

Sudden Infant Death Syndrome in the Middle East: An Exploration of the Literature on Rates, Risk Factors, High Risk Groups and Intervention Programs

¹Shereen M. Hamadneh, ²Noha Al-Shdayfat, ³Omar Al-Omari, ⁴Jehan M. Hamadneh, ¹Mohammad Bashtawi, ⁵Ahed Alkhatib, ⁴Basil H. Amarneh, ⁶Kate Andre and ⁷Anne M. Wilkinson
¹Department of Maternal Child Health, ²Department of Community and Mental Health, Faculty of Nursing, Al-albait University, Mafraq, Jordan
³Department of Children Health, Faculty of Nursing, Jerash University, Jerash, Jordan
⁴Department of Obstetrics and Gynaecology, Faculty of Medicine, Jordan University of Science and Technology (JUST), Irbid, Jordan
⁵Department of International Medicine, Jordan University of Science and technology, Irbid, Jordan
⁶School of Nursing and Midwifery, Edith Cowan University, Joondalup, Western Australia
⁷Centre for Nursing, Midwifery and Health Services Research, School of Nursing and Midwifery, Edith Cowan University, Joondalup, Western Australia

Abstract: Sudden Infant Death Syndrome (SIDS) is a problem world-wide. Since it was identified; Western nations have implemented extensive SIDS education campaigns to reduce SIDS risk which have resulted in dramatically decreasing SIDS death rates. In contrast, there is little information available about the impact of SIDS in Middle East (ME) countries where high infant mortality is common. To investigate SIDS incidence rates across various ME countries, ascertain specific SIDS risk factors relevant to ME populations, categorise high risk groups and identify SIDS intervention programs in the ME. A structured literature review was performed. A total of 10,509 study were identified with 11 proving to be most relevant to the research purpose. The SIDS incidence rates data available in ME countries is extremely limited with only five studies addressing SIDS rates in the ME. For a range of reasons, many infant deaths are registered as “cause unknown” with no associated autopsy report or other details. Additionally, limitations in the study designs restrict the ability to accurately estimate incidence rates from the research projects reported. The most significant risk factor for SIDS in ME countries identified in the literature is the high incidence of smoking, resulting from less political restrictions on smoking at home and public settings. Targeted public health SIDS education programs need to be developed and promoted in high risk ME countries with a specific focus on infant care practices, lifestyle and general living conditions.

Key words: SUID, SIDS, smoking, bedouins, refugees, Middle East

INTRODUCTION

Sudden Infant Death Syndrome (SIDS) is the leading cause of sudden unexpected infant death with approximately half of infant deaths each year caused by SIDS in the United States of America (USA). SIDS is defined as “the sudden death of an infant <1 year of age that cannot be explained after a thorough investigation is conducted, including a complete autopsy, examination of the death scene and review of the clinical history”. While the cause of SIDS is still unknown (Moon *et al.*, 2007) the international research from professional journals and international childcare associations have identified several risk factors linked to prenatal and pregnancy

outcomes, other factors linked to infant health and still others associated with infant care practices and home environments (Moon *et al.*, 2007; Athanasakis *et al.*, 2011). Literature from Western countries has shown that newborns with health problems such as Intra Uterine Growth Retardation (IUGR), Low Birth Weight (LBW), Small for Gestational Age (SGA) and prematurity are all associated with a higher risk of SIDS. Furthermore, the highest SIDS incidence is associated with infants aged from 2-6 months, infants suffering from anaemia, infants not breastfed and male infants (Athanasakis *et al.*, 2011; Morrison *et al.*, 2012; Nabukera *et al.*, 2008). Postnatal factors related to infant sleep care practices and home environment have also been associated with a higher risk

of SIDS. These risk factors include household moulds (Etzel, 2007; Vargas *et al.*, 1999) tobacco smoke exposure, elevated or reduced room temperature, excess bedding, excess clothing, sleeping caps, soft sleep surface and loose bedding, side or prone sleep position, co-sleeping, bed sharing or adding other soft objects to the infant's bed such as stuffed animals, pillows, quilts, blankets, sheepskins and fleeced, wedges and bumper pads (Moon *et al.*, 2007; Athanasakis *et al.*, 2011). It also appears that the incidence of SIDS increases during winter months (Harris *et al.*, 2012).

