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Collaborative Translation of Knowledge to Protect Infants During Sleep: A Synergy of

Discovery and Practice

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Abstract

The impact of discoveries from scientific research is manifested in their timely application to real-world conditions, with a goal of improving life. This is the desired research-to-practice transition for new knowledge, yet it is not always achieved. Where knowledge is simply transferred in its discovered form, there can be unintended consequences and harmful delays in achieving desired changes if there is not also a cultural and contextual fit with targeted populations. This has been the case, for example, in the failure of the "don't bedshare" message in protecting African American infants, a message derived from the discovery of heightened risk of death for infants who sleep in the same bed as others. Knowledge transfer implies movement in one direction: from researchers to end-users. Family scientists, who work with families, understand that knowledge in its discovered form needs to be translated, and not just transferred, if it is to be useful to families and fit with their values, preferences, and circumstances. Unlike knowledge transfer, knowledge translation is bidirectional, with multiple informants, including but not limited to the new discoveries themselves. In this article, we examine the history of discovery and practice as they relate to preventing sudden

infant death. Using safer infant sleep as an example, this review demonstrates the importance of collaboration between discovery and practice for developing health policies, interventions and messaging that are enabling for all families.

Key Words: Collaborative translation, health messaging, safe infant sleep, SIDS.

As has been illustrated in the preceding articles in this special issue, the strength of family science is in its synergy of discovery and practice (see Figure 1). Discovery informs practice, and knowledge gained in practice informs discovery. This bidirectional flow of knowledge helps family scientists establish evidence-based policy recommendations, educational programs, and clinical interventions, resulting in an effective *translation* of discoveries into language that is meaningful, appropriate, and effective practice with families. In contrast, policy, education, and interventions can be relatively weak, ineffective, or even harmful when the *transfer* of knowledge is unidirectional, that is, when the feedback loop from practice is absent in the realm of discovery.

The synergy of a bidirectional system for knowledge flow is well evidenced in discovery and practice related to preventing sudden infant death during sleep. In the early stages, prevention of such deaths centered on efforts to understand causes and related risk and protective factors (e.g., discovery that prone sleeping increases infants' risk of death during sleep; Mitchell, Aley, & Eastwood, 1992; Mitchell et al., 1991). Practice recommendations drawn from the substance of the discoveries were *transferred* to policy and educational efforts, such as the Back to Sleep campaign (American Academy of Pediatrics, 1992). These practices were offered as one-solution-fits-all recommendations, without consideration of variations across individuals and families in understandings and contexts because recommendations were uninformed by family knowledge.

Transition to a bidirectional flow of knowledge resulted in a *translation* of discovery for practice. The bidirectional nature of this translation provided opportunity to examine families' responses to discovery-based information and generate health messages for infant protection informed by families' understandings, beliefs, values, fears, real-life contexts, and cultures. In this article, we chronologically describe the history of efforts to prevent infant death during sleep and, in doing so, the importance of a bidirectional flow of information to inform by policy and practice becomes evident.

KNOWLEDGE DISCOVERY

The first steps in preventing sudden infant death during sleep were marked by discovery based on observations of infants' sleep environments and consideration of medical and forensic evidence (Athanasakis, Karavasiliadou, & Styliadis, 2011; Krous et al., 2004; Valdeś-Dapena, 1980). These early efforts to understand led to establishing definitions and steps for reducing incidence. In the United States, this was marked by infant death during sleep being identified as sudden infant death syndrome (SIDS) at the 1969 National Institute of Child Health and Human Development (NICHD) Conference (Willinger, James, & Catz, 1991). In 1974, SIDS was recognized as a public health issue in the United States with the passing of the National SIDS Act, through which the U.S. Congress directed the NICHD to study causes of SIDS (National SIDS Act of 1974). Subsequently, the American Academy of Pediatrics (AAP) Task Force on Infant Sleep Position and Sudden Infant Death was formed in 1992 (AAP, 1992).

Further understanding of SIDS grew out of epidemiological research conducted in New Zealand (Mitchell et al., 1991), the United Kingdom (Hoffman, Damus, Hillman, & Krongrad, 1988; Hoffman & Hillman, 1992), and later in Australia (Henderson-Smart, Ponsonby, & Murphy, 1998) and the United States (Hauck et al., 2003). One outcome from these and other research studies was the triple-risk model (Filiano & Kinney, 1994), which

organized known risk factors for SIDS events into three broad domains: (a) a *critical period* of risk associated with infants from 1 to 6 months of age and peaking in incidence between 2 and 4 months; (b) *infant vulnerability* associated with higher risk among infants exposed to smoke and those with premature birth, low birth weight, or illness; and (c) risk associated with *exogenous factors*, such as infants' sleep position, overheating, use of bedding or toys that impede breathing, or parents' use of substances that compromise awareness.

