternity leave, availability of a lighter job, and provision of information about breastfeeding options. Breastfeeding support was slightly better in public and multinational sites than in private and national sites.

Mothers in 12% of the workplaces reported that they had breaks to breastfeed or express breast milk. This was similar to the findings of Dodgson et al. (11%) (14) and Weber et al. (16%) (22). Heymann et al. (23) found that, globally, the rate of exclusive breastfeeding of children under six months of age was 9% greater in countries that ensured paid breastfeeding breaks at workplaces. A qualitative study in Pakistan by Hirani et al. (15) also found that job flexibility and a flexible schedule at the workplace were important if working mothers were to sustain breastfeeding while employed.

However, our findings with regard to breastfeeding breaks are not consistent with those of many studies in developed countries, possibly because of the existence in those countries of workplace breastfeeding policies, lactation programmes and additional support to mothers in the form of education...
and resources (24–28). The availability of breastfeeding corners, a breast milk pump and a place for storing breast milk (refrigerator) would allow women to feel more confident and encourage them to breastfeed (3,29).

In our study, only two sites had a designated breastfeeding corner and workplace crèche for child care. These findings are similar to those of some previous studies (14,29), but different from the studies by Allen et al. (25) and Bai et al. (27), which reported 70% and 80%, respectively. The large difference is most likely the result of policies, programmes and awareness-raising of women by lactation consultants in those study settings, all of which are lacking in Pakistan.

Almost 86% of the mothers were given paid maternity leave for three months in our study, similar to what was found in studies in Malaysia and India (93%) (29,30). However, the paid maternity leave cannot be compared with many other studies in countries such as Australia, Canada, China and the Islamic Republic of Iran, which offer more than three months paid or unpaid maternity leave (9,23,31,32).

The finding that women in only 5% of the sites reported receiving information about breastfeeding options on their return to work is consistent with that of Weber et al. (5%) (23). The lack of policies and lactation programmes in Pakistan limits the relevance of comparison of the findings with other studies (25,27,28).

Little literature is available for comparison of the perspectives of the employer or owner on workplace breastfeeding facilities. A qualitative study in Pakistan concluded that the employer’s perspective is critical for understanding and supporting breastfeeding in workplaces (15). Tan et al. reported that the employer’s behaviour influences working mothers’ perception of workplace breastfeeding support (33).

Employers tended to overestimate the available workplace breastfeeding facilities, possibly for fear of harming the reputation of the organization or of negatively affecting their status if the data were shared with the government. Employers may think that providing facilities for breastfeeding mothers could be financially damaging for the workplace, or that breastfeeding is a personal activity that reduces the time employees spend working. The employers may have thought that the data would be communicated to international or nongovernmental organizations, which might then put pressure on the government to take action against sites without facilities. Finally, breastfeeding facilities may be confused with other staff facilities (routine breaks over breastfeeding breaks, female common room as a breastfeeding room, etc.) (3,33,34).

On the other hand, mothers may have under-reported breastfeeding facilities in order to obtain additional benefits or to attract the attention of decision-makers. Mothers may have little awareness of workplace breastfeeding rights set by labour organizations (local and international). Finally, in large workplaces, mothers may not be aware of all the available facilities, especially the less visible ones (separate rooms, separate refrigerators, etc.).

However, the two groups of respondents showed general agreement on the availability of the following breastfeeding facilities: a breastfeeding corner, a refrigerator, a breast milk pump and a nursery. This agreement may be because all these were physical facilities and could be verified. The mothers are probably the more reliable group, because of their direct interest and benefit from breastfeeding facilities.

The significant difference observed between private and public sector organizations, with regard to breastfeeding breaks, maternity leave, task adjustment and information regarding breastfeeding options, is consistent with the findings of other studies (14,23,29). In Pakistan, mothers working in the public sector tend to have greater workplace breastfeeding support than those in the private sector, because of the nature of the work. The majority of banks, factories, and companies with a rigid type of job and short rest periods

<table>
<thead>
<tr>
<th>Workplace breastfeeding facilities</th>
<th>Mothers responding yes</th>
<th>Employers responding yes</th>
<th>Test of difference in proportion (95% Cl)</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No.</td>
<td>%</td>
<td>No.</td>
<td>%</td>
</tr>
<tr>
<td>Breastfeeding breaks</td>
<td>36</td>
<td>12</td>
<td>285</td>
<td>96</td>
</tr>
<tr>
<td>Breastfeeding corners</td>
<td>2</td>
<td>0.7</td>
<td>17</td>
<td>6</td>
</tr>
<tr>
<td>Breast milk pump</td>
<td>2</td>
<td>0.7</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Jobsite crèche for child care</td>
<td>2</td>
<td>0.7</td>
<td>5</td>
<td>1.7</td>
</tr>
<tr>
<td>Paid maternity leave</td>
<td>255</td>
<td>86</td>
<td>297</td>
<td>100</td>
</tr>
<tr>
<td>Lighter job or task adjustment</td>
<td>45</td>
<td>15</td>
<td>134</td>
<td>45</td>
</tr>
<tr>
<td>Breastfeeding options (part-time work, etc.)</td>
<td>16</td>
<td>5</td>
<td>63</td>
<td>21</td>
</tr>
</tbody>
</table>
There is a need for national legislation to address these problems. Without national laws or regulations, employers are not legally obliged to provide the necessary facilities at the workplace for encouraging mothers to breastfeed their infants. This legislation could be based on the WHO International Code of Marketing of Breast-Milk Substitutes (36), which aims to promote breastfeeding and enhance infants’ health.

We recognize that our study had several limitations. First, it focused only on an urban area of Pakistan; the results, therefore, cannot be generalized to rural areas, which account for one-third of female workers (16). Secondly, unregistered workplaces, such as shops, small clinics and home-based businesses, were not included. Though such workplaces are small in number, they may influence the internal and external validity of our study. Thirdly, our sample was dominated by private sector companies, mainly banks and schools, and this may also have influenced our results through under-representation of the public sector and sites such as hospitals and factories. Finally, the mothers were enrolled purposively because of limited time and resources, which could have influenced the results.

Nevertheless, the study setting (Karachi) is the largest city of Pakistan and the second-largest city in the world by population size, and includes almost every social class and ethnic group living in Pakistan (16). We believe the results could be generalized to the other cities in the country, since it is likely that working mothers have similar working conditions, tasks, culture, and socio-economic status. Our study could also serve as a baseline in specific settings, for follow-up studies to examine the impact of interventions, such as policy reform and workplace lactation programmes. Our findings could also inform future large population-based surveys in urban and rural areas, to get a clear picture of breastfeeding facilities at workplaces in Pakistan.

### Acknowledgements

The authors thank Professor Per Nafstad, Department of Community Medicine, University of Oslo for his technical support throughout the study period. **Funding:** The authors acknowledge the research committee at the Section for International Health, University of Oslo, Oslo, Norway for funding the study. **Competing interests:** None declared.
References


Psychobehavioural responses to the 2014 Middle East respiratory syndrome-novel corona virus (MERS CoV) among adults in two shopping malls in Jeddah, western Saudi Arabia

N.S. AlNajjar, 1 L.M. Attar, 1 F.M. Farahat 2,3 and A. AlThaqafi 2

ABSTRACT Sporadic cases of Middle East respiratory syndrome caused by a novel corona virus (MERS-CoV) were first detected in Saudi Arabia in June 2012. The number of cases was highest during April and May 2014. To assess determinants of psychobehavioural responses among the general population in Jeddah, western Saudi Arabia, a cross-sectional survey was conducted at the end of June 2014. Data included sociodemographic characteristics, level of anxiety, protective measures and social avoidance responses. A total of 358 participants completed the questionnaire; 58.4% were female, and the age range was 18–72 years. None of the participants was diagnosed with MERS-CoV. More than half (57.7%) recorded a moderate anxiety score using a visual analogue scale. Anxiety level was significantly associated with increased perception of susceptibility to infection and social avoidance responses related to travel and being in public places.

Réactions psycho-comportementales à l’infection par le coronavirus du syndrome respiratoire du Moyen-Orient (MERS-CoV) de 2014 chez des adultes interrogés dans deux centres commerciaux de Djeddah, dans l’ouest de l’Arabie saoudite

RÉSUMÉ Des cas sporadiques d’infection par le coronavirus du syndrome respiratoire du Moyen-Orient (MERS-CoV) de 2014 chez des adultes interrogés dans deux centres commerciaux de Djeddah, dans l’ouest de l’Arabie saoudite ont été détectés pour la première fois en Arabie saoudite en juin 2012. Le nombre de cas le plus élevé a été observé en avril et mai 2014. Afin de mesurer les déterminants des réactions psycho-comportementales de la population générale de Djeddah, dans la partie occidentale de l’Arabie saoudite, une étude transversale a été conduite fin juin 2014. Les données incluaient les caractéristiques socio-démographiques, le niveau d’anxiété, les mesures de protection et la mise en place de mesures d’éviction sociale. Un total de 358 participants ont rempli le questionnaire, dont 58.4% étaient des femmes, et l’âge moyen était compris entre 18 et 72 ans. Le MERS-CoV n’a été diagnostiqué chez aucun patient. Plus de la moitié (57,7 %) a rapporté un score d’anxiété modéré en se basant sur une échelle visuelle analogue. Le niveau d’anxiété était associé de façon significative à une perception augmentée de sensibilité à l’infection et au phénomène d’éviction sociale lié à la possibilité de voyager ou de se rendre dans les lieux publics.
Introduction

A Middle East respiratory syndrome caused by a novel corona virus (MERS-CoV) was first detected in Saudi Arabia in June 2012. The number of cases increased to a peak in April and May 2014 (1,2). The total number of reported cases up to June 2014 was 714, with a case fatality rate of 40.8% (1). Another peak occurred in 2015, however, with fewer cases (440 to end of December 2015) (1).

Most patients with MERS-CoV infection were severely ill with pneumonia and acute respiratory distress syndrome, and some had acute kidney injury (3). Up to June 2014 the mode of transmission was uncertain but was thought to be through direct (droplet) or indirect (touching contaminated surfaces) contact (4).

Unconfirmed beliefs about modes of transmission and doubts regarding the adequacy of national preparedness influence public compliance with precautionary measures and have been associated with avoidance behaviours and increased psychological distress (5,6). Avoidance behaviours and anxiety symptoms were experienced during the human avian influenza outbreaks and the SARS epidemic (7–9). During the 2009 H1N1 pandemic, anxiety was associated with high perceived susceptibility to infection and disease severity that influenced hygiene measures (5) or led to social distancing, rather than substantial changes in hygiene behaviour (10).

People are more compliant if they believe they may be affected by the outbreak (11,12), the recommended behaviours are effective (13), the illness has severe consequences (14) or is difficult to treat (15) and there is sufficient information on controlling the spread of infection (16).

Knowledge of psychobehavioural responses among the general public during epidemics could determine risk communication and public health interventions (10,17).

A study conducted on healthcare workers in a tertiary care hospital in Jeddah during the 2014 MERS-CoV outbreak reported emotional distress and reluctance to work overtime in despite their feelings of ethical and professional obligation towards their profession (18). During the 2014 emergence of MERS-CoV, other generally observed public responses (e.g. avoiding crowded places and hospitals, wearing face masks in mosques and public areas and changing travel plans) have not yet been explored.

Accordingly, our study aims to address psychobehavioural responses in terms of psychological distress/anxiety and avoidance behaviours associated with MERS-CoV occurrence among the Saudi population in Jeddah, western Saudi Arabia, where the majority of cases were reported during the 2014 outbreak.

Methods

We carried out a cross-sectional study in June 2014 in 2 shopping centres in Jeddah, western Saudi Arabia. These centres were selected by a simple random sampling technique from a list of 12 large shopping malls which people visit for shopping, recreation and to meet friends.

Study participants were selected using a convenience sampling technique among people who were sitting in the open dining areas from 17.00–22.00 hours during the study period (16–26 June 2014). Study participants included male and female adult (> 18 years) Saudi Arabian and non-Saudi Arabian people residents of Jeddah during the 2014 MERS-CoV outbreak.

Verbal consent was obtained from each participant to voluntarily participate in the study. The purpose of the study, procedures, risks, benefits and alternatives to participation were explained to each potential participant. Each potential participant was afforded sufficient time to ask questions and consider whether or not to participate in the study and complete the questionnaire.

Data were collected through a self-administered questionnaire developed based on similar previous studies conducted in China and Hong Kong during the H7N9 and H1N1 epidemics (10,19). The questionnaire included data on sociodemographic characteristics of the participants, avoidance responses, use of protective measures, perceptions and overall knowledge about the 2014 MERS-CoV outbreak. Knowledge was assessed through 7 questions on mode of transmission, clinical features, severity, prevention and availability of a vaccine. One point was given for every correct response and zero for an incorrect response. Those who scored ≥ 4 out of 7 (> 50% correct) were considered as having average/ high knowledge.

