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Is it Time for a Sudden Infant Death Syndrome (SIDS) Awareness Campaign? Community Stakeholders' Perceptions of SIDS

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Abstract

Background—Sudden infant death syndrome (SIDS) remains a leading cause of infant death in the United States and in Virginia, the SIDS rate is higher than the national average. We sought to gauge the perceptions among community-identified stakeholders as to community resource needs to reduce SIDS.

Methods—We used snowball sampling to identify important community stakeholders to be interviewed as key informants. A semi-structured interview lasting 45 min–2 hours was delivered to determine resource needs to reduce SIDS, and whether high-risk community members were aware of SIDS risk factors among stakeholders representing a variety of disciplines. Interviews were conducted in two geographic areas with higher than average rates of infant mortality, an urban district, Winchester City, VA and a rural district, Page County, VA.

Results—A total of 74 interviews were completed with stakeholders in healthcare, health departments, social services, law enforcement, education/childcare, faith-based institutions, non-profit agencies and non-affiliated community members. The majority of respondents perceive that high-risk community members are not aware of factors that can lead to SIDS (50%). Participants suggested that more “education” is needed to further reduce the rates of SIDS in their communities (73%). Respondents detailed that more pervasive, strategic, and multi-channeled education is necessary to reduce cases of SIDS.

Conclusion—Community leaders perceive that high-risk community members are not fully aware of risk factors that can lead to SIDS. Maternal/child health stakeholders in these Virginia locales suggested more community-based education as a potential solution to SIDS.

Keywords

Infant mortality; sudden infant death syndrome; stakeholders; community-based participatory research

Introduction

Sudden infant death syndrome (SIDS) remains a leading cause of infant death in the United States. Approximately 4,000 infants die each year of SIDS as the 3rd leading cause of infant death behind congenital malformations and disorders related to low birthweight and/or short gestation (US DHHS, 2015). In Virginia in 2013, the SIDS rate was 0.48 deaths per 1,000 births, higher than the national average at 0.40 deaths per 1,000 births (US DHHS, 2015). SIDS rates for the nation have remained relatively stable over the last decade (Gregory & MacDorman, 2015) and are higher than in comparable developed nations (MacDorman, Matthews, Mohangoo, & Zeitlin, 2014).

SIDS remains a diagnosis of exclusion for the death of an infant whose postmortem examination and often a death scene investigation identified no certain cause of death. Previously in 1994, the national “Back to Sleep” campaign realized a substantial reduction in the US SIDS rate from 1.2 to 0.53 deaths per 1,000 births by encouraging supine sleep position for all healthy infants (Rasinski, Kuby, Bzdusek, Silvestri, & Weese-Mayer, 2003). The American Academy of Pediatrics (AAP) Task Force on SIDS updated recommendations in 2000 and 2005 to resolve controversies regarding soft bedding surfaces, loose blankets, bedsharing, overheating, and smoking in the infants’ sleep environment (Task Force on Sudden Infant Death & Moon, 2011). Further in 2011, the AAP updated recommendations again to account for additional modifiable risk factors during the prenatal period, at birth, and during the infant’s first year (Task Force on Sudden Infant Death & Moon, 2011). Modifiable risk factors identified by the AAP include prone and side sleep position, sleeping on a soft surface, maternal smoking during and after pregnancy, dressing too warmly for sleep, not breastfeeding, bed-sharing, not using a pacifier during sleep, late or no prenatal care, alcohol and illicit drug use during pregnancy and after birth, and using home cardiorespiratory monitors for risk reduction (Task Force on Sudden Infant Death & Moon, 2011). The 2011 expansion reflects more focus on the sleep environment to reduce risk of death due to all sudden infant deaths including SIDS, suffocation, asphyxia, and entrapment (Adams, Ward, & Garcia, 2015).

