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VIEWPOINT

When shared decision-making and evidence based practice clash: Infant sleep practices

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Abstract: In complex decisions, there are times when there may be a conflict between the recommendations from clinical practice guidelines and the outcome of a shared decision-making process between the clinician and the patient. Sticking rigidly to practice guidelines can be seen as paternalistic and even dismissive of a patient's specific circumstances and preferences; however, failing to adhere to such guidelines can be troubling for many doctors. In this article, we present and discuss this conflict using the common problem of how to provide family-centred, yet evidence-based guidance on infant sleep practices. Infant sleep practices are a common discussion topic at well-baby visits, and family preferences for infant sleep practices are often at odds with national recommendations. With three cases as a backdrop, we discuss how cultural humility, complexity and trust can be key factors in how the clinician-parent discussion on infant sleep can incorporate safe sleep guidelines into a family-centred, culturally relevant discussion.

Doctors and health-care teams can simultaneously practice evidence-based medicine, and engage with patients in shared decision-making. However, there are times when the two principles of practice may be in conflict, in particular, for more complex decisions.[1] Clinical practice guidelines are defined by the Institute of Medicine (IOM) as 'statements that include recommendations, intended to optimise patient care, that are informed by a systematic review of evidence and an assessment of the benefits and harms of alternative care options'.[2] They are meant to establish norms of practice.[3] The IOM's 'Crossing the Quality Chasm',[4] emphasised the importance of shared decision-making and of responding to patient preferences and choices.[4] The IOM recommendation aligns with extensive literature on managing cross cultural consultations that requires physicians to provide care with cultural humility. This includes the ability to work with the patient's cultural beliefs, values and practices in developing a relevant management plan.[5]

Using complexity theory, and in particular the Cynefin framework, categories of complexity in medicine range from obvious (low complexity) to complex (high complexity).[1] Practice guidelines are particularly useful for obvious problems where there is a high level of evidence (thus there is 'best' practice), but also for complicated problems in which a 'good' practice can be defined. By their nature, complex problems are not well managed solely by a protocol or guideline and require judgement and trial and error to find the best way forward. As clinical concerns gain complexity, and in particular multiple dimensions of complexity (e.g. medical complexity and social complexity), it becomes more likely that outcomes from shared decision-making may be at odds with recommendations from evidence-based clinical guidelines. To explore this problem, we consider the issue of infant sleep practices for the prevention of sudden unexpected death in infants (SUDI).

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Case study 1

Mrs A, a 38-year-old woman comes for the 6-week check with her daughter. This is her third child. Mrs A is a non-smoker and non-drinker. She plans to return to work part-time as a city planner having arranged day-care. She is exclusively breastfeeding and bed shares with her daughter and husband in a king size bed. Her daughter wakes up frequently during the night and it is much more convenient to bed share as she can feed her and put her down without getting up. She explains that she bed shares to get a better night's sleep. She raised her other two children the same way and does not think there is a need to change.

You know Mrs A well as you cared for her other two children. You discuss the recommendations on safe sleep with her, emphasising the evidence that bed sharing increases SUDI risk.[6,7] She asks you exactly what risk there is that her daughter might die of SUDI and how that might compare with the increased risk her daughter would face if her mother was more stressed and sleep deprived, and as a result less safe in the kitchen and when driving. You reassure her by pointing out that she does not smoke or use soft bedding, such as a comforter or pillows, and that the baby is sleeping supine. You tell her that you are unable to answer her specific questions about varying degrees of risk. You sense that she probably will not change her infant sleep practices and take careful notes to document that you discussed the safe sleep recommendations.

Case study 2

Ms B, a 22-year-old woman, comes for the 6-week check with her twins. The twins spent the first 3 weeks of their life in the neonatal intensive care unit. Ms B appears tired and somewhat anxious. She tells you that she may have to move out of her apartment soon and is having trouble making ends meet. She says she gets no support from the twins' father, although her mother lives nearby and helps a bit. You know from the antenatal history that she smoked during pregnancy but denied significant alcohol intake. She reports that the twins bed-share with her. They settle better on their stomachs. She says she is severely sleep deprived and the two cots that she has do not fit into her bedroom and the only other empty room in the apartment is a living room she shares with her roommate.