The questionnaire was pretested for face and content validity, length and comprehensibility. Face validity was established by expert opinion. The pretest was conducted on 10 volunteer participants (5 male and 5 female) randomly selected from the same location. After pretesting, no changes were required. A 5-point Likert response scale was applied and the average time for completion was about 10 minutes.

A 10 cm horizontal line visual analogue scale (VAS) was used to assess level of anxiety among the study population (20–21). At the left edge zero = not at all anxious, and at the right edge 10 = extreme anxiety. Each participant marked the point on the line that they felt represented their level of anxiety towards the MERS CoV infection. The distance from the left edge to the mark was measured to the nearest mm and used in analyses as the participant anxiety score (21,22). The VAS is a valid, reliable, simple to administer tool that has been used successfully for assessing a variety of health outcomes including
pain (23), quality of life (24), mood (25) and anxiety (21,22).

All questionnaires were anonymous. Approval of the Institutional Research Board of King Abdullah International Medical Research Center was obtained to conduct the study.

Sample size was estimated assuming 25% prevalence of anxiety related to the emergence of MERS CoV in Jeddah based on a similar study by Rubin et al. during the swine influenza outbreak (26). At 95% confidence interval, 5% margin of error, 285 was estimated as the sample size. This was increased to 400 to compensate for incomplete questionnaires or non-response.

### Statistical analysis
Data were analysed using SPSS, version 21. The Mann–Whitney and Kruskal–Wallis tests were applied to compare anxiety scores in different groups. Associations between independent variables and anxiety were assessed using univariate and multivariate logistic regression analysis, with calculation of odds ratios.

### Table 1 Regression analysis of independent variables associated with anxiety among a sample of adults in Jeddah, 2014, n = 358

<table>
<thead>
<tr>
<th>Variable*</th>
<th>Anxiety VAS ≥ 5</th>
<th>Anxiety VAS &lt; 5</th>
<th>Unadjusted OR (95% CI)</th>
<th>Adjusted OR (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>77 (52.4)</td>
<td>70 (47.6)</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Female</td>
<td>129 (61.4)</td>
<td>81 (38.6)</td>
<td>1.45 (0.95—2.22)</td>
<td>1.14 (0.65—2.01)</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤ 30 years</td>
<td>102 (55.4)</td>
<td>82 (44.6)</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>&gt; 30 years</td>
<td>67 (63.2)</td>
<td>39 (36.8)</td>
<td>1.38 (0.85—2.26)</td>
<td>1.21 (0.62—2.35)</td>
</tr>
<tr>
<td>Nationality</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Saudi Arabian</td>
<td>146 (56.4)</td>
<td>113 (43.6)</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Non-Saudi Arabian</td>
<td>42 (60.9)</td>
<td>27 (39.1)</td>
<td>1.20 (0.70—2.07)</td>
<td>1.55 (0.71—3.40)</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>79 (51.6)</td>
<td>74 (48.4)</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Married</td>
<td>127 (62.6)</td>
<td>76 (37.4)</td>
<td>1.57 (1.02—2.40)</td>
<td>1.67 (0.98—2.85)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than university</td>
<td>47 (54.7)</td>
<td>39 (45.3)</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>University</td>
<td>155 (58.9)</td>
<td>108 (41.1)</td>
<td>1.19 (0.73—1.95)</td>
<td>1.14 (0.98—1.33)</td>
</tr>
<tr>
<td>Income*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Enough</td>
<td>178 (58.0)</td>
<td>129 (42.0)</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Not enough</td>
<td>28 (56.0)</td>
<td>22 (44.0)</td>
<td>0.92 (0.51—1.69)</td>
<td>1.03 (0.40—2.66)</td>
</tr>
<tr>
<td>Perception of personal health status</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Satisfied</td>
<td>143 (53.8)</td>
<td>123 (46.2)</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Not satisfied</td>
<td>63 (68.5)</td>
<td>29 (31.5)</td>
<td>1.87 (1.13—3.09)</td>
<td>2.49 (1.31—4.75)</td>
</tr>
<tr>
<td>Know of MERS CoV positive case</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>158 (56.8)</td>
<td>120 (43.2)</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Yes</td>
<td>45 (61.6)</td>
<td>28 (38.4)</td>
<td>1.22 (0.72—2.07)</td>
<td>1.03 (0.52—2.04)</td>
</tr>
<tr>
<td>Perceived probability of being infected with MERS CoV</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unlikely</td>
<td>99 (47.4)</td>
<td>110 (52.6)</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Likely/very likely</td>
<td>105 (73.4)</td>
<td>38 (26.6)</td>
<td>3.07 (1.94—4.86)</td>
<td>3.25 (1.86—5.70)</td>
</tr>
<tr>
<td>Overall knowledge on MERS CoV</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not enough</td>
<td>66 (56.4)</td>
<td>51 (43.6)</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Enough</td>
<td>137 (591)</td>
<td>95 (40.9)</td>
<td>1.11 (0.71—1.75)</td>
<td>1.15 (0.64—2.06)</td>
</tr>
</tbody>
</table>

CI = confidence interval.
OR = odds ratio
VAS = visual analogue scale (5 is the median score of the study sample);
*Data missing for some variables.
*Self-reported income: enough = being able to cover monthly expenses.
and 95% confidence intervals. Anxiety score was used as a binary variable (≥ 5 vs < 5) in the regression analysis. Only those variables which were statistically significant in the crude analysis were introduced in the final model. Statistical significance was set at $P < 0.05$.

## Results

A total of 400 participants of about 420 approached agreed to complete the questionnaire. Questionnaires that were returned blank or with the majority of the questions unanswered, including those which were not marked on the anxiety VAS, were excluded: a total of 358 questionnaires were analysed. Demographic characteristics can be seen on Table 1. More than half of the participants were female (210, 58.7%). Age ranged between 18 and 72 years. The majority of the participants were Saudi Arabian (259, 72.3%). About three-quarters reported feeling satisfied about their general health condition. None of the participants had been diagnosed with MERS-CoV. Around one-fifth of them (73, 20.4%) knew of a confirmed case of MERS-CoV (Table 1), of whom 87.7% ($n = 64$) had been admitted at hospital and 74.0% ($n = 54$) had died. When asked about the probability of being infected with MERS CoV, 58.6% perceived the probability of infection as unlikely compared with 27.2% who perceived it as likely and 13.8% as very likely (Table 1).

More than half the participants (57.7%) reported anxiety level score of ≥ 5 (study sample median) on a 10 cm VAS [mean anxiety score 4.94, standard deviation (SD) 2.29].

Univariate logistic regression showed that married people, those who were not satisfied with their health status and those who perceived they had a greater probability of being infected were at greater risk of anxiety compared with their counterparts [odds ratio (OR) = 1.57, 95% confidence interval (CI): 1.02–2.40; OR = 1.87, 95% CI: 1.13–3.09; OR = 3.07, 95% CI: 1.94–4.86 respectively] (Table 1). In the multivariate regression analysis, only perception of personal health status and perception of greater probability of being infected were significant predictors of anxiety during the 2014 outbreak (OR = 2.49, 95% CI: 1.31, 4.75; OR = 3.25, 95% CI: 1.86, 5.70 respectively) (Table 1).

Level of anxiety was significantly associated with several avoiding behaviours, including changing plans for performing Umrah, postponing domestic or international travel, avoiding eating outside the home and avoiding visiting hospitals and public places ($P < 0.05$) (Table 2). Analysis was done among those who responded they had plans for Umrah or travel.

Mean anxiety level was significantly associated with hand washing after

### Table 2. Mean anxiety score regarding MERS-CoV infection a sample of adults in Jeddah, 2014, $n = 358$

<table>
<thead>
<tr>
<th>Avoiding behaviour</th>
<th>Anxiety score$^a$</th>
<th>$P$-value$^b$</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Change plan for Umrah</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes ($n = 54$, 30.68%)</td>
<td>5.78 (2.35)</td>
<td>0.001</td>
</tr>
<tr>
<td>No ($n = 122$, 69.32%)</td>
<td>4.52 (2.17)</td>
<td></td>
</tr>
<tr>
<td><strong>Postpone planned domestic travel</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes, due to MERS CoV ($n = 50$, 17.36%)</td>
<td>5.66 (2.31)</td>
<td>0.01</td>
</tr>
<tr>
<td>Yes, not due to MERS CoV ($n = 238$, 82.64%)</td>
<td>4.74 (2.21)</td>
<td></td>
</tr>
<tr>
<td><strong>Postpone planned international travel</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes, due to MERS CoV ($n = 35$, 12.23%)</td>
<td>6.09 (2.21)</td>
<td>0.002</td>
</tr>
<tr>
<td>Yes, not due to MERS CoV ($n = 251$, 87.76%)</td>
<td>4.79 (2.25)</td>
<td></td>
</tr>
<tr>
<td><strong>Avoid eating outside the home</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes, due to MERS CoV ($n = 67$, 21.54%)</td>
<td>5.91 (2.41)</td>
<td>0.001</td>
</tr>
<tr>
<td>Yes, not due to MERS CoV ($n = 244$, 78.46%)</td>
<td>4.71 (2.17)</td>
<td></td>
</tr>
<tr>
<td><strong>Avoid visiting hospitals</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes, due to MERS CoV ($n = 155$, 48.29%)</td>
<td>5.34 (2.28)</td>
<td>0.03</td>
</tr>
<tr>
<td>Yes, not due to MERS CoV ($n = 166$, 51.71%)</td>
<td>4.78 (2.25)</td>
<td></td>
</tr>
<tr>
<td><strong>Avoid public places</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes, due to MERS CoV ($n = 84$, 26.33%)</td>
<td>5.89 (2.27)</td>
<td>0.001</td>
</tr>
<tr>
<td>Yes, not due to MERS CoV ($n = 235$, 73.67%)</td>
<td>4.67 (2.19)</td>
<td></td>
</tr>
</tbody>
</table>

$^a$scored on a 10 cm visual analogue scale.  
$^b$Mann–Whitney test.
coughing or sneezing ($P = 0.013$) and wearing a face mask ($P = 0.002$) (Table 3).

The main information source for MERS-CoV was television (TV) (50.7%) followed by WhatsApp messenger (32.9%) and the Ministry of Health website (30.8%) (Table 4).

## Discussion

None of the participants in the current study had ever been diagnosed with MERS-CoV but some knew confirmed cases, of whom the majority had died. A moderate level of anxiety was reported among almost half of the participants. However, overall of knowledge about the mode of transmission of MERS-CoV, clinical manifestations and prevention was modest.

Prevalence of anxiety about MERS-CoV in our study was higher ($57.7\%$ scored 5 or more on 10 centimeter VAS) compared with the findings of Rubin et al. where $23.8\%$ scored ≥ 12 out of 24 on the 6-item State-Trait Anxiety Inventory (STAI), suggesting anxiety about swine influenza (26). The higher prevalence of anxiety in our study could be attributed to lack of communication and information about mode of transmission and sources of infection and the unique location of Jeddah, very close to Mecca, where there is increased concern about spread of infection among pilgrims.

Anxiety was associated with perception of increased susceptibility to infection, in concordance with Cowling et al. (10), as well as satisfaction with general health status.

Only 13.8% of our participants perceived themselves as very likely to acquire MERS-CoV, similar to the findings of Lau et al., who reported that $10\%$ of participants considered themselves to have a high or very high chance of contracting influenza A/H1N1 during the prepandemic period (27).