Even more troubling than the recent stagnant SIDS rates in the US is the widening degree of social inequalities as contributors to SIDS. While overall rates of SIDS declined with the “Back to Sleep” campaign for all racial/ethnic groups, the odds ratios for SIDS increased with lower social class between 1989–1991 and 1996–1998 and the racial disparity in SIDS increased after the “Back to Sleep” campaign (Pickett, Luo, & Lauderdale, 2005). Indeed, several more studies have identified race and poverty as important contributors to SIDS and sleep-related infant deaths suggesting that socioeconomic status needs to be considered in the context and design of targeted interventions (Hogan, 2014; Malloy & Eschbach, 2007; Oliva, Rienks, & Smyly, 2010; Unger et al., 2003). As the special emphasis on reduction of health disparities remains a national priority as identified in Healthy People 2020 (ODPHP, 2015), identifying unique and strategic ways of reaching communities of greatest need is increasingly necessary.

In an effort to better understand why some socioeconomic groups have higher rates of SIDS than others, researchers have conducted focus groups to gather important perceptions of

SIDS directly from mothers and/or families. Herman and colleagues and Moon and colleagues studied SIDS perceptions by African-American mothers (Herman, Adkins, & Moon, 2015; Moon, Oden, Joyner, & Ajao, 2010) and Aslam and colleagues studied this among migrant Indian mothers in Australia (Aslam, Kemp, Harris, & Gilbert, 2009). Both studies demonstrated that some groups of mothers are not following current guidelines because they are in cultural conflict with their norms or otherwise the messaging was unclear. For example, some African-American women expressed confusion by safe sleep recommendations because SIDS cases are those that do not have a clear cause, and thus the connection to safe sleep was not clear (Moon et al., 2010). Others did not trust some advice (e.g. not to use blankets in the crib or putting the baby down alone) or perceived the recommendations to be in direct conflict with their cultural beliefs (e.g. Indian tradition of co-sleeping). Furthermore, other studies have identified inconsistent messages and gaps in knowledge from healthcare providers either in discharge instructions or as modeling during hospital stays post-delivery and from childcare providers as well (Barsman, Dowling, Damato, & Czeck, 2015; Grazel, Phalen, & Polomano, 2010; Moon, Calabrese, & Aird, 2008; Patton, Stiltner, Wright, & Kautz, 2015). These studies underscore the importance of understanding how decisions and behavior are influenced by socio-cultural practices as well as advice from professionals (Aslam et al., 2009; Barsman et al., 2015). By placing a greater emphasis on understanding community perceptions of infant care practices, we can ensure the correct messages are effectively reaching the populations of need.

As SIDS continues to remain a leading cause of infant death in the United States, and as rates have declined little in recent years, we aimed to develop local community support to tackle this issue through the use of community-based participatory research principles (CBPR) (Israel et al., 2010; Israel et al., 2005; Schulz et al., 2002). CBPR is a way to equitably partner with community stakeholders, key informants, as well as high-risk communities to collectively conduct health research and create social change (Israel et al., 2010). While also developing community support for a community-based coalition centered around infant mortality, our primary goal for this study was to assess perceptions of community stakeholders as to their community's needs regarding SIDS risk reduction. We hypothesized that community stakeholders from a variety of backgrounds (e.g. healthcare, social services, faith-based institutions, etc.) would identify different community priorities based on their unique experiences. The community stakeholder perceptions would then be used as a springboard for formulating the new community coalition's CBPR agenda.

Methods

As a starting point for forming a new community-based coalition centered around the theme of infant mortality, we employed a snowball sampling procedure to identify relevant community stakeholders in two distinct geographic areas: Winchester City/Frederick County, VA and Page County, VA. Snowball sampling is a convenience method for studying hard-to-reach, and/or difficult to identify or locate populations whereby the first set of interviews serves as the "seed" through which additional subjects are identified (Biernacki, 1981). Wave 1 subjects are then asked to refer other subjects and the sample then expands like a growing snowball. This nonprobability sampling method has been used extensively in social sciences research as well as public health research to study social structures in special

populations (Heckathorn, 2011). Further, we chose this method as a way to empower the community members to identify their own relevant stakeholders who should be interviewed for this community-based project, rather than the principal investigators choosing the stakeholders. The first interviewee in both locales was identified as a well-known maternal-fetal nurse who works with high-risk populations and was highly recommended by one principal investigator and many nonprofit organizations as being influential in the community.