The twins both cried throughout the entire visit. You use your best active listening skills to attend to Ms B as she describes the infants' sleep practices of prone sleep and bed sharing. Sitting across from her, you acknowledge just how hard it has been for her to get any sleep as a mother of twins. You compliment her on the care of her infants, and let her know how wonderful it is that she has not gone back to smoking since the babies were born. Before you have the chance to tell Ms B about the infant safe sleep recommendations, she burst into tears saying she is worried that she will not be able to afford her rent anymore, since she took on a new car payment in order to get a car that could fit two rear-facing car seats in the back seat. You spend the rest of the consultation calling the social worker to try to help with her housing needs, assessing her depression risk, and organising more community resource support for her own mental health needs and food insecurity. At the end of your day, while writing up your notes, you realise that you forgot to discuss the safe sleep recommendations and feel bad that you are providing her with inferior care.

Case study 3

Dr C, a 38-year-old paediatrician comes for the 6-week check with her daughter and her husband. She has recently returned to work part-time. They have a live-in nanny to help with household tasks, who is working out very well. Although Dr C is really tired, she tells you that she is managing okay with the support of her husband. She reports that she is a non-smoker, non-drinker that her daughter sleeps supine in her own cot in an adjoining room, and she is exclusively breastfed.

The visit with Dr C was straightforward. She is a colleague, and it was good seeing her doing so well. She clearly knows the infant safe sleep recommendations from the way she reports her daughter's care. You congratulate her on the good job she is doing as both a mother and doctor. Later in the day the clinic receptionist tells you that she overheard Dr C talking to her husband in the waiting room telling him that he must not tell the doctor they are bed-sharing with their daughter.

Evidence and Guidelines/Recommendations

Case 1 illustrates the problems clinicians face when implementing recommendations: often the information necessary for shared decision-making is not a part of the clinical guidelines or recommendations. Mrs M asked a reasonable question that extends beyond safe sleep recommendations.[6,7] Safe sleep recommendations focus on preventing SUDI; they do not address Mrs M's concern of how safe sleep recommendations impact her ability to maximise restful sleep and minimise stress, although the mother's stress level, sleep, and overall mental health is a critical factor in the wellbeing of the infant. This is not just a problem with sleep guidelines but a feature of many guidelines.[8] Consider the adult type 2 diabetic patient with an HbA1c above the target range despite maximal oral treatment. The clinician asks the patient to start insulin. The patient asks just how much benefit they will receive from adding insulin compared to cutting their cigarette use down to just five a day, or cutting out fried foods. To be able to have a shared decision-making discussion with a patient, the clinician needs to be able to communicate the benefits and risks of the proposed intervention compared to not intervening, or intervening in a different way. A significant problem with the evidence base is that this information is hard to measure in aggregate, let alone apply to a specific patient. For example, Dr C is likely to be aware of the recommendations and took several precautions to limit risk for her infant. She has arranged her bed so that it had a firm surface and had only light coverings (relying on wearing more nightclothes for warmth rather than relying on blankets/duvets). She uses an in-bed co-sleeper in an attempt to limit the likelihood of her rolling over the baby while asleep. Dr C knows that there is no evidence for the effectiveness of these types of co-sleepers, but to her it seems like a good compromise. These precautions may have diminished the risk of SUDI but we could only hazard a guess at what the remaining risk might be. The approach of recommending the same course of action for every patient is an effective strategy if the intervention is straightforward with few harms associated (e.g. folic acid tablets in pregnancy to prevent neural tube defects[9]) but it may not be an ideal strategy for the more complex problem of addressing infant sleep practices.

The doctor must also provide the recommendations in context of the patient, family and community, and their complexities, both medical and social. Patients may have additional clinical or social needs that make their particular combination of factors very different from patients that the evidence-based recommendations or guidelines were originally developed for. For example, in New Zealand, a public health campaign on sleep position led to a significant drop in SIDS between 1988 and 1992[10]; however, this reduction occurred mostly amongst the non-Māori population. In 2002, there were 5 SUDI deaths per 1000 live births in Māori compared to 2.2 per 1000 live births in non-Māori.[11] Māori-led research developed a Maori-specific strategy that included a basket or 'pēpi pod' for baby to sleep in, placed on the bed next to the mother.[12] After implementation of this strategy, Māori SUDI rates dropped from 4.5 to 2.8 SUDI deaths per 1000 live births, between 2009 and 2015.[11]

Guidelines are inevitably reflective of the culture and needs of the populations included in research to create those guidelines, and may not work for different cultural groups.