The most common source for information on the disease in this study was TV, which is consistent with previous studies during other influenza epidemics. Akan et al. found the majority of the university students in their study ($89\%$) had received information from the mass media (TV) (28). Also, TV was the major source of information ($38.6\%$) in a study carried out in India during the 2009 H1N1 pandemic (5). This finding is important as it demonstrates that mass media (specifically TV) continues as a major source of health information, contrary to the expected shift towards internet sources and other smart mobile applications. An interesting observation in our study was related to the use of new applications (e.g. WhatsApp) and short message services (SMS) as important sources for public awareness. Considering how widespread the use of these applications is among the study population, they might lead to increased public panic because of rumors and incorrect or insufficient information. Trust in information is an essential element in risk perception (29) and behaviour change (30). During the early stages of an epidemic, and in particular with new emerging infectious diseases like MERS-CoV, people seek information from different sources (internet, social media, peers, etc) if official public health advice is lacking or inadequate (31,32). Health authorities should respond promptly with clear, evidence-based public health information in order to maximize trust

### Table 3 Mean anxiety score and personal hygiene behaviour among a sample of adults in Jeddah, 2014, n = 358

<table>
<thead>
<tr>
<th>Variable</th>
<th>Anxiety level mean (SD)</th>
<th>$P$-value*</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Cover mouth</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Always</td>
<td>4.96 (2.91)</td>
<td></td>
</tr>
<tr>
<td>Usually</td>
<td>4.72 (2.92)</td>
<td>0.506</td>
</tr>
<tr>
<td>Sometimes</td>
<td>4.74 (2.99)</td>
<td></td>
</tr>
<tr>
<td>Rarely</td>
<td>4.62 (4.03)</td>
<td></td>
</tr>
<tr>
<td>never</td>
<td>5.41 (3.26)</td>
<td></td>
</tr>
<tr>
<td><strong>Wash hands after cough or sneeze</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Always</td>
<td>5.48 (3.08)</td>
<td></td>
</tr>
<tr>
<td>Usually</td>
<td>5.13 (2.84)</td>
<td>0.013</td>
</tr>
<tr>
<td>Sometimes</td>
<td>4.67 (2.77)</td>
<td></td>
</tr>
<tr>
<td>Rarely</td>
<td>3.79 (2.65)</td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td>3.53 (2.93)</td>
<td></td>
</tr>
<tr>
<td><strong>Wash hands after coming back home</strong></td>
<td></td>
<td>0.44</td>
</tr>
<tr>
<td>Always</td>
<td>5.14 (3.00)</td>
<td></td>
</tr>
<tr>
<td>Usually</td>
<td>5.06 (2.70)</td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td>4.63 (2.85)</td>
<td></td>
</tr>
<tr>
<td>Rarely</td>
<td>3.7 (2.90)</td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td>6.25 (3.50)</td>
<td></td>
</tr>
<tr>
<td><strong>Wear face mask</strong></td>
<td></td>
<td>0.002</td>
</tr>
<tr>
<td>Always</td>
<td>5.47 (3.09)</td>
<td></td>
</tr>
<tr>
<td>Usually</td>
<td>6.1 (2.83)</td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td>5.64 (2.88)</td>
<td></td>
</tr>
<tr>
<td>Rarely</td>
<td>4.92 (2.81)</td>
<td></td>
</tr>
<tr>
<td>never</td>
<td>4.28 (2.91)</td>
<td></td>
</tr>
</tbody>
</table>

$SD = \text{standard deviation.}$

*Determined using a 10 cm visual analog scale.

*Kruskal–Wallis test.*
and ensure public compliance with preventive behaviours. (33).

Awe found that anxiety was associated with several avoidance behaviours and precautions, especially relating to travel or being in public places. This was in consistency with Cowling et al. during the 2009 influenza H1N1 pandemic (10) and other studies of previous epidemics where a positive correlation between level of anxiety and hygiene measures (28,34,35) and wearing face masks (36) has been reported. However, adherence to health protective behaviours (e.g., hand washing, wearing face masks and social distancing) varies with perceived health threats and effectiveness and the demographic characteristics of the population (25,31,37).

Table 4 Sources of information for the 2014 MERS CoV outbreak among a sample of adults in Jeddah, 2014, n = 358

<table>
<thead>
<tr>
<th>Source</th>
<th>No</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Television</td>
<td>182</td>
<td>50.8</td>
</tr>
<tr>
<td>WhatsApp</td>
<td>118</td>
<td>33.0</td>
</tr>
<tr>
<td>Ministry of Health website</td>
<td>110</td>
<td>30.7</td>
</tr>
<tr>
<td>SMS</td>
<td>96</td>
<td>26.8</td>
</tr>
<tr>
<td>Social media</td>
<td>93</td>
<td>26.0</td>
</tr>
<tr>
<td>Friend*</td>
<td>92</td>
<td>25.7</td>
</tr>
<tr>
<td>Healthcare provider</td>
<td>89</td>
<td>24.9</td>
</tr>
<tr>
<td>Internet search (Google)</td>
<td>78</td>
<td>21.8</td>
</tr>
<tr>
<td>Newspaper</td>
<td>61</td>
<td>17.0</td>
</tr>
<tr>
<td>Medical website</td>
<td>52</td>
<td>14.5</td>
</tr>
<tr>
<td>School/university</td>
<td>36</td>
<td>10.1</td>
</tr>
</tbody>
</table>

SMS = short message service.
*Includes direct communication and means other than WhatsApp or SMS.

Limitations of this study include timing of data collection in June 2014 where the outbreak in Jeddah was declining, the cross-sectional nature of the design with an inability to infer causal pathways and the sampling methods, which may preclude generalization to all inhabitants in Jeddah.

In conclusion, the current study showed a moderate level of anxiety and modest knowledge among participants. Level of anxiety was associated with several avoidance behaviours related to the domestic and international travel and being in public places. Wearing face masks and washing hands after cough or sneeze were associated with increased level of anxiety. Traditional sources of information (e.g. TV) continue to have great impact on the population knowledge. However, new applications (e.g. WhatsApp) and short message services (SMS) are important sources for public awareness.

During such outbreaks providing immediate evidence-based information to the public using both traditional media (e.g. TV) and new communications software/applications may be useful in controlling anxiety and associated psychobehavioural responses. Health authorities should be encouraged to take the lead in informing the public about proper prevention and control measures rather than abandoning the stage to the spread of rumors through social media.

Acknowledgements

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Association between attitudes towards Internet usage and health practices in high-school students in 2 schools in Turkey: a cross-sectional study

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ABSTRACT Excessive usage of the Internet can negatively affect health and health practices especially among youth. To examine the issue among Turkish students, this study determined the association between high-school students’ attitudes towards Internet usage and their health behaviour. The sample (n = 2043) was randomly drawn from all students at two high schools in Turkey: one in Anatolia and one (a vocational school) in Istanbul. Data were collected using the Structured Questionnaire, Attitude Scale towards Internet Usage (ASTIU) and Adolescent Lifestyle Profile (ALP). The mean age of the students was 16.3 years, 77.7% were male and 96.9% used the Internet; mean duration of Internet use was 18.8 h/week. Female students had more positive attitudes towards Internet usage. Mean scores for ASTIU and ALP were 72.58 (SD 17.64) and 111.34 (SD 16.61) respectively, which were average levels. There was a statistically significant but weak overall negative correlation between adolescents’ attitudes towards Internet usage and their health behaviour. Our results concur with studies in different cultures which suggest some negative effects, of heavy Internet use.

Association entre les attitudes à l’égard de l’utilisation d’Internet et les pratiques sanitaires des élèves du secondaire dans deux établissements en Turquie : étude transversale

RÉSUMÉ Une utilisation excessive d’Internet peut nuire à la santé et aux pratiques sanitaires, notamment chez les jeunes. Afin d’étudier la question parmi les élèves turcs, la présente étude a déterminé l’association entre les attitudes des élèves du secondaire à l’égard d’Internet et leurs comportements en matière de santé. L’échantillon (n = 2043) a été constitué de façon aléatoire à partir de l’ensemble des élèves des deux établissements d’enseignement secondaire en Turquie : l’un en Anatoile et l’autre dans une école de formation professionnelle à Istanbul. Les données ont été collectées à partir d’un questionnaire structuré, de l’ASTIU [échelle d’attitude à l’égard de l’utilisation d’Internet] et de l’ALP [profil de mode de vie des adolescents]. L’âge moyen des élèves était 16,3 ans, 77 % étaient des garçons et 96,9 % utilisaient Internet, avec une durée moyenne totale d’utilisation de 18,8 heures par semaine. Les élèves de sexe féminin avaient des comportements plus positifs à l’égard de l’utilisation d’Internet. Les scores moyens pour l’ASTIU et l’ALP étaient de 72,58 (ET 17,64) et 111,34 (ET 16,61) respectivement, qui correspondaient aux scores moyens. Il existait une corrélation négative statistiquement significative, mais assez faible d’un point de vue global, entre les attitudes des adolescents à l’égard de l’utilisation d’Internet et leurs comportements en matière de santé. Nos résultats recoupent ceux d’études réalisées dans différentes cultures et qui suggèrent l’existence de certains effets négatifs liés à une utilisation excessive d’Internet.

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Introduction

Internet usage in all fields, such as education, health, communication, transportation, trade and finance affects the world we live in (1,2). The Internet has become pervasive in the lives of young people and there is evidence that it has a negative effect on academic attainment (drop in grades), family relations (having to hide excessive Internet usage from parents), physical health (sleep deprivation due to long hours of Internet usage), mental health (depression) and finance (cost of accrued Internet expenses) (3).

For high-school students, the Internet is one of the main sources of information and social interaction (4,5). It enables them to access to information, do research and develop skills such as problem solving, creativity and critical thinking. On the other hand, excessive, uncontrolled and unthinking usage can have a negative effect on the development of personal skills and health and health practices (6–8). For example, regular physical activity is essential for a healthy productive life. Modern life, with its cars, televisions, computers and video games, can lead to low levels of physical activity and necessitate deliberate commitment of leisure time to physical activity to gain health benefits (9,10).

Health-risk behaviours are usually adopted in adolescence but their impact may not be felt until adulthood and may lead to a considerable increase in mortality and morbidity. Adolescents are therefore at a critical time in their life for making independent health care decisions; hence health promotion is especially important in this population (11). Health promotion aims to enable individuals to adjust their behaviours to attain a high level of physical and mental health.

As the Internet is an increasingly important resource of information in the lives of young people, it could be a valuable platform to deliver health interventions to youth populations; however, there is a lack of research in this field (12). This study among Turkish adolescents was therefore conducted to examine students’ attitudes to the Internet and their health practices in view of the social norms in Turkey, such as strong family ties (13–15).

The specific aims of this study were to evaluate:
- the attitudes of students towards the Internet usage and their health practices;
- any correlation between Internet usage and students’ health practices;
- the effect of sociodemographic and Internet-related characteristics on attitudes towards Internet usage and health practices.

Methods

Study design and sample

This was a cross-sectional study conducted in 2011/12. The study population consisted of all the students enrolled at one Anatolian high school and one vocational high school in Istanbul (total number of students = 3955). Students were selected randomly from each school separately (by drawing names from separate bags for Anatolian and Istanbul students); thus 310 students were selected from the Anatolian high school and 1733 from the vocational high school in Istanbul (Table 1).

We conducted post hoc power analysis using G*Power 3.1.9.2 program. A significant difference was observed in the ASTIU scores (z = 3.66, P < 0.001) between Internet users and non-users (Table 2). The statistical power analysis result for this difference was 0.97.

Data collection

Data were collected by the researchers through face-to-face interviews with the students outside the classroom lessons using three data collection tools (Structured questionnaire, Attitude Scale towards Internet Usage and Adolescence Lifestyle Scale). The interviews were conducted in Turkish. To reduce social desirability bias, a randomized response technique was used (16,17).

Data collection tools

Structured Questionnaire: It included questions regarding students’ age, sex, body mass index (BMI) as measured by the researchers, and computer and Internet usage.

Attitude Scale towards Internet Usage (ASTIU): It was designed by Tavşancıl and Keser to assess attitudes towards Internet usage (18). It consists of 6 sub-dimensions: Usage of Internet in Instruction, Usage of Internet in Research, Usage of Internet in Social Interaction, Enjoyment of Usage of Internet in Instruction, Usage of Internet in Communication and Usage of Internet in Sharing of Knowledge. The 5-point Likert type scale consists of 31 items. The lowest and highest scores are 31 and 155 respectively. The higher the score in all sub-dimensions, the more positive the attitude towards Internet usage (amount and type of Internet use). The internal consistency coefficient for the whole scale was 0.89 (18). In the present study, the internal consistency coefficient was 0.88, indicating ASTIU was a valid assessment tool for our study.

Adolescent Lifestyle Profile (ALP): The ALP is the version of Healthy Lifestyle Profile II developed for adolescents (9). Validity and reliability studies were conducted by Hendricks, Murdaugh and Pender (9), and a Turkish version was adapted by Arđç (10). ALP consists of 40 items and 7 sub-dimensions: health responsibility, physical activity, nutrition, positive life appreciation, interpersonal relations, stress management, and spiritual growth. The lowest and highest scores obtainable are 40 and 160 respectively. The higher the score, the higher the level
of health practice. The Cronbach alpha coefficient for the whole scale was 0.87, range 0.54 to 0.77 for sub-dimensions (9). For the present study, it was 0.89 for the whole scale, range 0.53 to 0.72 for sub-dimensions. Internal consistency coefficients in our study were similar to Ardaç’s (10), thus scale-related values had internal consistency.