All participants identified through snowball sampling were contacted by phone, email or a personal visit to set up a face-to-face interview with either one or both principal investigators. If no response was received, up to two additional phone calls were made. In two cases, the individual identified was considered tangential or out of the geographic area and so was not contacted. Two additional individuals did not speak English and so were not interviewed due to an inability to find an appropriate interpreter. The snowball sampling ended when those referred by interviewees were consistently already on the list suggesting the important community stakeholders were already identified.

All interviews were conducted by one or both principal investigators and lasted between 45 min and 2.5 hours. During the interview, responses were recorded with permission and repeated back to the interviewee if clarification was needed. Themes were not identified at the time of interview. Before initiating interview questions, all participants were provided with a description of the study and signed an informed consent document. All participants were at least 18 years of age. The protocol was approved by the Institutional Review Boards at Shenandoah University and the Virginia Department of Health.

The semi-structured interview included 17 questions, including three demographic questions (age, gender and race/ethnicity). The questions were community-focused and primarily pertained to perceptions of high-risk groups for infant mortality, reasons for poor maternal and infant health and resource needs pertaining to infant mortality reduction. The principal investigators developed the interview questions based on a thorough literature review, planning discussions with several maternal/infant health professionals, and gaps in knowledge based on what was considered important to these community members. The questions to be analyzed for the current paper focus on sudden infant death syndrome. Two specific questions focused on SIDS: 1) Are high-risk community members aware of factors that can lead to SIDS? And 2) What resources are needed in your community to help high-risk groups lower their rates of SIDS?

Statistical Analysis

All interview data was recorded and transcribed verbatim by principal investigators and kept in password-protected university computers. Transcripts were analyzed line-by-line using standard qualitative techniques and additionally using quantitative techniques. Following the identification of initial themes, qualitative responses were coded into relevant categories. Themes were developed and revised in an iterative manner as new themes emerged. Multiple responses to the same question were coded into separate categories while also coding the order of responses (first, second, third, etc.). Authors worked independently but met on a

regular basis to discuss themes and develop a shared understanding of the data until consensus was met. Once themes were coded, categorical data analysis was employed with chi-squared statistics to compare themes between geographic regions and by occupational category. Categorical data analysis was completed using SAS 9.2 (SAS Institute, Inc., Cary, NC).

Results

A total of 74 interviews (n=40 in Winchester/Frederick, VA and n=34 in Page County, VA) were conducted with both male and female stakeholders in the two geographic regions. The majority of respondents in both locales were female (82%) and between 40–59 years of age (54%). The racial/ethnic distribution of the respondents reflected the underlying populations from which they reside. One hundred percent of respondents in Page County, VA, i.e. those who answered this question, were non-Hispanic White, whereas 75% were non-Hispanic White, 8% were non-Hispanic Black, and 15% were Hispanic in Winchester/Frederick, VA. Respondents represented a variety of professions and organizations including healthcare, health departments, social work and law enforcement/legal, faith-based organizations, other health and human services non-profits, education and childcare providers, and unaffiliated community members (Table 1).

In response to the first question, “Are high-risk community members aware of factors that can lead to SIDS,” the majority of stakeholders in both locales responded “no” (n=37, 50%), and this distribution was consistent for both regions (Winchester/Frederick, n=20 (50%) and Page County, n= 17 (50%)) (Table 2). The regions differed significantly in the percentage that responded with “Yes” and “don’t know” (p=0.05). In Page, approximately 1/3 of participants responded with “I don’t know” whereas 18% responded with “yes.” In contrast, in Winchester/Frederick, fewer responded with “I don’t know” (12.5%) and nearly twice the percentage responded with “Yes” (37.5%).

The follow-up question queried about participants’ perceptions of resource needs to address SIDS in high-risk groups in their respective communities. Most participants gave multiple answers to this question (n=73 gave at least one answer, n=32 gave at least 2 answers, and n=9 gave 3 answers). Of all first responses, “education” was the overwhelming response (n=53 out of 73 responses, 73%) and similarly, was the most common second tier response as well (n=5 out of 32 responses, 16%) (Figure 1; Table 3). While “education” was still the most common first response for every occupational category, the likelihood that education was the first response differed significantly by occupation (p=0.04). For example, those who work in health and human service nonprofit industries (94%), law enforcement (88%), education/childcare (71%) and health departments (62.5%) were more likely to suggest more education is needed than were those working in healthcare (53%).