KNOWLEDGE TRANSFER

The grouping of infant vulnerability by age, exposure, and context embodied in the triple-risk model helped transfer discoveries to policy and practice and became the foundation of initial campaigns to protect infants during sleep. With a unidirectional transfer of information, policy was constructed using the substance and language of discovery. For example, substantive findings that placing infants on their backs to sleep was protective were transferred into the Back to Sleep policy and practice recommendations. Missing from the process was knowledge of how families understood SIDS risks, how they made decisions about infant sleep, and whom they trusted for advice. Consequently, barriers to families' utilization of health recommendations, such as parents' fears that infants might choke or have flat heads if placed to sleep on their backs (Oden, Joyner, Ajao, & Moon, 2010), were unknown or not accounted for in the recommendations.

Successes With Knowledge Transfer

New Zealand was among the first countries to implement a national SIDS prevention program. Epidemiological research had revealed high SIDS rates and the National Cot Death Study, leading to a 3-year, case—control examination of causes of infant death during sleep (see Mitchell et al., 1991, 1992). On the basis of discoveries in the first year of this study, prone sleeping, maternal smoking, and not breastfeeding were identified as risk factors for infant death during sleep, and prevention efforts based on this knowledge were promptly

initiated (Mitchell, Brunt, & Everard, 1994; Mitchell, Thach, Thompson, & Williams, 1999; Mitchell et al., 1991). Rates of prone sleeping decreased from 43% in 1987–1988 to 10% by 1991, and SIDS deaths decreased from 4.4 infant deaths per 1,000 live births in 1988 to 2.5 infant deaths per 1000 in 1991 (Mitchell et al., 1991). Soon after, Australia launched the National SIDS Council of Australia (now Red Nose) to advocate for safe infant sleeping practices (Henderson-Smart et al., 1998). This campaign was associated with a 57% reduction in the number of SIDS deaths between 1991 and 2000 in Australia (Tursan d'Espaignet, Bulsara, Wolfenden, Byard, & Stanley, 2008). In 1992, the Back to Sleep campaign was established in the United States through the NICHD as a joint effort of the U.S. Public Health Service, the AAP, the SIDS Alliance (now First Candle), and the Association of SIDS and Infant Mortality Program. After implementation of this campaign, the SIDS death rate in the United States declined by 71%—from 130.3 to 93.4 deaths per 100,000 live births—between in 1992 and 2000 (Centers for Disease Control and Prevention, 2016; Pollack & Frohna, 2002).

As is the nature of applied practice and policy, the effectiveness of these campaigns depended not only on the strength of the science but also on acceptance of the recommendations by parents and parental figures according to their beliefs, norms, and capacity to comply. Because of the unidirectional nature of this knowledge transfer and the absence of feedback from families, these campaigns did not benefit all infants equally. Thus, despite initial decreases in SIDS events, overall the campaigns had only modest success relative to the respect that the robustness of the research should have commanded (Carpenter et al., 2013).

Persisting Disparities

Examination of the changes in SIDS rates revealed substantial disparities across racial and ethnic groups. SIDS rates were higher for African American and Native American infants in

the United States (Hauck et al., 2003; Moon, Oden, Joyner, & Ajao, 2010; Parks, Erck Lambert, & Shapiro-Mendoza, 2017), for Māori infants (infants in families of Polynesian descent) in New Zealand (Mitchell et al., 1994), and for Aboriginal infants in Australia (Alessandri, Read, Burton, & Stanley, 1996). For example, in the United States in 1995, there were 237.5 infant deaths per 100,000 live births and 203.0 infant deaths per 100,000 live births for Native American and African American infants, respectively. This stood in striking comparison to the rates of infant deaths for White (93.0), Hispanic (62.7), and Asian/Pacific Island (59.3) infants in the United States (Parks, Erck Lambert, & Shapiro-Mendoza, 2017). In each location, similar disparities persisted across the next 2 decades. In the United States, SIDS rates in 2013 were 177.6 and 172.4 infant deaths per 100,000 live births for African Americans and Native Americans, respectively, compared with 84.5, 49.3, and 28.3 for White, Hispanic, and Asian/Pacific Islander infants, respectively (Parks, Erck Lambert, & Shapiro-Mendoza, 2017).