Statistical analysis
SPSS 17 for Windows (version 11.0; SPSS Inc, Chicago, IL, USA) was used to analyse the data. Medians, minimum and maximum values and arithmetic means [standard deviation (SD)] were used for ordinal data evaluation. Frequency and percentages were used for nominal data evaluation. The Kolmogorov–Smirnov test was used to determine normality of distributions. As some distributions were abnormal, non-parametric methods were used for the statistical analysis. When comparing qualitative data, the Mann–Whitney U test was used to compare variables between two groups. The Kruskal–Wallis test was used to compare variables with more than two groups. The Bonferroni-adjusted Mann–Whitney test was used to identify the responsible group for the difference with secondary multiple comparison analysis when the differences between the parameters of more than 2 groups were found statistically significant. Spearman correlation analysis was used to determine correlation between scales.

Ethical considerations
Prior to the study, authorized written approval was obtained from the Faculty of Medicine Ethics Committee, Istanbul University Cerrahpaşa (03.02.2011/8087/C-07) and the Istanbul Provincial Directorate for National Education (02.04.2011/19532). Student participants were informed about the aims and benefits of the study and their roles were explained; all agreed to participate. Their written approval was taken on the consent form. No names were entered on the data collection forms and they were kept separately from the consent form to protect the anonymity of the students.

Results

Students’ characteristics
Of the 2043 students included in the study, 1587 (77.7%) were male. The reason for the difference was due to the higher number of male students in the vocational high school. The age of the participants ranged from 14 to 19 years, mean age was 16.3 years; just over half (55.2%) were aged 14–16 years. In addition, 70.4% were at a normal weight in terms of BMI, 68.4% had personal computers and 96.9% used the Internet. The mean duration of Internet use was 18.8 hours per week (SD = 17.0) (Table 2).

Association between sociodemographic & Internet-related characteristics and ASTIU & ALP scores
Sex was significantly associated with ASTIU score; female students had more positive attitudes towards the Internet usage (P < 0.001) (Table 2). Age was not significantly associated with either ASTIU or ALP scores (P > 0.05) (Table 2).

BMI was significantly associated with ALP scores (P < 0.05). The difference between BMI groups resulted from the differences in scores obtained by normal-weight and overweight students (χ² = 8.28, P = 0.041). In line with this finding, the students with normal weight had more positive lifestyle practices compared to overweight students (Table 2).

The students with personal computers had significantly lower ASTIU scores (P < 0.001) than those who did not own one. However, the opposite was true for ALP scores with computer-owning students having higher ALP scores (P < 0.001). This finding shows that students owning a computer had more negative attitudes towards the Internet but reported more positive lifestyle practices than those not owning a personal computer (Table 2).

ASTIU scores of those using the Internet were also significantly lower than those who did not do so (P < 0.05), indicating that students using the Internet had more negative attitudes towards the Internet than non-users (Table 2).

ASTIU and ALP scores were associated with weekly duration of Internet usage; the longer the Internet usage of students, the more negative were their attitudes towards Internet usage and the more negative their health practices (Table 2).

ASTIU & ALP scores and correlations between them
The mean (SD) ASTIU score was 72.58 (SD 17.64). For sub-dimensions, the mean (SD) scores were: 17.87 (SD 72.58) for Usage of Internet in Research, 10.44 (SD=4.38) for Usage of Internet in Instruction, 16.16 (SD 4.65) for Usage of Internet in Social Interaction, 10.54 (SD 3.26) for Enjoyment.
of Usage of Internet in Instruction, 9.26 (SD 3.35) for Usage of Internet in Communication, and 8.32 (SD 3.57) for Usage of Internet in Sharing of Knowledge. For ALP, the mean (SD) score for the whole scale was 111.34 (SD 16.61). The mean (SD) scores for sub-dimensions were: 10.69 (SD 2.91) for health responsibility, 16.08 (SD 3.76) for physical activity, 15.97 (SD 3.23) for nutrition, 24.38 (SD 4.35) for positive life appreciation, 15.54 (SD 2.89) for interpersonal relations, 14.68 (SD 2.70) for stress management, and 13.99 (SD 2.92) for spiritual growth (Table 3).

While there was no correlation between students’ attitudes towards the Internet usage and health responsibility, a very weak negative correlation was found between students’ attitudes towards Internet usage and physical activity, nutrition, positive outlook on life, interpersonal relations, stress management, spiritual growth and general lifestyle practises (Table 4).

**Discussion**

Overall, we found a very weak negative association between attitudes towards the Internet usage and adolescents’ health practices.

With regard to students’ individual characteristics and Internet usage, we found that the majority of participants used both computers and the Internet, and more than half of them had their own personal computer. Similarly, a study conducted by Cömert and Kayıran among children and adolescents showed that 35.7% of the families had a computer in their homes and 21.7% had Internet access (19). Given the fact that the Internet facilitates access to information, the high access shown in our study is overall a positive finding because students can easily benefit from the opportunities afforded by the Internet.

### Table 2 Distribution of students’ scores in ASTIU and ALP according to the individual and Internet-related characteristics (n = 2043)

<table>
<thead>
<tr>
<th>Variable</th>
<th>No. (%)</th>
<th>ASTIU Mean (SD)</th>
<th>ALP Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>456 (22.3)</td>
<td>76.18 (16.75)</td>
<td>111.08 (14.32)</td>
</tr>
<tr>
<td>Male</td>
<td>1587 (77.7)</td>
<td>71.54 (17.75)</td>
<td>111.42 (17.22)</td>
</tr>
<tr>
<td><strong>Age groups (years)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14–16</td>
<td>1127 (55.2)</td>
<td>72.26 (16.88)</td>
<td>111.80 (16.18)</td>
</tr>
<tr>
<td>17–19</td>
<td>916 (44.8)</td>
<td>72.97 (18.53)</td>
<td>110.78 (17.12)</td>
</tr>
<tr>
<td><strong>Body mass index</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 18.50 (underweight)</td>
<td>337 (16.5)</td>
<td>71.89 (16.95)</td>
<td>110.39 (17.03)</td>
</tr>
<tr>
<td>18.50–24.99 (normal)</td>
<td>1439 (70.4)</td>
<td>73.00 (17.59)</td>
<td>111.93 (16.58)</td>
</tr>
<tr>
<td>25–29.99 (overweight)</td>
<td>229 (11.2)</td>
<td>71.47 (19.09)</td>
<td>108.85 (16.33)</td>
</tr>
<tr>
<td>30 (obese)</td>
<td>38 (1.9)</td>
<td>69.13 (16.23)</td>
<td>112.45 (14.46)</td>
</tr>
<tr>
<td><strong>Owns computer</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>1397 (68.4)</td>
<td>70.52 (17.34)</td>
<td>112.54 (16.42)</td>
</tr>
<tr>
<td>No</td>
<td>646 (31.6)</td>
<td>77.02 (17.47)</td>
<td>108.75 (16.74)</td>
</tr>
<tr>
<td><strong>Uses the Internet</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>1979 (96.9)</td>
<td>72.31 (17.56)</td>
<td>111.38 (16.60)</td>
</tr>
<tr>
<td>No</td>
<td>64 (3.1)</td>
<td>80.77 (18.06)</td>
<td>110.25 (16.98)</td>
</tr>
<tr>
<td><strong>Duration of Internet usea (h/week)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Mean (SD), (Min–Max))</td>
<td>18.75 (17.01), (1–93)</td>
<td>r = −0.198, P &lt; 0.001</td>
<td>r = −0.084, P &lt; 0.001</td>
</tr>
</tbody>
</table>

*a Examined in the 1979 individuals who used the Internet.

z = Mann–Whitney U test; χ2 = Kruskal–Wallis test. Statistical significant set at P < 0.05.

ASTIU = Attitude Scale towards Internet Usage; ALP = Adolescent Lifestyle Profile; SD = standard deviation.
In the current study, significant sex differences in Internet usage were observed; male students used the Internet more than females. Other studies have shown sex differences in amount and type of Internet use, but not consistently for one sex or the other (20–22). Macharia & Nyakwende found that female university students in Kenya reported greater use of the Internet for study purposes than males (20). Similarly, a study conducted among high school students in Turkey reported that female students spent more time on the Internet than male students (6). However, a study in Australia observed that male adolescent students spent more time on the Internet than their female counterparts (21). Males in the United States of America were reported to use the Internet mainly for purposes related to entertainment and leisure whereas women used it primarily for interpersonal communication and educational assistance (22).

The correlation between the duration of the Internet use and ASTIU and ALP scores showed that longer Internet usage was associated with more negative attitudes towards its use and poorer health practices. Several studies confirm the negative effects of Internet use on health practices if it is used for extended periods of time. A study among students in Hong Kong reported that heavy Internet users were much less likely than others to engage in health-promoting behaviours such as attempting to eat a healthier diet, taking nutritional supplements and trying to increase physical activity levels (23). In a study among Turkish high-school students, Kelleci et al. showed that Internet usage in excess of 2 hours a day led to mental health disorders (6). Among a sample of adults (median age of 20 years), higher levels of computer usage were associated with both lower physical activity levels and perception of computer usage as a barrier to physical activity (24). Moreover, Morgan and Cotton, and Yang et al. suggested that excessive use of the Internet caused students to deviate from the real life and fail to cope with difficulties they encounter (25,26). Participants of a study conducted by Rotunda et al. reported certain negative outcomes of Internet usage and that problematic practices, which were less prevalent, became more common (27).

The students’ ASTIU scale total score was at a medium level (mean 72.58 in a range of 31–155). Also Internet Usage in Instruction was the sub-dimension on which students got the highest scores. A study among adolescents in Lebanon indicated that 84.2% the Internet usage was for communication and messaging, 65.7% for information and research, 51.8% for entertainment such as gaming, 51.2% for music and movies, and 4.6% for other purposes (28). Thanks to its interactive nature, the Internet contributes to education and provides resources and materials in almost every field that can be used directly in the classroom. Furthermore, students in this information

### Table 3 Distribution of students’ scores from the Attitude Scale towards Internet Usage (ASTIU) and Adolescent Lifestyle Profile (ALP) scales (n = 2043)

<table>
<thead>
<tr>
<th>Scale</th>
<th>Potential range</th>
<th>Minimum</th>
<th>Maximum</th>
<th>Median</th>
<th>Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>ASTIU</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Usage of the Internet in instruction</td>
<td>8–40</td>
<td>8</td>
<td>40</td>
<td>17</td>
<td>17.87 (6.03)</td>
</tr>
<tr>
<td>Usage of the Internet in research</td>
<td>7–35</td>
<td>7</td>
<td>35</td>
<td>16</td>
<td>16.16 (4.65)</td>
</tr>
<tr>
<td>Usage of the Internet in social interaction</td>
<td>4–20</td>
<td>4</td>
<td>20</td>
<td>10</td>
<td>10.44 (4.38)</td>
</tr>
<tr>
<td>Enjoyment from usage of the Internet in instruction</td>
<td>4–20</td>
<td>4</td>
<td>20</td>
<td>10</td>
<td>10.54 (3.26)</td>
</tr>
<tr>
<td>Usage of the Internet in communication</td>
<td>4–20</td>
<td>4</td>
<td>20</td>
<td>9</td>
<td>9.26 (3.35)</td>
</tr>
<tr>
<td>Usage of the Internet in sharing of knowledge</td>
<td>4–20</td>
<td>4</td>
<td>20</td>
<td>8</td>
<td>8.32 (3.57)</td>
</tr>
<tr>
<td>Total</td>
<td>31–155</td>
<td>31</td>
<td>148</td>
<td>72</td>
<td>72.58 (17.64)</td>
</tr>
<tr>
<td><strong>ALP</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health responsibility</td>
<td>5–20</td>
<td>5</td>
<td>20</td>
<td>10</td>
<td>10.69 (2.91)</td>
</tr>
<tr>
<td>Physical activity</td>
<td>6–24</td>
<td>6</td>
<td>24</td>
<td>16</td>
<td>16.08 (3.76)</td>
</tr>
<tr>
<td>Nutrition</td>
<td>6–24</td>
<td>6</td>
<td>24</td>
<td>16</td>
<td>15.97 (3.23)</td>
</tr>
<tr>
<td>Positive life appreciation</td>
<td>8–32</td>
<td>8</td>
<td>32</td>
<td>25</td>
<td>24.38 (4.35)</td>
</tr>
<tr>
<td>Interpersonal relations</td>
<td>5–20</td>
<td>5</td>
<td>20</td>
<td>16</td>
<td>15.54 (2.89)</td>
</tr>
<tr>
<td>Stress management</td>
<td>5–20</td>
<td>5</td>
<td>20</td>
<td>15</td>
<td>14.68 (2.70)</td>
</tr>
<tr>
<td>Spiritual growth</td>
<td>5–20</td>
<td>5</td>
<td>20</td>
<td>14</td>
<td>13.99 (2.92)</td>
</tr>
<tr>
<td>Total</td>
<td>40–160</td>
<td>40</td>
<td>160</td>
<td>111</td>
<td>111.34 (16.61)</td>
</tr>
</tbody>
</table>

SD = standard deviation.
Table 4 | Correlation between students’ scores on the Attitude Scale towards Internet Usage (ASTIU) and Adolescent Lifestyle Profile (ALP) scales (n = 2043)

<table>
<thead>
<tr>
<th>ALP</th>
<th>Usage of the Internet in instruction</th>
<th>Usage of the Internet in research</th>
<th>Usage of the Internet in social interaction</th>
<th>ASTIU Enjoyment from usage of the Internet in instruction</th>
<th>Usage of the Internet in communication</th>
<th>Usage of the Internet in sharing of knowledge</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health responsibility</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><em>r</em></td>
<td>-0.190**</td>
<td>0.070*</td>
<td>-0.048*</td>
<td>0.016</td>
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*Correlation significant at the 0.05 level (2-tailed).
**Correlation significant at the 0.01 level (2-tailed).
*r* = Spearman correlation.
*P* = Correlation significant at the 0.05 and 0.01 level (2-tailed).
age are expected to self-learn through various resources, including the Internet, and be able to analyse and use information accessed. Using the Internet in a healthy and conscious fashion facilitates learning performance and enables adolescents to acquire and benefit from a variety of skills such as selecting collecting and categorizing information (19,29).