The “education” theme was derived from responses that focused on more accessible prenatal and parenting education, and more widespread awareness of SIDS risk factors. Many respondents gave a simple, one-word answer, “education,” whereas others elaborated on challenges the community faces in delivering effective education. Some respondents explained the need for multifaceted, targeted and strategic education whereas others

identified specific types of information that needs to be conveyed and ideas of how best to reach high-risk or underserved populations in their specific community. Many of the most detailed and/or unique responses came from community members who consider themselves an active part of the underserved population, such as community health workers or other paraprofessionals.

Q1: “Through more education. Through a simpler way. Why you need to go to the doctor. They think you just need to go for a delivery or to find out the sex. Or just for a c-section. They just wait until 7 months because they don’t understand the reasons for the bloodwork.”

Q2: “More pervasive education. A more effective way to get education across. Maybe that has to do with who people will listen to. Certain cultures listen to the matriarch; education here is at a moment of crisis. A moment where [they are] so overwhelmed, they can’t receive the message...they need to hear it over and over again in a variety of ways. Some are visual, some are auditory learners.”

Q3: “Education teamed with incentives to want to come learn more about it.”

Q4: “Education in a culturally appropriate way. Elder generations are not here for them to consult with. Young women only have other young women to consult. If had elders accessible, they would have the older generation to give information.”

Q5: “More classes on health. How to care for your baby, care for yourself during pregnancy, effects of drugs on the child, domestic violence, and the importance of vaccines.”

Q6: *“More education. Youtube videos, podcasts on the Winchester website, or in the waiting rooms at the Free [Medical] Clinic or library with 24 hr service.”*

Q7: *“Education. Outlets for information for Latinos. A community center that is language accessible. Educate women to be community leaders. In Mexico, a program paid people to participate. [For] low-income Latinos, there needs to be financial reimbursement for them to come.”*

Despite differences in demographic profile, the majority of participants in both regions believed that “education” was the answer to addressing SIDS in their communities ($p=0.58$).

Beyond education, there were a variety of other responses that told a story of the unique perceptions of resource needs to lower SIDS in these communities. The next most common theme focused on “access to healthcare,” ($n=5$) but was far fewer than the number that cited “education” ($n=53$) as the first response. Terms related to “access to healthcare” included “access”, “physician follow-up”, “free medical clinic” and “prenatal care.” Other less common but frequently cited themes included, “drug/smoking treatment,” “networking/social support groups,” “home visits” and “poor parenting skills” (Table 3).

One respondent discusses the need for social support for individuals struggling with multiple demands and also raising a newborn:

“Having more support groups. We should provide free support groups for us to support it more. Maybe having a hotline or something, maybe not say who they are but where mothers can call to get help. Somebody to turn to.”

This respondent explains the challenges with drug addiction treatment for pregnant women:

“I think that we don’t do a good job of our substance abuse. In WV they put our moms on methadone but they don’t wean them off. They stay on methadone a long time. There is no next step to get them off drugs. More support groups, rehab centers, counselors, and communities to help support these women.”

Discussion

In this qualitative assessment of two communities’ perceptions of needs to address SIDS, we found that these two demographically and geographically distinct communities had similar perceptions of need. The majority in both locales responded that most high-risk families are not aware of SIDS risk factors and that “education” was the greatest resource need to reduce SIDS. While other studies have examined perceptions of SIDS and infant sleep practices among parents directly, we have examined the community perceptions of SIDS among stakeholders as a community mobilization technique for CBPR. As such, we could not identify other similar studies for direct comparison, but the perceptions of community members agree with a vast array of literature suggesting that culturally-appropriate and targeted educational strategies are one way to further reduce rates of SIDS through addressing extrinsic risk factors (Ball & Volpe, 2013).