These disparities highlight where prevention was succeeding and where it was failing. Researchers turned their attention to family-related issues to identify barriers to campaign success (Hauck & Tanabe, 2008; Moon, Hauck, & Colson, 2016; Tipene-Leach, Able, Haretuku, & Everard, 2000). In the United States, research conducted in 2010 (Moon et al., 2010) revealed that disparities in adherence to recommendations among African American mothers was not a result of lack of knowledge of the SIDS recommendations; rather, the disparities were driven by the varied values families of different races and ethnicities tended to place on certain sleep practices associated with SIDS. This and other research during this period helped to identify two missteps that contributed to noncompliance with campaign recommendations: (a) contradictory definitions for causes of infant death during sleep and (b) a population rather than targeted approach to informing families about contributors to risk that vary according to infant vulnerabilities, family lifestyle behaviors, and infant care

practices (see Trachtenberg, Haas, Kinney, Stanley, & Krous, 2012). These missteps diminished the potential impact of the recommendations that were disseminated and failed to convey key information to those at heightened risk.

Policy and messaging intended to promote changes in behavior were hampered by inconsistent terminology and definitions (i.e., SIDS, sudden unexpected infant death [SUID], sudden unexpected death in infancy [SUDI], and crib death; see American Academy of Pediatrics Task Force on Sudden Infant Death Syndrome, 2016). Increases in coroners' listings of unexpected, unascertained, and unknown as the cause of death further contributed to lack of clarity in definition. This confusion in terminology, as well as the continued dissemination of health policy and messaging based largely in the language of discovery led to (a) distrust by families who were uncertain the nature of their care could make any difference in reducing risk; (b) coroners' reporting of parents knowing but not acting on recommended advice; (c) a growing list of risk factors presented without context or perspective, many of which were derived from evidence rather than defined by it; and (d) a heavy reliance on information strategies using talk and print materials (Cowan, 2010).

The transfer of knowledge without consideration for the barriers to understanding and adoption of recommended practices within families impeded the effectiveness of communication with families about the risk of infant death. This was evidenced in mothers' reports of SIDS as "random" or as "God's will" (Moon et al., 2010). With the cause of SIDS deaths still unclear, concrete but inaccurate beliefs—such as the prone position (tummy sleeping) protecting infants if they were to choke, spit up, or vomit in their sleep (Joyner, Oden, Ajao, & Moon, 2010; Moon et al., 2010)—were more salient to parents than seemingly counterintuitive recommendations to have infants sleep on their backs in the absence of compelling information concerning the cause of death.

Policies focused on making population-wide, one-solution-fits-all recommendations rather than conveying targeted, context-dependent recommendations to families. The resulting misdirection in safe sleep policy may have been overlooked initially as attention was diverted toward controversy concerning the strength of evidence for one aspect of the population-wide recommendation. For example, the recommended total bedsharing ban became a major obstacle to prevention in many countries, including the United States (Middlemiss, Yaure, & Huey, 2014), as research findings supported both (a) bedsharing as a central risk for SIDS and (b) bedsharing as a potentially safe practice contingent on factors addressed by the triple-risk model (Gordon, Rowe, & Garcia, 2015; Vennemann et al., 2012). For example, researchers reported that bedsharing was a statistically higher risk for infants exposed to cigarette smoke than those not exposed to cigarette smoke (notably, these findings were recently replicated in New Zealand; Mitchell, Cowan, & Tipene-Leach, 2016). However, bedsharing became the scapegoat for the comorbidity of bedsharing and smoking, and a ban on bedsharing was recommended for all families regardless of contextual factors.

Those affected at disproportionate rates by the population-wide recommendation against bedsharing were infants of families for whom bedsharing was a treasured practice, infants of parents who opted to bedshare occasionally as a way to manage the challenges of nighttime care, and infants in families with no dedicated infant sleep space. In short, indigenous, racial and ethnic minority, and low-income families tended to be detrimentally affected by the misdirected and insufficiently nuanced information at relatively high rates (Ford & Nelson, 1995; Fu, Colson, Corwin, & Moon, 2008; Malloy & Eschbach, 2007; Moon et al., 2010).

Family-Focused Knowledge Transfer and Disparities

In New Zealand in 1994 and in the United States in 2004, messaging adaptations were made to better inform families whose infants were at high risk for SIDS. Voices representing their communities were sought to work with existing agencies and organizations to create subculture-specific messages better aligned with the practices, risks, and context of those identified subcultures. Notably, this feedback became the first step in knowledge translation.