The total score on the ALP scale was at a medium level (mean 111.34 in a range of 40–160). On the other hand, “positive life appreciation” was the sub-dimension on which students got the highest scores. Scores for positive life appreciation indicate the level of adopting a positive view on life and having positive thoughts. It can be said that if young people have a positive outlook on life, it is a desirable outcome for their future in terms of adopting and maintaining positive health practices (10).

We observed that as students’ ASTIU scores increased, physical activity, nutrition, positive outlook on life, stress management, spiritual growth and general lifestyle practices became more negative. A previous study in Turkey revealed that children and youngsters who spend a lot of time on the Internet become more and more isolated and experience difficulties in establishing face-to-face interactions (30). Other studies in the United States and Australia reported that excessive usage of the Internet could cause considerable problems in daily practices, interpersonal relations and business, and that some students could not establish close relationships with their friends due to the Internet usage (31,32). Clark et al. confirmed that students who constantly use the Internet develop eyestrain, headache and pain in their neck and wrists in time and women exhibit more physical symptoms compared to men (33).

A main limitation to our study is that it was conducted in only 2 schools is Turkey and the sample may not be representative of schools across Turkey; hence the results may not be generalized to a wider population.

**Conclusion**

This current study was conducted to determine the effects of high school students’ attitudes towards the Internet usage on their health practices. Weak negative correlations were found between students’ attitude towards the Internet usage and physical activity, nutrition, positive outlook on life, interpersonal relations, stress management, spiritual growth, and general lifestyle practices. Thus it may be said that Internet use appears to have little effect on students’ health practices. However, while showing weak effects, our results are similar to studies in different cultures which suggest some negative effect of heavy Internet use; some control of the heavy usage of the Internet may be warranted.

**Acknowledgements**

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**Competing interests:** None declared.

**References**


Short communication

Implementation of a mentored professional development programme in laboratory leadership and management in the Middle East and North Africa


ABSTRACT Laboratories need leaders who can effectively utilize the laboratories’ resources, maximize the laboratories’ capacity to detect disease, and advocate for laboratories in a fluctuating health care environment. To address this need, the University of Washington, USA, created the Certificate Program in Laboratory Leadership and Management in partnership with WHO Regional Office for the Eastern Mediterranean, and implemented it with 17 participants and 11 mentors from clinical and public health laboratories in 10 countries (Egypt, Iraq, Jordan, Lebanon, Morocco, Oman, Pakistan, Qatar, Saudi Arabia, and Yemen) in 2014. Designed to teach leadership and management skills to laboratory supervisors, the programme enabled participants to improve laboratory testing quality and operations. The programme was successful overall, with 80% of participants completing it and making impactful changes in their laboratories. This success is encouraging and could serve as a model to further strengthen laboratory capacity in the Region.

Mise en œuvre d’un programme de mentorat en développement professionnel pour les directeurs et les cadres de laboratoire au Moyen-Orient et en Afrique du Nord

RÉSUMÉ Les laboratoires ont besoin de directeurs à même d’utiliser les ressources internes de façon efficace, de maximiser leurs capacités à dépister les maladies, et d’ouvrir pour le bien de ces établissements dans un environnement de soins de santé en perpétuel changement. Pour répondre à ces besoins, l’Université de Washington (États-Unis), en partenariat avec le Bureau régional de l’OMS pour la Méditerranée orientale, a mis au point le Programme de certification en direction et gestion du laboratoire qui a été suivi par 17 participants et 11 mentors issus de laboratoires de santé clinique et publique dans 10 pays (Arabie saoudite, Égypte, Iraq, Jordanie, Liban, Maroc, Oman, Pakistan, Qatar et Yémen) au cours de l’année 2014. Conçu pour former les responsables de laboratoire aux compétences de direction et de gestion, le programme a permis aux participants de renforcer la qualité du dépistage et des opérations de leurs laboratoires. Le programme a été une réussite dans l’ensemble puisqu’il a été suivi jusqu’à son terme par 80 % des participants et que ceux-ci ont ensuite pu mettre en place des changements réels dans leurs laboratoires. Ce succès est encourageant et pourrait servir de modèle afin de renforcer davantage encore les capacités des laboratoires dans la Région.
Introduction

Countries around the world have been implementing the International Health Regulations (IHR) since 2007, requiring all countries to detect, assess, notify, and respond to public health threats (1–3). Health laboratories are a key component of this response and quality practice is essential; unfortunately, many countries are falling behind in these capabilities (3–5). Laboratories are complex, people-driven systems that require strong leadership and effective management to deliver accurate, timely and reliable test results (6,7). Unfortunately, many laboratory leaders have not had formal management training or experience leading organizations (8–10). While some training programmes exist, most have been designed for audiences in the United States of America, are proprietary or fee-based, lack formal mentorship, are offered exclusively online without opportunity to meet faculty or fellow participants, and have lacked a curriculum that addresses core competencies (8,10–18). While field epidemiology training programmes have been envisioned as a mechanism to deliver laboratory management training, they have historically focused on the laboratory’s role in outbreak response and have lacked a structured curriculum in laboratory management and leadership. Additionally, some donors have funded trainings through disease-specific programmes. There remains a global need to strengthen laboratory capacity and quality from a systems approach (19).

Because of these gaps, we developed a competency-based, blended-learning, mentored professional development programme in health laboratory leadership and management which can be tailored to local environments and implemented globally. The Certificate Programme in Laboratory Leadership and Management (CPLLM) was designed to strengthen the leadership and management skills of laboratory supervisors with the goal of improving their laboratories’ operations (8,10) and advancing national and regional progress in disease detection and response, laboratory quality and biosafety and biosecurity.

Methods

Programme design

The CPLLM was structured into an in-person programme orientation and course on laboratory systems, 4 online courses, and the applied Capstone Project (Figure 1). Learning objectives were aligned with key laboratory leadership competencies (8,10). Adult learning programmes that include components of work-based training significantly impact attainment of competencies and behaviour change (20–24). Accordingly, the CPLLM’s Capstone Project component was an individualized opportunity for participants to address areas in their laboratories’ operations that needed improvement; expand and apply leadership, management, analytical, and communication skills; and implement principles of continuous quality improvement. Capstone Project assignments reinforced these concepts and were due during breaks in coursework.

Curriculum development

The curriculum for the CPLLM (Figure 1) was developed using adult learning methodologies, and included 1 course delivered in person, 4 online courses [including > 85 recorded lectures and videos, interactive assignments, readings, quizzes, and surveys; all accessible through a learning management system (LMS, Canvas®)] (20–23,25). Each online course lasted 4 weeks (except for Laboratory Leadership and Management, which was 8 weeks) and required 20–25 hours of work. Participants spent 5–6 hours per week on coursework and Capstone Project work.

The Canvas® learning management system is an internet-based application used for the delivery, administration, monitoring and evaluation of the CPLLM; a University of Washington survey indicated that 79% of users prefer this interface to other learning management systems (26,27). Canvas® was customized for the CPLLM, and was a central gateway where participants and mentors could access all programme content, including reading materials, videos, lectures and links to resources—all organized into modules for easy navigation. Participants could also download all materials for offline viewing. Canvas® contained robust capabilities for communication and collaboration, including discussion boards, messaging, email, schedule notifications and announcements, and allowed posting of multiple file types, including voice and video. Each online course was led by an instructor and teaching assistant, who monitored participants’ assignments, guided online discussions and provided support as needed.

Participant recruitment and selection

To facilitate appropriate candidate recruitment within multiple ministries of health, a detailed profile was developed which described the required experience of participants. The ideal participant would be a director or manager in a public clinical or public health laboratory (mid-career); hold a Bachelor’s degree (or equivalent) with > 5 years experience in laboratory medicine; > 1 year in a supervisory role; regarded as an emerging leader with strong motivation for laboratory improvement and self-improvement. Recruitment began in September 2013; 3 candidates from the public sectors in Egypt, 2 each from Iraq, Jordan, Oman, Pakistan, Qatar, Saudi Arabia and Yemen, and 1 each from Lebanon and Morocco were accepted. Selected participants had no previous training in leadership or management.
Figure 1 Programme curriculum The curriculum comprises 5 courses (1 delivered in-person (purple boxes), 4 online (yellow boxes)) and the capstone project (in grey). Each online course runs for 4 weeks with each week’s module addresses various topics (shown as yellow squares above). Each weekly module is comprised of pre-recorded lectures, readings, interactive assignments and real-time, case-base discussions. Capstone assignments (shown in grey boxes, n=7) are due during breaks between courses.
Mentor recruitment and participation

Mentorship in the laboratory can improve worker performance (28–30) and mentors played an important role in the CPLLM. A detailed profile was developed and used to recruit qualified mentors and 11 were selected for their reputations as leaders in health laboratory practice, their experience in laboratory management, their reputations as results-driven and skilled problem solvers, and as communicative and encouraging teachers. Mentors were coached on mentoring skills at the programme kickoff meeting and throughout implementation. Each mentor supported 1–2 participants, both remotely (Canvas™, Skype™ or telephone) and in-person. Average time commitment to each participant was approximately 1–2 hours per week throughout the 9-month programme, and mentors helped participants address barriers to Capstone Project implementation and evaluated their leadership and management skills. Mentors also contributed to the online discussions where appropriate.

Programme implementation

The CPLLM began in Casablanca, Morocco in January 2014. At the orientation session, participants gave presentations about their laboratories and conveyed their goals for the programme. Orientation included an introduction to the purpose, goals and expectations of the programme, an overview of the online curriculum, Canvas™ and the Capstone Project assignments. The Laboratory Systems course followed, covering the roles and requirements of laboratories in a health system, elements of a functioning laboratory system and laboratory quality management (31). Participants then returned to their laboratories to conduct a laboratory self-assessment (32) and began the online portion of the CPLLM. Capstone Project work began in February with a comprehensive laboratory assessment; participants used the results to develop the goals and work plans for their Capstone Project. The Capstone Project had to have a direct, practical value within the laboratory, involve the laboratory staff and demonstrate leadership and management skills. Participants completed 7 Capstone Project assignments during the CPLLM and summarized their findings at the programme finale in September 2014.

Programme evaluation

Programme success and curriculum quality were based on a number of indicators (33), including programme completion rate, Capstone Project quality, discussion quality and participant and mentor feedback, and was evaluated by both quantitative and qualitative methods (24,33,34). Surveys assessed learner satisfaction with content, and pre/post-course tests, and in-course quizzes and assignments measured participants’ comprehension; Capstone Project assignments demonstrated the application of course theory. Participant and mentor input on discussion boards was also evaluated. Course evaluations collected quantitative and qualitative data about each course. Programme evaluations were also requested from mentors. Participant progress has also been monitored since completion of
the CPLLM, measured by informal survey.

**Results**

The CPLLM was highly successful with 14 (80%) of the participants completing the programme and making substantial improvements in their laboratories, particularly in the areas of quality management and biosafety and biorisk management (Figure 2). All participants improved their leadership and management skills and their laboratories’ performance during the programme. They also stated that course content was useful to their jobs, and said they would recommend the CPLLM to their peers. Participants indicated that mentors communicated frequently, that the frequency and duration of communications with their mentors were adequate and that their mentors were helpful, providing advice and feedback during the programme. Participant and mentor feedback sessions were also conducted at the finale meeting to get qualitative input on the programme (Table 1). This feedback was overwhelmingly positive, with the majority of responses indicating satisfaction with the programme.