In addition, some SIDS risk factors, including those associated with infant care practices and home environments have been shown to be modifiable by educating parents and other child care providers (Hauck and Tanabe, 2008, 2010). Western nations have implemented many SIDS education campaigns to improve infant care practices, dramatically decreasing the incidence of SIDS. For example, due to public health campaigns, SIDS rates from 1990-2005 were reduced from 0.56 per 1000 live births to 0.10 in the Netherlands (Hauck and Tanabe, 2008, 2010) and from 2.00 per 1000 live births to 0.39 in Scotland (Yikilkan *et al.*, 2011). However, similar campaigns have not been undertaken in most countries in the ME. Moreover, due to the poverty-level living conditions for many in the region, the incidence of SIDS is likely to be well above that in Western countries (Abdulrazzaq *et al.*, 2008). A literature review was undertaken in order evaluate the evidence relating to identify the incidence of SIDS in the ME, identify specific risk factors relevant to ME populations and high risk groups and ascertain the availability of SIDS intervention programs in the region.

MATERIALS AND METHODS

Grey literature was accessed and structured review was undertaken to utilize literature available (2000-2015) in data bases of PubMed, Medline and Embase; also utilized the associated referenced study and grey literature within the study. Search keywords included: SIDS, SIDS incidence/rates, high risk populations, SIDS risk factors and SIDS interventions in ME. Selection of study for inclusion were selected based on title first, abstract and finally, content of the article's relevance to the research questions. The initial search identified a total 10,509 initial study. Review of titles resulted in the selection of only 20 study being accepted for abstract review. Of these 20 study, 11 were deemed sufficiently relevant to the research questions to be included in this review.

RESULTS AND DISCUSSION

SIDS incidence rates in Middle East: Overall, the literature provided very limited information on the incidence of SIDS in the ME region. SIDS rates were reporting in only five countries among total 20 countries in the Middle East. While the literature was limited, however, it found a high incidence of SIDS. For example, it was found that among 4,912 registered infant deaths over a 5 years period (1994-1999) in Iraq, 20% (n = 1081) were attributed to SIDS (Awqati *et al.*, 2009). This means that around 216 infants die of SIDS each year in Iraq with a rate of 5.0 per 1000 live births, making SIDS the second most frequent cause of death in Iraq. Another study, conducted in an eastern region of Saudi Arabia, found that around 12 infants die of SIDS each year (Nofal *et al.*, 2011). In North Jordan, the SIDS rate was reported to be 1.32 per 1,000 live births, contributing 6% to the infant mortality rate (Bataneh *et al.*, 2008). Even in wealthy ME countries, such as the UAE, the SIDS rate was found to be 0.66 per 1,000 live births, contributing 7% to the infant mortality rate (Abdulrazzaq *et al.*, 2008). In contrast, the SIDS rate in Israel was estimated to be 0.28-0.42 per 1,000 live births (Eisenstein *et al.*, 2012) which is high compared to Western countries but much lower than other ME countries.

While there are a few studies reporting SIDS incidence, the great concern that the limited literature on SIDS incidence in the ME does not reflect the true extent of the actual incidence of SIDS in the region. Critics argue that the rates could be much higher than reported (Eisenstein *et al.*, 2012; Khoury and Mas, 2002; Eisenstein *et al.*, 2007). The discrepancy between identified rates and suspected rates are due to the limited information collected on causes of infant deaths in most ME countries (Khoury and Mas, 2002). With limited public health budgets and numerous political and social problems to address, establishing a SIDS risk factor public education campaign or a reliable infant mortality reporting system has not been a priority for these countries (Abdulrazzaq *et al.*, 2008; Bataneh *et al.*, 2008; Fathalla, 2014).