In the United States, this shift to include community-based knowledge to help address disparities in SIDS rates was seen in the NICHD working with the National Coalition of 100 Black Women Inc., Women in the NAACP, and Alpha Kappa Alpha Sorority to construct more culturally appropriate delivery systems. These efforts led to establishment of the Safe to Sleep campaign in 2012 (Eunice Kennedy Shriver NICHD, NIH, DHHS, 2012; Safe to Sleep Campaign, 2013). Safe to Sleep essentially shared the existing Back to Sleep campaign recommendations in ways that were more relevant to the targeted subcultures. For example, in the Safe to Sleep campaign, the discovery-based messages and related recommendations for discrete sleep practices were delivered to African American and Native American communities through Safe to Sleep champions, who were community members with respected voices in the community (Eunice Kennedy Shriver NICHD, 2012). To address the higher rate of SIDS in Native American families, the Healthy Native Babies Project led by the NICHD was established, creating culturally appropriate materials and messages for use in Indian Health Services locations in the northern United States where SIDS was the leading cause of post-neonatal death among American Indian and Alaska Native infants (Pierce-Bulger, 2013).

KNOWLEDGE TRANSLATION

Any effective translation requires sufficient proficiency of the two languages to understand the original meaning then retain that meaning in the target language; literal (e.g., word-byword) approaches to translation are often insufficient for this purpose. The Safe Sleep program in New Zealand is an example of how the shift was made from transfer to translation of knowledge to prevent sudden infant death during sleep.

Safe Sleep Program in New Zealand

In New Zealand in 2009, a major review of SIDS prevention led to a shift from a unidirectional to a bidirectional effort marked by knowledge translation. This shift focused attention on identifying what was contributing to the stalled rate of decline in infant death rates and the persisting disparities among subpopulations. An end-stage prevention approach was designed and is described in detail elsewhere (see Cowan, 2010).

In short, the revised approach translated knowledge of infant risk and protection by adhering to universal principles concerning how people learn, trust, and engage, as well as how people adopt and communicate information, while adapting the emphasis and delivery of the content being conveyed to reflect what was important to each target audience. The focus was placed on protecting infant breathing and preventing accidental suffocation, with no mention of SIDS, SUID, SUDI, or cot death. Among parents and other parental figures, the importance of protecting breathing and preventing suffocation was already well understood, and they accepted that suffocation is preventable.

In addition, this translation-based approach to sharing knowledge leaned heavily on diffusion of innovation theory (Rogers, 2002), which describes effective mechanisms for spreading ideas and influence within a social system. Diffusion of innovation theory proposes a three-step strategy: (a) align with evidence, (b) build networks of influence within vulnerable communities, and (c) design approaches of value to those communities. This strategy formed the foundation for the revised approach.

Alignment with evidence took the form of a Safe Sleep Education Blitz initiated in November 2009 (Cowan, Pease, & Bennett, 2013). The Education Blitz aimed to inform education-oriented practitioners from a broad base of health, social, and community services about the evidence from discovery science. In particular, evidence concerning several sleep

arrangements (i.e., face-up, face clear, smoke-free, and in own sleep space if not smoke-free) was provided to establish a shared knowledge base rooted in evidence among practitioners.

The second step was to formalize the role of the protection advocate. This was accomplished with an invitation for families to use their influence by role-modeling safe sleep practices and sharing safe sleep information with family and friends. This extended the reach of evidence-based education into communities most in need of it.

The third step was the introduction of a safe sleep space for improving the safety of bedsharing, based on knowledge from discovery that infants were better protected when sleeping in their own bed. The sleep space, called Pēpi-Pod, could be brought into the adult bed and was distributed to families with infants identified by practitioners as at increased risk of accidental suffocation, using evidence-based criteria that included newborn infant, smoke exposure in pregnancy, and preterm delivery. The associated education focused on aligning parental practice with sleep approaches for improving infant safety that respected personal values and beliefs. For example, among parents who valued bedsharing, the sleep space enabled a baby to be protected from accidental suffocation while the family continued bedsharing. The translation of "bedsharing risk" into "sleep space protection" was an approach that parents in these communities could value and did not unduly infringe on their sleep practices and beliefs.