**Discussion**

We developed the CPLLM to address the global need for improved laboratory management and leadership. It was designed for a global audience and fostered networking and collaboration, strengthening laboratory systems at the national and regional levels. The CPLLM achieved a high graduation rate due to a number of critical factors (33). First, appropriate participants were recruited and we ensured they had the support of their organizations and recognition by their supervisors. Strong mentorship and collective problem-solving helped ensure retention of participants in the online environment. Feedback received from this cohort was used to further refine the curriculum and optimize participant satisfaction for CPLLM implementation in other countries (the CPLLM is being implemented in Zambia in 2016).

Importantly, the CPLLM was highly regarded by participants because it delivered both theoretical and practical applications of effective laboratory leadership and management. The Capstone Project was a unique component of the CPLLM because it exemplified leadership and management theory, and resulted in measureable improvements within a short period of time, unifying the entire laboratory around a common goal. By developing strategic thinking skills, embracing process improvement and learning how to lead change, laboratory managers improved laboratory performance. Since programme completion in September 2014, many participants have communicated that they have started preparing for ISO 15189 accreditation using the new WHO Laboratory Quality Stepwise Implementation (LQSI) tool (35). While financial support for this cohort did not support long-term impact evaluations, these would be ideal to incorporate in future years.

The CPLLM affirms the impact of formal leadership and management training on laboratory capacity, and can build on previous investments for improved laboratory system operability and preparedness (36,37); the modular online curriculum allows the CPLLM to be customized with location-specific case studies for any country. The CPLLM was provided at no cost to participants thanks to generous United States of America government grants. However, for sustainability of the programme, user-fees and twinning partnerships with local universities may be pursued for future implementation. Additionally, continuing professional development credits could be pursued with national health professions associations, and may improve workforce retention (38–40).

**Acknowledgements**

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**Competing interests:** None declared.
<table>
<thead>
<tr>
<th>Programme evaluation question</th>
<th>Participant comments</th>
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<tr>
<td>What was your favourite part/aspect of the programme?</td>
<td>I enjoyed and benefited from the programme, all the topics were important and added to my information especially leadership and management. Although the programme was interesting and valuable in its online courses and it may save money or solve technical issues, the 2 face-to-face meetings, the kickoff and final meetings, were the preferred parts for me; in the end nothing is more valuable and informative like the face-to-face meetings. Using short videos of leaders from different institutions all over the world, sharing their points of view and experience was a great idea of the programme providers.</td>
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<td>Have you become more interested in a particular area of laboratory management or leadership as a result of taking this programme? If so what area?</td>
<td>Communication skills, planning, and importance of data analysis. Systems thinking. The use of tools for improving team management. I've become more sensitive to Biosafety and Biosecurity issues and the regulatory aspects of laboratory management. All the contents and courses were informative but if I have to put something first then I will choose laboratory quality management system, a very critical subject; we have real problems in organizing our laboratory work. As I said in one of the discussion boards, I believe that the implementation of a quality management system is a vital part of system thinking in laboratory work.</td>
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<td>What was the most challenging aspect of completing the Capstone assignments and why were they challenging?</td>
<td>Selecting the appropriate time for each steps of my work plan because it depend on my efforts also willingness of my stakeholders. Unexpected events that are outside our control, related to the general unstable condition in the country. The time for completing the project. because we all busy in many task in our job and also in continuity of online study. One of the challenges are needing approval of some implementation steps and I depending upon the prediction of the time that required for the implementation of these items in work plan. For example I need formal approval to get funds during the implementation course and this may need time. Preparing staff for change.</td>
</tr>
<tr>
<td>Were there any resources missing, that if you had them, would have helped you complete this assignment better?</td>
<td>More authority to implement changes. Financial resources. Time to connect with other infectious disease consultants to know from them their challenges and their concern. Stakeholders understanding of the importance of the project.</td>
</tr>
<tr>
<td>What was the most important thing(s) you learned from the Capstone project? What did you find to be of most value?</td>
<td>How I can organize my work and manage my time. Learning project management tools to foresee the challenges to be overcome, have a plan with detailed steps; also to have all the mitigation steps before hand and to write it down. The most valuable is to get a complete plan with all of the difficulties and how to go about it. Assigning responsibilities to my colleagues (staff of the unit). Reviewed relevant literature with practical approach to prepare meaningful project. How to develop work plan and this I shall use it in future projects. The most valuable is the part for potential challenges and mitigation plan. To act in a timely manner, to assign my priorities. Do not give up when challenges occur but always think of new ways to overcome obstacles. How to write a project implementation report. How to finish each task in its time, work in a team, cooperation with each other, and to be more creative. To compare and self-evaluate the progress during the period of implementation with organized and targeted thoughts. The most important thing I learned is the fact of being on track for information and using practical tools to ask the right questions, bring the right answers, and be structured in order to set a plan. That nothing is impossible, just you need to work hard at it. I learned presentation skills.</td>
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References


A well-functioning national health information system (HIS) is a prerequisite for the provision of reliable and timely health-related information. This information is essential for: 1) policy development and evidence-informed decision-making; 2) proper health management and rational resource allocation; and 3) monitoring and evaluation of health systems and other related social services performance. National HIS draw upon multiple data sources, including civil registration and vital statistics systems, census, population-based surveys, routinely generated data from health facilities and administrative information systems. These are supported by governance structures, human and financial resources infrastructure and information, communications technology, quality assurance procedures, data management and standards, and clear plans for dissemination, use of the information and evidence generated from the system.

Learning from the experience of the Millennium Development Goals (MDGs), generation, availability and accessibility of timely and quality information for key health indicators is essential for monitoring the progress towards achieving the targets of the health-related Sustainable Development Goals (SDGs). Despite the progress made by many countries in monitoring health during the MDG era, the lack of reliable, timely and comparable information in low- and most middle-income countries remains an issue (1) and often hampers tracking and evaluation of progress. As a result, there has been reliance on estimates and modelling to substitute for unavailable key indicators. This process surely comes with important limitations, including observations from national authorities that argue the estimates do not always reflect the reality in countries. This situation calls for effective and sustained action to strengthen national health information systems, as well as reinforce the capacity of countries in generating, compiling, analyzing, disseminating and reporting reliable data for the monitoring of health situations in countries.

For the specific case of the SDGs, several SDG3 targets focus on different measures of mortality. These range from maternal mortality, neonatal mortality, preventable mortality from noncommunicable diseases (NCDs), and mortality from environmental hazards, to road traffic accidents and other forms of violence (2,3). Consequently, strengthening national civil registration and vital statistics is imperative if countries are to have adequate data systems. This is especially important when 53% (4) of all deaths globally are not appropriately registered and only one in five deaths in the region (5) is medically certified and coded using the International Classification of Diseases (ICD), which also suffers from non-ignorable proportions of ill-defined causes (6,7). As a result, the reporting of cause-specific mortality in the SDGs’ monitoring and accountability framework will face notable constraints if further improvements are not achieved. This area has seen very little progress over the past 25 years; in 2014, only 50% of Member States, globally, reported cause-of-death data to WHO, compared to 45% in 1990 (8). Regionally, only 11 countries regularly reported to WHO cause-specific mortality data during 2008–2012 (9).

Strengthening HIS in countries of the Eastern Mediterranean Region (EMR) has been given a special priority in WHO’s work in the Region during the past five years. Extensive work was done by the WHO Secretariat and a series of regional meetings – engaging multisectoral representatives of Member States, relevant United Nations (UN) agencies and regional organizations – were organized. The aim was to review the regional situation, identify constraints and collectively develop and implement strategic directions to address these, and support countries in reinforcing informed decision-making and strengthening their capacity to monitor national health development. The outcome of this work was regularly presented, discussed and endorsed at the highest level by Ministers of Health and other health policy-makers during the annual sessions of the WHO Regional Committee for the Eastern Mediterranean and other high-level meetings. Two Regional Committee resolutions were passed, which now represent a roadmap for countries and serve as the basis of WHO’s work (10). The objective of this paper is to review the current status, actions taken and present the priorities and strategic directions for both countries, WHO and other partners in this area of work.

1WHO Regional Office for the Eastern Mediterranean, Cairo, Egypt
The current status

Throughout WHO’s work with EMR Member States, a number of common gaps have been identified, which hinder development and strengthening of national HIS. There is often a lack of clarity on the essential health indicators that should be monitored as core in all countries. In many countries, political commitment and priority given to HIS is inadequate due to fragmentation of existing systems coupled with low capacity to collect, verify and disseminate data and information.

In 2012, efforts to strengthen health systems in the Region were initiated with detailed situation analysis of the status of different components of the health systems in Member States (11). For practical reasons, Member States were categorized into three groups based on population health outcomes, health system performance and health expenditure (1). A more in-depth analysis of the situation of national HIS across the three groups of countries was reported during the 61st Session of the WHO Regional Committee for the Eastern Mediterranean in 2014 (9). The conclusion drawn was that although countries across the three groups are at different stages of development, availability of skilled human capacity and financial resources, there are still major gaps that are shared across the three groups of countries.

All Group 1 countries have national HIS centres or units with dedicated staff as well as national plans. However, some plans are of limited scope in the areas of data collection, data analysis and capacity strengthening. In all countries, national HIS are computerized, with varying degrees of functionality and integration. With regards to basic data quality assessments and feedback, they are performed in all countries, although the assessment is not based on standardized tools and processes. All countries regularly publish annual health statistics reports in various formats (i.e. print, digital and World Wide Web), noting that dissemination through the World Wide Web has improved substantially in recent years.

A set of defined national indicators exists in most Group 1 countries with varying degrees of quality, completeness and frequency of reporting. All, except one country, collect cause-specific mortality data using ICD, but the quality of the collected data is an issue in all except one country. At the time of the review in 2014, the percentage of reporting of indicators ranged from 25% to 80%. Specifically, the reporting of: i) health determinants and risks indicators ranged from 25% to 90%; ii) health status indicators in all countries except one; and iii) health system response indicators ranged from 10% to 80%. A key challenge is regular updating of population data by age, sex, and nationality due to the high rate of in- and out-migration in these countries.

All Group 2 countries, except one, have national (and subnational) HIS centres with predominately information technology (IT) staff, as well as a national plan in the majority of the countries. Basic data quality assessments and feedback are limited; while all countries publish annual health statistics reports, only two disseminate these reports through the World Wide Web.

A set of core national and programme-specific indicators are defined in most Group 2 countries, and range from 52 to 152 indicators. Only one country reports complete cause-specific mortality data using ICD on a regular basis. Birth and death data are generally incomplete, as well as data on human resources for health. At the time of the review in 2014, the reporting of: i) health determinants and risks indicators ranged from 50% to 60%; ii) health status indicators at 70%; and iii) health system performance indicators at 50%.

All Group 3 countries, except two, have national HIS centres or units that lack capacity in most countries, especially those at the periphery, with only a few having a national plan, which is often outdated or incomplete. Data quality assurance and analysis through systematic methods are lacking. While all countries, except one, publish annual health statistics reports, there is a 2 to 3 year time lag. Across all countries, dissemination of health statistics through the web is either unavailable or inaccessible. Population-based and facility-based surveys are not conducted on a regular basis.

Most Group 3 countries lack a system of routine reporting, especially on cause-specific mortality data, with ICD coding not systematically used in all countries. At the time of the review in 2014, the reporting of: i) health determinants and risks indicators was at 50%; ii) health status indicators were few and largely based on global estimates; and iii) health system performance indicators were less than 50% in the majority of countries.

Other constraints include:

1. Weak coordination between national stakeholders and fragmentation of health information and civil registration and vital statistics systems, both within and across ministries. This also includes:

   - Limited access to routinely generated health care service data from the private sector, and often services by public health systems not under the ministry of health (e.g.
insurance organizations, armed forces)  
– Lack of national comprehensive plans for health information systems including national population surveys and irregular conduct of such surveys  
– Limited governance or legal oversight from ministries of health and national statistics offices in obtaining the required data and ensuring their availability as part of use.

2. Weak and often incomplete reporting of deaths, cause-specific mortality data, the use of ICD and mortality statistics.  
– Out of 131 Member States, globally, with vital registration systems that provided summary data on cause-of-death statistics to WHO, only 60 countries had data that met certain criteria of completeness, accuracy, regular reporting and disaggregated by sex and age (12).
– Out of the 22 countries of the Region, seven have never reported to WHO causes of death using ICD. Eleven countries (50%) have major gaps in mortality data reporting and only four countries have continuously reported annual mortality data (13).