It has also been suggested that the use of the code "Sudden Unexpected Infant Deaths" (SUID) as a prominent cause of death in ME countries camouflages actual SIDS cases. However with few resources devoted to clarifying and reporting accurate causes of death, SIDS specific mortality rates cannot be teased out of the limited reported data (Awqati *et al.*, 2009; Bataneh *et al.*, 2008; Khoury and Mas, 2002). However, the main lead cause of sudden unexpected infant deaths is SIDS lending support to the perception that the actual incidence of SIDS is higher than is reported in the literature.

Furthermore, there is little education and training of public health or medical personnel in SIDS and insufficient health resources devoted to diagnosing SIDS in the ME. The current political situation associated with the war in the region also makes it more difficult to investigate SIDS rates, especially among the refugee populations who have extremely limited information about or access to pre-natal, birth and post-natal care.

Finally, other barriers to SIDS reporting are linked to the regions political systems, culture and religion (Eisenstein *et al.*, 2012). This is likely to have particular relevance for isolated and poorer communities where types of housing and a lack of health resources potentially contribute to both a higher incidence and a lower level of reporting of SIDS. Many studies conducted in the ME region have been recommended developing socially acceptable methods to effectively investigate infant deaths and improving diagnosis quality for sudden unexpected infant deaths including SIDS (Awqati *et al.*, 2009; Bataineh *et al.*, 2008; Eisenstein *et al.*, 2012; Khoury and Mas, 2002). The importance of using the new technologies has been also highlighted and commitment to allocate the necessary resources and support investigation these cases in the future (Eisenstein *et al.*, 2007).

SIDS risk factors most relevant to the ME: It appears that one of the most common SIDS risk factors in ME region are Low-Birth Weight (LBW) and prematurity (Ghanem *et al.*, 2012; Alchalabi *et al.*, 2012; Hizli *et al.*, 2012; Wahabi *et al.*, 2013).

Complicating the ability to track LBW infants and prematurity and establish a link to SIDS is the fact that large numbers of infants are not weighed at birth in developing countries. Available data, however, suggests that approximately 12% of infants in Middle East are low birth weight infants.

SIDS risk also is also linked to the high rate of tobacco smoking in these countries, including the use of "Argileh" (water pipes used for tobacco smoking) which is wide-spread in the ME (Abusalah *et al.*, 2012). Tobacco smoking among adults reportedly ranges between 21% in Oman to 71% in Jordan. Extensive research from international literature has confirmed an association between SIDS risks and tobacco use or exposure and the link to smoking and SIDS risk has been established. While these risk factors are understood among policy circles in the ME, there are few governmental restrictions against tobacco use in ME countries (Etzel, 2007; Bataineh *et al.*, 2008; Bahaj *et al.*, 2010; Azab *et al.*, 2013). As a result of the wide-spread use of tobacco in these countries, many ME women are routinely exposed to second-hand smoke

during pregnancy. Indeed, Jordan has the highest smoking rate of any country in the ME with more than 61% of adult men who smoke (Azab *et al.*, 2013; Salameh *et al.*, 2014). Furthermore, research found that infants in Middle East are highly exposed to second-hand smoke in their homes (Hawamdah *et al.*, 2003; Hesselink *et al.*, 2012).

Other SIDS risk factors in ME countries are associated with infant sleep care practices such as positioning, bedding, clothing and swaddling (Abdulrazzaq *et al.*, 2008; Sleuwen *et al.*, 2003). Families in ME use both side and supine positions for sleeping infants which are high risk positions and they add soft objects to the infant's bed such as stuffed animals, pillows, quilts, blankets, sheepskins and fleeced, wedges and bumper pads, all of which can cause loose bedding and increase the chance of damping the infant's face and can lead to suffocation. It also common practice to cover the infant's face by sheet, called a "Namlieh" in order to stop insects crawling or landing on their face as well as the use of caps to keep the infant's head warm (Sleuwen *et al.*, 2003; Efe *et al.*, 2007).