The community stakeholders generally believed that high-risk families were not aware of SIDS risk factors. Whether parents are not fully aware, not in complete understanding, or are just not compliant with recommendations is unclear. Some research has demonstrated that those with lower levels of education are less likely to comply with safe sleep recommendations, which could be related to low health literacy or less access to health information (D’Halluin, Roussey, Branger, Venisse, & Pladys, 2011; Horne, Hauck, & Moon, 2015). Some parents are aware of SIDS risk factors but state confusion as to the rationale or an objection due to cultural beliefs (Aslam et al., 2009; Herman et al., 2015; Moon et al., 2010). Indeed, Ball & Volpe summarize that public health messaging must be culturally-embedded in order to effectively change behavior with topics as sensitive as SIDS risk reduction (Ball & Volpe, 2013). They argue that certain messaging for African-American mothers, for example, challenged their cultural beliefs and innate wisdom regarding infant care and “made them feel stigmatized” (Ball & Volpe, 2013). Thus, the problem lies not only in message transmission but also in the acceptability of the message itself. Whether it is a lack of knowledge, awareness, or cultural objection, recent national trends demonstrate that over half of all babies are placed to sleep in an unsafe sleep environment and this trend is more common among the less educated, non-White race and ethnicity, and young maternal age (Shapiro-Mendoza et al., 2015). Indeed, it has been suggested that targeting these higher risk groups for educational needs may be an effective strategy when delivered in a culturally- and health literacy-appropriate level (Ball & Volpe, 2013; Creamer, Attridge, Ramsden, Cannings-John, & Hawthorne, 2015; Davis, Peterson, Rothschild, & Resnicow, 2011; DeWalt & Hink, 2009; McPheeters et al., 2012).

Further, stakeholders identified the need to reach high-risk groups with consistent messaging from multiple sources such that the advice penetrates fully and consistently from sources such as peer parents and friends, medical institutions, childcare providers, social services, relatives and the internet. Of concern is that not all sources are providing correct and consistent messages. For example, studies have shown that grandmothers (Aitken et al., 2016), the internet (Chung, Oden, Joyner, Sims, & Moon, 2012), and healthcare providers (Barsman et al., 2015; Grael et al., 2010; Patton et al., 2015) do not always recommend safe sleep practices that agree with the American Academy of Pediatrics, thus creating confusion among parents. To address relevant barriers in the hospital and institutional environment, in a recent call to action, a series of recommendations were made for hospitals and relevant institutions to overcome barriers to implementing safe sleep practices with urgency, including garnering support from top-level leaders, initiating policy change, and dispelling myths and controversies among staff (Hitchcock, 2012). Since consistent messaging from multiple sources is needed, community-wide interventions with rigorous evaluation plans are warranted to ensure that all agencies serving families are delivering similar messaging as well as reaching older generations (Salm Ward & Balfour, 2015).

This study has several limitations that should be acknowledged. This study population was limited to maternal/child health stakeholders in two geographic regions in Virginia and may not represent the beliefs of those living elsewhere. Further, to be included in the study sample, individuals had to be referred by other stakeholders in the same region, and so some important stakeholders may have been missed. However, snowball sampling is recognized as an important recruitment method through which to identify hard-to-reach populations (Biernacki, 1981). We successfully identified and recruited a wide range of stakeholders ranging from law enforcement and social services to faith-based institutions and healthcare. In addition, this study was based on qualitative responses to a semi-structured interview, and so results cannot be used to define the complete picture of any opinion base. It would be important to continue this research in other areas of Virginia and elsewhere to better understand the needs of unique communities regarding SIDS risk reduction.

Conclusion

These results were generated to be used as a springboard for the beginnings of a CBPR project focused on disparities in infant mortality. CBPR is increasingly recognized as an important strategy to address health disparities while effectively partnering with communities experiencing the disparate health outcomes (Israel et al., 2010; Schulz et al., 2002). In this case, we sought to partner with community stakeholders to better understand their perceptions of needs to address SIDS in high-risk groups. By assessing their community-level needs, we can better reach the communities at their current state and work together to achieve improved health outcomes, while not duplicating efforts already in place. Overall, most stakeholders were pleased to participate and share their voice towards this effort and viewed the project's vision as a positive one for the community.