3. Weak reporting on key morbidity indicators: population-based cancer registries and integrated disease surveillance are weak or non-existent in most countries.  
– In the 2015 Global Survey on assessing national capacity for the prevention and control of NCDs conducted by WHO, less than 60% (14) of countries are reporting data on cancer incidence and type based on a population based cancer registry.

4. Ineffective leveraging of opportunities provided by information communication and technology (ICT) in data collection, analysis and dissemination.

5. Inadequacy of quality assurance procedures and lack of use or shared understanding of data collection and use standards and procedures.
6. Routinely collected data (e.g. health service data) often are not linked with established quality assurance procedures.
7. Shortage of skilled human resources in epidemiology, statistics, IT and disease and risk factors surveillance.  
– Preliminary results from assessments of essential public health functions in countries of the Region clearly demonstrate shortage of skilled human resource capacity in related health information disciplines. In many cases where capacity exists in the countries, retention and adequate distribution poses a challenge.

What is an effective health information system?

Health information systems include all activities and resources related to public health monitoring and reporting. This includes collecting data from the health sector and other relevant sectors, analysing the data and ensuring their overall quality, relevance and timeliness, and converting data into information for health-related decision-making (15). Health information systems provide the underpinnings for decision-making and have five key functions: data generation, compilation, analysis and synthesis, communication of information, and use (Figure 1).

The Health Metrics Network defines a national HIS as being “made up of all the data and records about the population’s health. The sources of data include civil and vital registration (recording births, deaths and causes of death), censuses and surveys, individual medical records, service records and financial and resource tracking information” (16).

For policy-makers who recognize the major gaps that exist in their national HIS and the constraints encountered in addressing them, one practical question is to determine the essential health indicators that they need to monitor as part of their commitment to strengthen their health system and achieve universal health coverage. Because countries will vary in terms of socioeconomic development and health achievements, it is important to identify what is core for all countries irrespective of income and public health capacity and what can be added as an expanded list to cater for national priorities and programme-specific needs.

There is also agreement that good quality data on a small number of key indicators is more informative for policy, planning and prioritization than a larger number of indicators generated from unreliable data. With this understanding, the WHO Regional Office for the Eastern Mediterranean facilitated and led extensive discussions with Member States and partners through a series of technical meetings and expert consultations conducted between 2012 and 2014. The focus of the discussion was to have an in-depth assessment of the current status of health information systems including civil registration and vital statistics and identify the type of indicators that are considered essential in monitoring health trends and health development.

Two strategic initiatives to strengthen health information systems

It was clear from the in-depth assessment conducted in 2012 on the regional health challenges that reinforcing health information systems is one of the key priorities for WHO’s work with Member States. In this respect,
two main strategic directions were adopted: a) reaching consensus on a practical framework for national HIS and establishing a core set of indicators that can be feasibly implemented in all countries; and b) strengthening civil registration and vital statistics as one of the most critical elements of HIS.

Both strategic directions require the commitment and active engagement of other government sectors outside health.

**Health Information Systems framework and regional core indicators**

There have been several global frameworks proposed for HIS (17–19). The challenge policy-makers face is to adopt a framework that is practical, easy to understand, feasible to implement and covers the key areas necessary for health policy development and monitoring. Both WHO and Member States of the Region agreed that the three broad areas requiring action and monitoring are the essential determinants of health, health status, and health system capacity and response. This consequently led to consensus on the key components of a national HIS and identification of what needs to be monitored under each component (Figure 2). The three areas are: i) monitoring health risks and determinants; ii) assessing health status including morbidity and cause-specific mortality; and iii) evaluating health system performance.

To realize the Framework and ensure that national HIS are capable of effectively tracking health issues, it was agreed that a minimum dataset of core indicators should be prioritized and collected. Through a series of meetings, spanning 2013 and 2014, work continued to develop a list of core indicators (Figure 3) with a concise metadata registry. Every effort was made to ensure that the included indicators are valid, specific, relevant, feasible and affordable to generate. In consultation with Member States, stakeholders and experts, a total number of 68 core indicators were agreed, with an expanded (as relevant) list of 115 additional indicators for countries that need to have a wider coverage according to their capacity and needs. In this respect, since most countries are currently unable to report reliably on all the core indicators, it will be important for them to prioritize addressing the gaps before expanding.

An essential part of the initiative was the active engagement of stakeholders from ministries of health and interior, as well as central bureaus of statistics or national statistics offices; UN agencies; and international and regional experts.

The aim of the regional context-specific concise metadata registry (20), which draws upon the WHO global metadata registry, is to facilitate standardized data collection, analysis and reporting. A number of attributes are described for each indicator, including: the indicator name and abbreviated name, domain/subdomain, related/associated term(s), definition, measurement and estimation methods, primary/preferred and alternate/other possible data source(s), disaggregation and measurement frequency, numerator and denominator (see annex 1 for an example) (9,21).

Since its endorsement during the 61st Session of the WHO Regional Committee for the Eastern Mediterranean in 2014, WHO reports annually on the core indicators and verifies data with Member States (22). This has also served as the basis for the data that is included in the brief health system profiles that are updated annually and provide

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**Figure 1. National health information systems**

- **Key functions of a national health information system**
  - Data generation
  - Data compilation
  - Data analysis and synthesis
  - Information communication
  - Use for policy development, monitoring and evaluation

- **Key sources of data**
  - Civil and vital registration
  - Census and surveys
  - Individual medical records
  - Service and facility records
  - Financial and resource tracking information
a snapshot covering key health system indicators, achievements, strengths, weaknesses and priorities for action. The health system profiles aim to help policy-makers focus on the assets and challenges within their countries.

The Regional Office has embarked on a process to assess countries’ capacity in reporting on the core indicators, through a rapid assessment. The assessment of country capacity to regularly report on the core indicators is a basic step to support countries to plan for their HIS strategy and monitor their progress towards achievement of SDGs targets. The first phase of the initiative has entailed the development of an assessment tool on the capacity to report on the core indicators, covering key domains of: existing data sources, frequency of data collection, data analysis, existing resources and use of appropriate standards for data collection, processing and analysis. The first phase of the initiative has entailed the development of an assessment tool on the capacity to report on the core indicators, covering key domains of: existing data sources, frequency of data collection, data analysis, existing resources and use of appropriate standards for data collection, processing and analysis. Member States undertook the rapid assessment, which was completed by most countries in August 2016 through a web-based questionnaire.

The initial results of 19 countries that participated in the survey reveal that although there is an improvement in reporting on the core indicators since their endorsement in 2014, none of the countries in the Region are able to report on all 68 core indicators in a timely manner. In 2016, reporting on the core indicators ranged from a minimum of 38 indicators and a maximum of 58 indicators (Figure 4). The results were discussed during a regional meeting of country delegations during August 2016. Discussions included key challenges and approaches to ensure that countries have functional health information systems, are able to conduct population-based surveys, improve reporting of the core indicators, and report on the SDG indicators that are not part of the core health indicators.

Civil registration refers to “the continuous, permanent, compulsory, and universal recording of the occurrence and characteristics of vital events (live births, deaths, fetal deaths, marriages, and divorces) and other civil status events pertaining to the population as provided by decree, law or regulation, in accordance with the legal requirements in each country” (23,24).

A special priority has been given to CRVS by WHO as part of the regional initiative to strengthen national HIS in Member States. A starting point was to assess the current status in countries of the region. Rapid assessments of CRVS were carried out in 21 countries, using a standard assessment tool (25) in all countries from November 2012 to January 2013, through multi-stakeholder meetings. This was followed by comprehensive assessments (26) conducted in 21 countries from 2013 to 2016. Results of the assessments revealed that only 6 countries (29%) have satisfactory CRVS systems that produce data of sufficient quality to adequately cover the needs for policy decision-making (Figure 2). However, the systems in these countries cover only 5.3% of the EMR population. Eight countries (almost

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**Figure 2. Framework for health information systems – core indicators**

<table>
<thead>
<tr>
<th>Key components of a national health information system</th>
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<tbody>
<tr>
<td>Health determinants and risks</td>
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<tr>
<td>- A list of core indicators on:</td>
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<tr>
<td>- demographic and socioeconomic determinants</td>
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<tr>
<td>- risk factors</td>
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<tr>
<td>Health status</td>
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<tr>
<td>- A list of core indicators on:</td>
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<tr>
<td>- life expectancy and mortality</td>
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<tr>
<td>- morbidity</td>
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<tr>
<td>Health system response</td>
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<tr>
<td>- A list of core indicators on:</td>
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<tr>
<td>- health financing</td>
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<tr>
<td>- health workforce</td>
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<td>- health information system</td>
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<td>- medicines and medical devices</td>
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<td>- service delivery</td>
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<td>- service coverage</td>
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**Improving civil registration and vital statistics systems**

As mentioned before, assessing health status is one of the three basic components of HIS. It covers reporting and monitoring of cause specific mortality, which represents a major gap in HIS globally and in the EMR particularly. Addressing this gap requires strengthening of civil registration and vital statistics (CRVS).
### Health determinants and risks

#### Demographic and socioeconomic determinants
- Population size
- Population growth rate
- Total fertility rate
- Adolescent fertility rate (15-19 years)
- Net primary school enrollment
- Population below the international poverty line
- Literacy rate among persons 15-24 years
- Access to improved drinking water
- Access to improved sanitation facilities

#### Risk factors
- Low birth weight among newborns
- Exclusive breastfeeding rate 0–5 months of age
- Children under 5 who are stunted
- Children under 5 who are wasted
- Children under 5 who are overweight
- Children under 5 who are obese
- Overweight (13-18 years)
- Obesity (13-18 years)
- Overweight (18+ years)
- Obesity (18+ years)
- Tobacco use among persons 13-15 years
- Tobacco use among persons 15+ years
- Insufficient physical activity (13-18 years)
- Insufficient physical activity (18+ years)
- Raised blood glucose among persons 18+ years
- Raised blood pressure among persons 18+ years
- Anaemia among women of reproductive age

### Health status

#### Life expectancy and mortality
- Life expectancy at birth
- Neonatal mortality rate
- Infant mortality rate
- Under-five mortality rate
- Maternal mortality rate
- Mortality rate by main cause of death (age-standardized)
- Mortality between ages 30 and 70 from cardiovascular diseases, cancer, diabetes, or chronic respiratory diseases
- Mortality rate from road traffic injuries

#### Mortality
- Cancer incidence by type of cancer
- Tuberculosis notification rate
- Estimated number of new HIV infections
- Number of newly reported HIV cases
- Incidence of confirmed malaria cases
- Incidence of measles cases

### Health system response

#### Health financing
- Per capita total health expenditure
- Out-of-pocket expenditure as % of total health expenditure
- General government expenditure on health as % of general government expenditure
- Population with catastrophic health expenditure
- Population impoverished due to out-of-pocket health expenditure

#### Health workforce
- Density of health workers: a-physicians, b-nurses, c-midwives, d-pharmacists, e-dentists
- Density of recent graduates of registered health profession educational institutions

#### Health information system
- Birth registration coverage
- Death registration coverage

#### Medicines and medical devices
- Availability of selected essential medicines in health facilities
- Density per million population of 6 selected medical devices in public and private health facilities

#### Service delivery
- Density of primary health care facilities
- Hospital bed density
- Surgical wound infection rate
- Annual number of outpatient department visits, per capita

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Figure 3. Framework for health information systems and core indicators
40%) have either weak or dysfunctional CRVS systems (27). Additionally, the assessments revealed a major gap in birth and death registration, where more than six million (40%) births and more than three million (67%) deaths are unregistered (Figure 5). Furthermore, only 19% of deaths are registered and medically certified with adequate cause-of-death registration (Figure 6). Analysis of death registration figures by country indicated that almost half of the countries in the region (12 countries) attain registration figures equal to or greater than 80% while only 6 countries have registration figures lower than the regional average of 33%. These six countries are now the focus of WHO’s efforts to strengthen this area of work.

A regional strategy for the improvement of civil registration and vital statistics systems was developed by WHO, through intensive consultations with Member States and stakeholders. The strategy endorsed by the WHO Regional Committee in 2013, includes seven strategic domains (6):

1. Ensure a sound legal and regulatory framework for civil registration and vital statistics systems.
2. Strengthen registration infrastructure, resources and capacities.
3. Remove barriers at all levels to registration and the issuance of related legal documentation.
4. Improve mortality certification and coding practices.
5. Improve production, use and dissemination of vital statistics.
6. Improve intersectoral coordination and alignment among civil registration and vital statistics stakeholders.
7. Maintain and strengthen the existing regional and global partnerships in support of country strategies.