Finally, breastfeeding women often share their sleep surface with their infants which is a common practice in the ME, especially during winter as it makes breastfeeding more convenient (Abdulrazzaq *et al.*, 2008; Inbar *et al.*, 2005). However, literature confirms that bed sharing is associated with increased the risk of SIDS. Specific risks associated with winters, including clothing infants heavily, adding excessive bedding, mouldy environment, heating burns toxins associated with using of basic heating resources such as wood, gas and kerosene and poor ventilating homes (Abdulrazzaq *et al.*, 2008; Hesselink *et al.*, 2012; Sleuwen *et al.*, 2003). Thus, the limited literature on specific risk factors for SIDS in ME countries include Low-Birth Weight (LBW) and prematurity, exposure to tobacco smoke, infant sleep care practices and breastfeeding practices. Overall, this literature review supports the observation that Middle Eastern families appear to provide un-safe SIDS care practices and their home environments are SIDS-unsafe. However, most Middle Eastern families are unaware about these risks (Abdulrazzaq *et al.*, 2008; Hesselink *et al.*, 2012). Unsafe infant care practices were found to be linked to lower economic and lower education levels in the ME which in turn are considered as a challenge to adopt SIDS-safe care practices (Inbar *et al.*, 2005).

SIDS high risk groups in the ME (Teenage women who marry early in life, multiple pregnancies and refugees): Marriage customs in the ME make women a high risk group for SIDS. Women in ME tend get married and

become pregnant while still in their teenage years, they have short inter-pregnancy intervals and many children and these practices occur most among families with lower socio-economic status and less education (Tal and Bataineh, 2006; Khalaf *et al.*, 2008; Ziadeh, 2001). Pregnancy early in life and multiple births are linked to SIDS. The survival of low birth weight babies is directly related to their weight at birth as well as in reducing the risk for SIDS (Blair *et al.*, 2000).

In addition, refugees, rural and Bedouin families living in isolated and remote regions in the ME are also a high SIDS risk group as this group have lower socio-economic status and less education than groups living in the city centres and capitals (Ghanem *et al.*, 2012; Awqati *et al.*, 2009; Bahaj *et al.*, 2010). Pregnant women from these groups lack knowledge about and access to sufficient pregnancy care, often have unbalanced nutrition and have higher incidence of LBW infants (Ghanem *et al.*, 2012; Hizli *et al.*, 2012; Bahaj *et al.*, 2010; Okour *et al.*, 2012; Ziadeh, 2001). All those factors are leading directly to unsafe practices to take care of newborn which leads to SIDS.

SIDS interventions in the Middle East: It appears that little effort has been made to promote SIDS-prevention strategies in ME countries; some efforts have been made in Israel and Turkey. The Israeli Ministry of Health issued a formal recommendation to use the supine sleeping position in order to prevent SIDS (Inbar *et al.*, 2005) based on a public campaign “back to sleep” which run in many Western Countries during the 20th century. However, complaints against this recommendation from parents ended this initiative (Inbar *et al.*, 2005) as many people from Jewish and Muslims have cultural beliefs against using Supine for sleeping babies. In Turkey, an European SIDS education program “happy mothers, happy baby” was subsequently implemented and evaluated (Hesselink *et al.*, 2012). The evaluation involved an RCT of education for SIDS prevention behaviour, including SIDS-safe bedding strategies and anti-smoking massages. About 119 women were included in the intervention group and 120 women in the control group. Questionnaires were administered by interviewers at three times during pregnancy, once each trimester and last one conducted six months after delivery. The intervention program appeared to be highly welcome; the intervention group showed improved knowledge of SIDS and increased intention to engage in SIDS prevention practices. However, no intervention effect was found for smoking during pregnancy and SIDS prevention behaviour in the long term (Hesselink *et al.*, 2012). Overall, these intervention programs were limited in scope, the Israeli

program was only designed to reduce the risk associated with infant positioning practices and while the Turkish intervention included multiple SIDS risk factors, it was limited to a very narrow sample and more consideration will need to include behavioural changes. In contrast, SIDS topic still not takes enough consideration in the region.