The Education Blitz was the extensive population-oriented component of the intervention. It was delivered via an online education tool (with voiceover) for health and community professionals and parents (Change for Our Children, 2016). This educational video, called *Baby Essentials*, used the voices of infants from across the four main cultural groups of New Zealand to introduce content and promote the universal nature of the need for protection. Distributed in an online format (Cowan et al., 2013), the presentation was an alignment tool. It facilitated a move away from simply presenting a checklist of safe sleep

messages and discrete practices that told parents what to do to engaging them in personalized discussions about protecting their babies in a variety of contexts, thereby empowering and enabling them to implement any needed sleeping behavior modifications on their own terms.

A major aim of this educational initiative was to resolve the bedsharing controversy. This was achieved by highlighting areas of strong scientific agreement (Carpenter et al., 2013). For example, there was strong evidence-based agreement among researchers and practitioners that infants most at risk from bedsharing also were those exposed to one or more of the following risks: smoking in pregnancy; born before 37 weeks' gestation; weighing less than 2,500 grams at birth; or cosleeping with another child or with a person under the influence of alcohol, medications, or recreational drugs. Infants not exposed in these ways had a small, but much reduced, risk (Carpenter et al., 2004).

The blitz aspect of the Educational Blitz aligned people with evidence and supported a unified voice and consistency of message within a short time. It enabled family practitioners to convey evidence-based knowledge beyond the information contained in the leaflet (i.e., beyond knowledge transfer) by personalizing information for families and responding to their perspectives on infant nighttime care in a culturally appropriate way. Discussion of safe sleep became a dialogue with families rather than a directive. Families, in turn, were better able to understand and believe the severity of risk to infant breathing associated with the most salient risk factors (as already outlined). The goal was that, by conveying information about risk and protection within the context of their own ecological realities and from a perspective that aligned with their own values and worldview, parents would be more likely to adopt recommended practices and arrange for their infants to sleep safely. *Baby Essentials* primed families for the introduction of portable infant sleep spaces in 2011.

In-Bed Sleepers for Translating Knowledge Into Practice

The introduction of a sleep space for improving the safety of bedsharing was the final step in this knowledge translation (Cowan et al., 2013) and was the intensive and targeted component of the broader Safe Sleep intervention. The initial distribution of these sleepers began as an emergency response to a devastating earthquake in Christchurch, New Zealand, in 2011. Six years later in 2017, they were supplied to infants identified as more vulnerable to accidental suffocation as an established health-funded service across the country. These portable infant sleep spaces offer a dedicated sleep place—in an adult bed, on a couch, or as a makeshift bed when needed—for infants in all circumstances identified as being associated with high risk (Mitchell et al., 2016).

Recipients of sleepers, which were offered to families in the context of an educational setting and as a means to protect infants' breathing, were invited to try the sleeper for a couple of weeks to see if it was useful to them. They also were asked to share the information they received about protecting infant breathing with others in their social networks. To assist with this, small cards with a plastic tube attached to simulate infants' airways ("Your Tube" cards) were provided, with an explanation on the card for how to protect airways during sleep. Cultural belongingness of the health message for Māori was enhanced by a companion device, called a *wahakura*, which is portable sleep space hand woven from flax that has been promoted in Māori communities through weaving workshops since 2006 (Abel, Stockdale-Frost, Rolls, & Tipene-Leach, 2015).

The success of the Safe Sleep campaign with its focus on protecting infants by protecting their breathing is evidenced by the changes in infant deaths since the program was launched (Mitchell, Cowan, & Tipene-Leach, 2016). Rates of infant death from all causes in the post-perinatal period (7–364 days) decreased by 36% between 2009 and 2016 (from 2.78 to 1.77 per 1,000 live births; Figure 2). The campaign moved beyond transferring knowledge about infants' risk to engaging families in practices that help create a safe sleep environment

for their infants. Further, including families as partners in the protection effort by encouraging them to have conversations with others about infant airway safety conveyed inherent trust in what and how families choose to communicate, giving them ownership of the message, how it was translated, and its impact. In these ways, discoveries from science and practice have been integrated and translated into a language that is understood, relevant, believed, and owned by those with particularly vulnerable infants. Efforts to bring these messages to families in the United States have been undertaken with an indication of increases in safe sleep practices (Middlemiss, 2016).

American Academy of Pediatrics Expanded Policy and Knowledge Translation

When the Safe Infant Sleeping Environment policy was revised by the American Academy of Pediatrics Task Force on SIDS (2011), a co-chair of the committee noted that the health-care community needed to "do a better job translating what the research identifies as best practices into the day-to-day practice of caring for infants in both the hospital and home environment" (p. 128). The revised policy was expanded in 2016, which marked a clear shift to a framework of knowledge translation and moved decisively toward informing parents about the reality of risk, as well as adapting some recommendations that created challenges for families, such as bedsharing while breastfeeding (American Academy of Pediatrics Task Force on SIDS, 2016).