In this study we observed that two distinct communities viewed their needs related to SIDS risk reduction as primarily one of education. Respondents identified the need for culturally-appropriate, strategic, and multi-channeled education coming from multiple sources, which

agrees with recommendations from others (Salm Ward & Balfour, 2015). Another key point in this collection of perceptions by stakeholder's in infant mortality is that they rather overwhelmingly believe that the high-risk groups are unaware, or do not know the basics of SIDS. This should be a critical message as SIDS is a form of infant death that has known risk reduction strategies. While some causes of infant death are still too complex to easily implement positive change, the recommendations to minimize SIDS are practical and easily implemented. That isn't possible if high-risk families are known to be unaware of the risks in the first place, much less the methods to minimize those risks. At the same time, we were able to mobilize community stakeholders for a new community coalition aimed at reducing infant mortality through CBPR. With SIDS remaining the leading cause of death for post-neonatal infants in the United States, it represents an important public health priority. Including community members in the discussion and design of public health interventions is an important step in realizing sustainable change in communities most affected by disparate health outcomes.

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Figure 1.
Respondents' perceptions of community need to address sudden infant death syndrome.

Table 1

Demographic Characteristics of Respondents (n=74)

Characteristic	Total n (%)	Winchester n (%)	Page n (%)
Age (years)			
18 – 29	7 (9.4)	5 (12.5)	2 (5.9)
30 – 39	14 (18.9)	11 (27.5)	3 (8.8)
40 – 49	19 (25.7)	9 (22.5)	10 (29.4)
50 – 59	21 (28.4)	12 (30.0)	9 (26.4)
60 – 69	9 (12.2)	3 (7.5)	6 (17.6)
70	1 (1.3)	0 (0)	1 (1.4)
Missing/refused	3 (4.0)	0 (0)	3 (8.8)
Race/ethnicity			
Non-Hispanic White	62 (83.8)	30 (75)	32 (94.1)
Non-Hispanic Black	3 (4.0)	3 (7.5)	0 (0)
Hispanic	6 (8.0)	6 (15.0)	0 (0)
Asian	1 (1.3)	1 (2.5)	0 (0)
Refused	2 (2.7)	0 (0)	2 (5.9)
Sex			
Male	13 (17.6)	4 (10.0)	9 (26.5)
Female	61 (82.4)	36 (90.0)	25 (73.5)
Occupation/affiliation			
Healthcare	13 (17.6)	9 (22.5)	4 (11.8)
Health department	8 (11)	6 (15.0)	2 (5.9)
Social work/law enforcement	14 (18.9)	5 (12.5)	9 (26.5)
Education/childcare	11 (14.9)	5 (12.5)	6 (17.8)
Health non-profit	18 (24.3)	11 (27.5)	7 (20.6)
Other/unaffiliated	10 (13.5)	4 (10.0)	6 (17.7)

Table 2

Distribution of Respondents' Perception of Community Awareness of SIDS by County: Winchester/Frederick County, VA and Page County, VA.

High-risk groups aware of SIDS	Winchester/Frederick County: n (%)	Page County: n (%)	* p-value
Yes	15 (37.5)	6 (17.7)	0.05
No	20 (50)	17 (50)	
I don't know	5 (12.5)	11 (32.4)	
Total	40 (100)	34 (100)	

* P-value calculated based on the chi-square test.

Table 3

Categorized Common Themes for Community Resource Needs to Address SIDS

Rank (among first responses)	Theme	n (%) First responses	n (%) All responses
	Total	73 (100)	114 (100)
1	Education	53 (73)	59 (51.8)
2	Access to healthcare	5 (6.9)	9 (7.9)
3	Drugs/treatment	3 (4.1)	7 (6.1)
3	Networking/social support	3 (4.1)	3 (2.6)
5	Home visits	2 (2.7)	2 (1.8)
5	Poor parenting skills	2 (2.7)	2 (1.8)
	Total	73	114