The literature review while based in a limited number of research-based study, indicated that SIDS risk factors are alarmingly high in the ME countries and unlike Western countries, SIDS prevention interventions have not been a national health policy priority. However, as has been found in SIDS research in the West, most SIDS risk factors are modifiable and can be reduced by increasing knowledge, changing parental behaviours and practices regarding SIDS risks (Task, 2005). Although, only 11 SIDS related study focusing on the ME were identified, the cumulative conclusion to be drawn from this review strongly indicates the need for the development and implementation of holistic and targeted SIDS intervention campaigns in the region to decrease cases of infants’ death due to SIDS.

There has not been a major investment in educating Middle Eastern families about current SIDS risks and relevant prevention practices and Middle Eastern families are unaware of the current SIDS risks. Nonetheless, holistic approaches to public health interventions, rather than narrow educational programs have been shown to be the most effective in changing risk behaviours (Hesselink *et al.*, 2012). Moreover, while an intervention developed in the Europe was successfully transported to Turkey, the limited literature leave great gaps in our understanding of whether all types of interventions that have been successful in Western countries can be as successful in geographically and culturally diverse nation states such as those comprise the ME (Sleuwen *et al.*, 2003). Nevertheless, the initial effort made in Israel and Turkey could provide a useful base. However, it is clear from even the limited literature on the ME that such interventions may need to be more comprehensive than those few that have been tried in ME countries. There appears to be a need to create comprehensive SIDS prevention programs in the ME region that are targeted and tailored to the specific SIDS risk behaviours and high risk groups identified in the literature so far. Moreover, these programs should be region-specific and relevant SIDS prevention messages for the most common identified risk factors. Adaptation of Western campaigns will be useful but the ME region is distinguished by its’ unique and diverse cultures and religion which highly influence the population. Therefore, it is very necessary and desirable to develop a SIDS education intervention,

using current best available literature but tailored to the ME settings and that incorporates the culture, life style, living origins and general living conditions among ME societies.

It is especially important to target high risk families including infants of families living in remote rural, deserts and refugee camps. They would practice un-safe SIDS care as an adaptation with their economic circumstances. In addition, families with a history of having LBW and premature births will need further attention as will families with smokers. Therefore, it is necessary and desirable to focus on anti-smoking advice in ME targeted SIDS prevention recommendations. Combining public health anti-smoking programs with SIDS risk-factor messages will strength SIDS interventions.

Future research in this area is needed, including investigations of the incidence of SIDS within the unexpected death mortality category, especially deaths occur during winters. Research is also needed into family homes to evaluate indoor air quality, especially in Winter. Moreover, public health and medical personnel should be fully educated about diagnosing SIDS, SIDS risk factors and prevention strategies in order to more accurately identify SIDS risks but also help educate the population about SIDS risks and strategies to prevent SIDS. Developing a comprehensive Middle Eastern SIDS education campaign could be further extended by continued research and evaluation on the effectiveness of specific initiatives in different ME countries. State sanctioned public health education campaigns and resources devoted to health worker education and training, supported by broad media programs, could make a difference in ME countries but will require a commitment to these programs by the power elite. If adopted, however, SIDS incidence in ME countries could be reduced, just as it has been in Western developed nations.

CONCLUSION

There is a large data base about SIDS programs and research in Western health and social service peer-reviewed journals and Western countries have initiated numerous public health campaigns for SIDS prevention education which have had a significant impact on SIDS incidence and improved SIDS-safe sleep practices. In the ME, however, it appears that SIDS is a significant problem and could be a leading cause of mortality among infants. This literature review identified a strong need to investigate causes of under 5 mortality in ME countries. Developing a comprehensive SIDS intervention campaign targeted to the ME region will yield incredible benefits for an infant's health care practice and enhance their survival rates. However, this cannot be achieved without understanding the risks and issues associated with these particular communities.

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