The expanded policy has two key and new recommendations: (a) The policy supports defining infant deaths during sleep as related to infant suffocation, and (b) the policy acknowledges that there may be instances in which families do not adhere to the recommendation against bedsharing for numerous reasons, and that parents should therefore be encouraged to make all sleep spaces safe. Thus, the recommendation against bedsharing was essentially translated in acknowledgment of the realities of family practices, and particularly the possibility that behaviors may not always align with the recommendations—

for example, due to contextual factors such as falling asleep while breastfeeding. In this regard, to reduce risk to infants, the policy set out recommendations that assure breastfeeding can occur in places that do not pose a suffocation risk to infants. This effort, similar to those that have preceded it in New Zealand, is intended to inform parents about risk and protective strategies while acknowledging the diversity of sleep practices across families (American Academy of Pediatrics Task Force on SIDS, 2016).

SUMMARY

The work of creating and implementing initiatives that strengthen families is more fruitful when knowledge obtained through practice is as valued as knowledge obtained through discovery. Without the contribution of both, there is risk that health messages will go unheeded despite their empirical strength. Further, a unidirectional transfer of knowledge increases the likelihood of constructing policy that is harmful to children and parents and costly to communities (McCreanor, Tipene-Leach, & Abel, 2004). In the area of infant sleep, for example, the unintended but negative outcome of ill-advised policy can be seen in families who have lost custody of their children or been charged with child endangerment because of their sleep practices (Fleek, 2014; Sharpe, 2015; Snyder, 2016). Unintended and negative outcomes can also be seen in infant mortality disparities stemming from delayed access to or acceptance of new knowledge due to the transfer of that knowledge without translation.

In summary, strong science is at the core of an effective intervention, and the combined knowledge of family scientists and practitioners is the essence of culturally relevant and belief-aligned practice recommendations that derive from that science. We call this teamwork *collaborative translation*, which defines a symbiotic relationship centered on cooperation and respect for working together toward the shared goal of producing timely and effective applications of new knowledge in the form of policies, recommendations, and

practices that benefit all families. Collaborative translation is the key to achieving synergy between discovery and practice—and ultimately to strengthening families.

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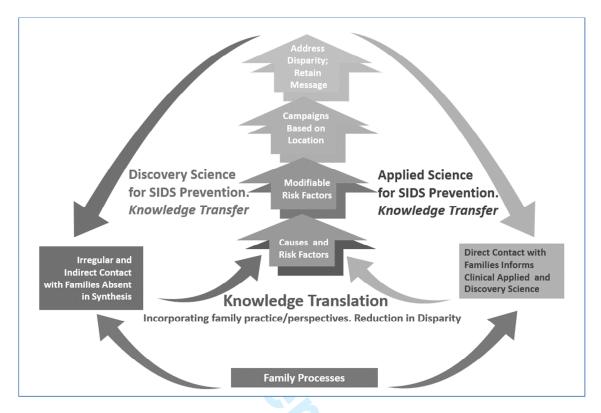


Figure 1. Accommodation of practice information in discovery science research and the role of discovery in practice assures a dynamic conversation between applied and discovery family science. This network of information leads to knowledge translation facilitated by feedback from families gained through application of discovery across diverse family contexts. This feedback, whether in regard to policy or practice, helps to inform next steps in discovery. In the realm of infant sleep research, the combined knowledge of discovery science and clinical applied family science provides the tools to create paths forward that support families by creating culturally relevant and belief-aligned practice recommendations. This accommodated approach allows for engaging in science across both resources of great knowledge. Note. Adapted from Grzywacz and Allen, this issue.

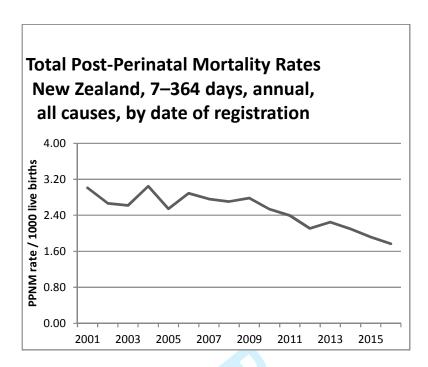


Figure 2. Decrease in post-perinatal mortality (PPNM) rates across the years of New Zealand's Safe Sleep Campaign.