The strategy is designed to provide Member States with a list of interventions to implement, based on the level of development of their civil registration and vital statistics systems, country contexts, resources and capacities.

Based on the results of the rapid and comprehensive assessments conducted in countries over the past few years, WHO recently provided each Member State with a specific road map with a list of prioritized actions. Work has focused on providing technical expertise to help the relevant national authorities...
to take appropriate action and address the identified gaps.

The country-specific recommendations focus on a number of shared issues: 1) establishing national committees to oversee CRVS implementation; 2) establishing and updating electronic civil registration systems to follow international standards for recording births, deaths and causes of deaths; 3) developing a birth/death notification process to capture vital events that occur in communities; 4) enforcing decrees that forbid burials without death certificates; 5) expanding registration infrastructure by providing required resources; 6) capacity building in ICD-10 for physicians and training of medical students; and 7) capacity building in analysis and quality checks of vital statistics data.

The way forward and policy implications

The work conducted over the last five years has provided comprehensive information and a clear picture of the situation in each country with regards to their national HIS including civil registration and vital statistics. The joint work with countries and other stakeholders has also resulted in a clear vision and an evidence-based roadmap for both the Region and individual countries.

The HIS framework adopted in the Region has been appreciated by policymakers as a well-defined, practical and focused approach, yet covering the essential data necessary for policy-making and monitoring of national health development. As mentioned before, a core set of 68 indicators under the three key components of the framework provides a comprehensive assessment of health situation in countries and the capacity and response of the health system. Some countries may argue for a higher number of indicators covering additional aspects and will use the expanded list. However, there is consensus among countries that the first priority is to address the gaps that currently exist in reporting on the core indicators. In this respect, it is encouraging to observe a significant improvement in the reporting of the core indicators since their endorsement in 2014.

The extensive work with Member States and other stakeholders has also laid the foundation for improving the completeness and accuracy of registration of birth and causes of death. Countries now have sound and clear guidance represented by the regional strategy for the improvement of civil registration and vital statistics 2014–2019. More specifically, using the rapid and comprehensive assessments, each country has been provided with an inclusive list of key gaps and a set of strategic actions to address them.

Several factors have contributed to the achievements made over the last five years. The wisdom of Member States in endorsing the five key priorities has resulted in a practical agenda for the joint work between WHO and Member States, which included a focus on strengthening HIS as an integral part of the strategic directions set for each of the five regional priorities. Within WHO, the leadership and commitment of all departments and the active engagement across the three levels of the Organization was a prerequisite for successful initiatives. An effective approach to improve HIS and civil registration and vital statistics will not be possible without the ownership and joint work with other key sectors within countries and other stakeholders and UN agencies at the country and regional levels. The participation of representatives of ministries of interior and national statistics offices has been key in designing the framework and development of rational and feasible multisectoral strategic actions.

Further and sustained progress is dependent on the commitment and leadership of the relevant sectors at the national level. Monitoring progress in implementing the framework and the recommendations for improving civil registration and vital statistics will motivate national action and is essential in guiding effective support from WHO and its partners.

Functional HIS will require sustained investments in strengthening national capacities in epidemiology,
Finally, implementing the health information framework, the regional strategy for the improvement of civil registration and vital statistics system, and the WHO recommendations to countries in the Region—particularly low- and middle-income countries—will require adequate resources, both technical and financial. Global and regional support will be needed. Countries should be able to receive support from existing global initiatives (28,29) and efforts that provide a platform for collective and aligned action and the monitoring of progress towards the SDGs.

<table>
<thead>
<tr>
<th>11. Exclusive breastfeeding rate 0-5 months of age</th>
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<tr>
<td><strong>Abbreviated name</strong></td>
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<td><strong>Indicator name</strong></td>
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<td><strong>Domain/subdomain</strong></td>
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<td><strong>Related/Associated terms</strong></td>
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<tr>
<td><strong>Definition</strong></td>
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<td><strong>Numerator</strong></td>
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<td><strong>Denominator</strong></td>
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<td><strong>Method of estimation</strong></td>
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<td><strong>Disaggregation</strong></td>
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<td><strong>Primary/preferred data sources</strong></td>
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<td><strong>Alternative/other possible data sources</strong></td>
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<td><strong>Measurement frequency</strong></td>
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Annex 1 Sample from the Eastern Mediterranean Region core indicators registry

statistics, data collection, compilation, quality assessment, validation and adjustment, as well as analysis and review. Training is therefore a priority in all countries, irrespective of their healthcare status or socioeconomic development.
References


26. Improving the quality and use of birth, death and cause-of-death information: guidance for a standards-based review of


WHO events addressing public health priorities

Developing capacity-building of general practitioners in the Eastern Mediterranean Region

Introduction

Participants in a recently held regional consultation on development of the bridge programme for capacity-building in the Eastern Mediterranean Region (EMR) (1) agreed that Member States should advocate for establishing, strengthening and expanding sustained and effective refresher course(s) for general practitioners (GPs) working in public/private sectors to develop further their knowledge and skills to improve the quality of healthcare provided at primary health care level.

In this regard, through a joint collaboration with the Department of Family Medicine at the American University of Beirut Medical Center (AUBMC), WHO has developed a short online course to orient GPs on principles and elements of primary care services, including clinical management of common diseases. The objectives of the joint collaboration were discussed in two-day regional consultations with representatives from health ministries, higher education ministries and GP syndicates/associations from Egypt, Islamic Republic of Iran, Jordan, Kuwait, Lebanon, Morocco, Oman, Pakistan, Saudi Arabia, Sudan and Tunisia.

Objectives

- To share regional situation of family practice programmes: challenges and priorities.
- To present the contents and curriculum of the proposed online training course for GPs to the key focal points/institutions responsible for continuing medical education programmes in selected EMR countries.
- To seek perceptions of key stakeholders who may intend to adapt/adopt the bridging programme in their respective countries.
- To agree on practical steps for rolling out the bridging programme, building local capacities and its institutionalization in countries of the Region.
- To build consensus on scaling up production of family medicine specialists and enhancing system capacity to attract family physicians in the Region.

Although physicians often work for many years serving the local community/patients who are happy with the healthcare provided, they may not have had access to investment in their professional education or clinical services. These physicians may therefore need significant knowledge updating, and also a much broader awareness of how to be proactive (for example, for prevention and management of noncommunicable diseases) rather than giving reactive care. Another issue to address is modern orientation to appropriate primary care: many GPs received their training in medical schools, which is taught in hospital settings, and recommend tests and drugs that may not be relevant or useful in first-contact care. Finally, many physicians have had a partial case mix (only adults, children or women, etc.) and in order to give good general medical care in a primary care team they may need to revise some areas of clinical practice.

However, up-skilling GPs will not work unless all parts of the health care system understand why these broad, integrative, person-centred skills are needed. A clear timeline, resource plan and support for ongoing practice and skill retention are required. This investment will only be cost-effective if other parts of the system—financing models, hospital sector, other primary health care staff and patients—use the services appropriately. Existing and upcoming family medicine specialists need a clear role and interface with their GP colleagues who are learning new skills—perhaps mutual mentorship, supervision and even referrals. Both groups will need to develop as team leaders, data analysts, service developers and evidence-based practitioners. They will need to understand the application of culturally-sensitive values that work best with their individual patients and communities, to analyse and address health needs, empower and support, and manage risks and resources.

Dr Ala Alwan, WHO Regional Director for the Eastern Mediterranean, highlighted in his opening address that the shortage of family physicians is felt worldwide. However, the situation in the WHO EMR is acute and requires urgent action. Although Member States should do their best to strengthen family medicine departments in academic institutions, the huge shortage of family physicians will not

1 This report is extracted from the Summary report on the Regional consultation on development of the bridge programme for capacity-building of general practitioners in the Eastern Mediterranean Region, Cairo, Egypt, 10–May 2016 (http://apps.who.int/iris/handle/246160/10665)
be overcome solely by the establishment of more academic departments. Other factors, including issues related to service delivery, must also be addressed based on local capacities and needs.

The Regional Director brought attention to the fact that the current annual output of trained family physicians in the Region is around 681, against identified needs of almost 21 000 family physicians (2). According to a situation analysis carried out in late 2014, in collaboration with the World Organization of Family Doctors (WONCA) and Aga Khan University in Karachi, Pakistan, only 20% of all medical schools in the Region have functional family medicine departments (2).

In this regard, the short online course developed by WHO and AUBMC includes training module that blend theoretical knowledge and practical skills based on global best practices. It has an online component along with elements of face-to-face training in which GPs can readily participate. The training curriculum covers the main competencies that a GP/family physician has to master including: primary care management, person-centred care, specific problem-solving skills, comprehensive approach and community orientation.

The training course is to be delivered in a blended format which covers 48 topics, including the management of common medical problems in primary care and family medicine core concepts. It runs over 24 weeks and is divided into four main blocks, starting with an orientation session and ending with final examinations. Each block spans a 5-week period, whereby the first 4 weeks are delivered online and the fifth week includes a 6-hour face-to-face session or live review.

In conclusion, the consultation recommended a set of actions to enhance the bridge programme for capacity-building of general practitioners (Box 1), as well as actions for countries to enhance health system capacity to implement family practice (Box 2).

### Box 1 Actions to enhance the bridge programme for capacity-building of general practitioners

- Committees to be established at the country level to review the training course contents and oversee adaptation/revision of curriculum and implementation of the programme, based on local needs and capacities.
- AUB and WHO to work on programme evaluation, to identify measurable outcome indicators and incorporate an evaluation kit (pre- and post-test) into the course curriculum.
- Country training activities to be mentored/coached by the national trainers.
- AUB to elaborate on course methodology and develop mentorship/trainers’ guide/manual to facilitate organizing the course at country level.
- Countries to consider incentives for candidates entering the family medicine specialty or enrolling in the bridge programme, such as career path incentives or entering the postgraduate course on family medicine in local universities/fellowships with the 6-month online course as credit.
- WHO to work on advocacy, networking and marketing of the bridge programme.
- Online course to be usability tested in Lebanon in a small cohort and results shared with countries of the Region.
- WHO to work with AUB to ensure the online course is user-friendly and easy to operate. An information technology specialist from each country may attend the last day of the training of trainers to be back-up support for trainers at the country level.
Box 2 Actions for countries to enhance health system capacity to implement family practice

- Linkage of the family practice approach with national health policies, Sustainable Development Goals and other development plans.
- Allocation of funds to enhance the family practice programme at national level.
- Update the essential package of health services based on community needs and ensure its implementation at all primary health care facilities on gradual basis (based on countries’ capacities and availability of health workforce).
- Review laws/regulations and standards of service delivery based on family practice approach.
- Strengthen partnerships (with other service providers, private sector, nongovernmental organizations) through contracting out of services, covering family practice by insurance organizations, etc.
- Establish/strengthen family medicine departments; capacity of intake of residency programmes to be increased.
- Organize transitional period training activities for countries to move from GPs to family physicians.
- Strengthen family medicine departments and incentives to ensure a certain percentage of medical doctors enter a family practitioner residency.
- Involve/train other health workforce cadres (paramedics, nurses, midwives) on family practice approach.
- Medical and nursing school curriculum to be amended to be more community-oriented, problem-based and in line with family practice approach in order that undergraduate students become more familiar with the concept of primary care and family medicine after graduation.
- Incorporate family medicine in medical, nursing and other health professional education and curriculum (undergraduate courses) along with appropriate clinical training in primary care settings.
- Sustainable funding for expansion of the family practice programme.
- Strategic purchasing, costing of essential package of health services and capacity for contracting out.
- Collaborate with health insurance organizations for family practice implementation.
- Introduce appropriate incentives for family practice teams to enable them to perform as expected.
- Measure service delivery performance and improvement.
- Define catchment population per primary health care facility, identify patient rostering, family/individual folders and registration of individuals with primary health care facilities.
- Integrate noncommunicable diseases as a priority in primary health care; strengthen referral channels; improve logistics, monitoring and evaluation; home health care; team work; and ensure equity in access to services for rural, urban and poor population.
- Encourage a team approach in family practice, involving multidisciplinary teams including nurses, midwives and other health professionals as needed, and ensure an enabling working environment for them to practice as a family practice team.
- Countries to be encouraged to strengthen and engage private practitioners in service delivery through family practice approach.
- Implement WHO quality standards/indicators framework.
- Enforce accreditation programme.
- Establish community health boards, engage in awareness building on benefits of family practice and engage in local planning.
- Strengthen staff communication skills with the community.

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1. Regional consultation on development of the bridge programme for capacity-building of general practitioners in the Eastern Mediterranean Region. World Health Organization Regional Office for the Eastern Mediterranean, 10–11 May 2016, Cairo, Egypt.

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