Need for a Joint Shared-Decision-Making and Evidence-Based Guidelines Approach

Much of the bioethical discussion relating to parents and doctors disagreeing on management is based on hospital-based scenarios involving very sick children. Concepts such as best interests,[13] the

harm principle[14] or the zone of parental decision-making[15] are used when there is disagreement between the parents and the clinicians, but are predicated on having the power to ensure that the intervention deemed as necessary by the medical team occurs, as Gillam puts it:

> *If doctors, alone or in conjunction with clinical ethicists, come to believe that following the parents' wishes would or is likely to cause significant harm to the child, then they are obliged to resist that course of action. This may involve going to court to seek an order, or making a notification to Child Protection, but, as noted above, often this degree of coercive intervention will not actually be required. A firm refusal or strong persuasion may be sufficient.*[15]

For safe sleep guidance, a doctor's main influence on parent behaviour is through relationship-building and trust – through developing an agreed management plan. Strong persuasion in case 2 is unlikely to lead to significant change, but the doctor may feel better for having recommended the guidelines, whether the parent agrees to use them or not. By contrast, a more detailed negotiation may lead to an agreed mitigation of risk, even if the guidelines are not completely followed. Ms B may agree to use a supine sleep position for her infants, and remove her pillows and comforter, while the doctor acknowledges that bed sharing is likely to continue in the short term.

When the doctor provides evidence-based guildelines without allowing the recommendations to be tailored to the specific needs of the family, the parent–doctor relationship may suffer, and the parent may not follow the guidelines at all. However, when the two parties come together and develop an agreed plan that fits the needs of the family, taking into account the guideline recommendations, the parent is likely to have identified those elements that they can implement and thus comply with some elements of the guidelines.

In case 2, if the doctor provided the guidelines without shared decision-making, it is possible that Ms B may have heard the guidelines, but decided not to follow any of the safe sleep practices because she could not see how they would fit into her life. This could put the infants at increased risk of SUDI. Additionally, if the guidelines were presented to Ms B without efforts towards shared decision-making, this may have signalled to Ms B that the parent–doctor relationship was not going to be a collaborative one, and may have discouraged Ms B from sharing her concerns regarding housing and income insecurity, leading to more unmet health-related social needs that could have significant impact on the well-being of the infants.

By contrast, the use of shared decision-making with evidence-based guidelines encourages the development of trust, the elicitation of the patients' views and beliefs, and the negotiation of an agreed management plan. The detail of how to achieve this is documented in the Calgary-Cambridge guide to the consultation, which is widely used to teach consultation skills at medical schools.[16] It also aligns with commonly used frameworks for conducting a cross-cultural consultation.[17] There is good evidence of better outcomes utilising this approach.[18] Shared decision-making would facilitate the visit with Mrs A, helping the doctor and Mrs A come to a mutually agreeable decision. With shared decision-making, the risks to Ms B from unstable housing, insufficient income and social support could have been seen as more important to address at the visit than the risk of SUDI, and could have been prioritised by the doctor with a clear conscience. It would have enabled Dr C to admit to bed sharing and have a discussion with the doctor about whether she was doing the best she could to mitigate the risk.

Conclusion

Shared decision-making is increasingly being seen as an essential component of clinical practice. As Hoffmann *et al*. note:[19]

> *Australia's health training and delivery organisations need urgently to begin prioritising and planning to make shared decision making a reality in Australia.*

In the case of infant safe sleep guidance, the use of guidelines in isolation from shared decision-making is significantly flawed. It can manifest as a paternalistic approach that does not provide information on the level of risk averted by following the recommendations, or the extent to which it applies to the particular parent and their own circumstances. By failing to take into account the parent's views and beliefs, it breaches one of the central tenets of cultural humility. Evidence-based practice has an essential place in our practice but with more complex problems, it must be combined with shared decision-making to lead to optimal outcomes.

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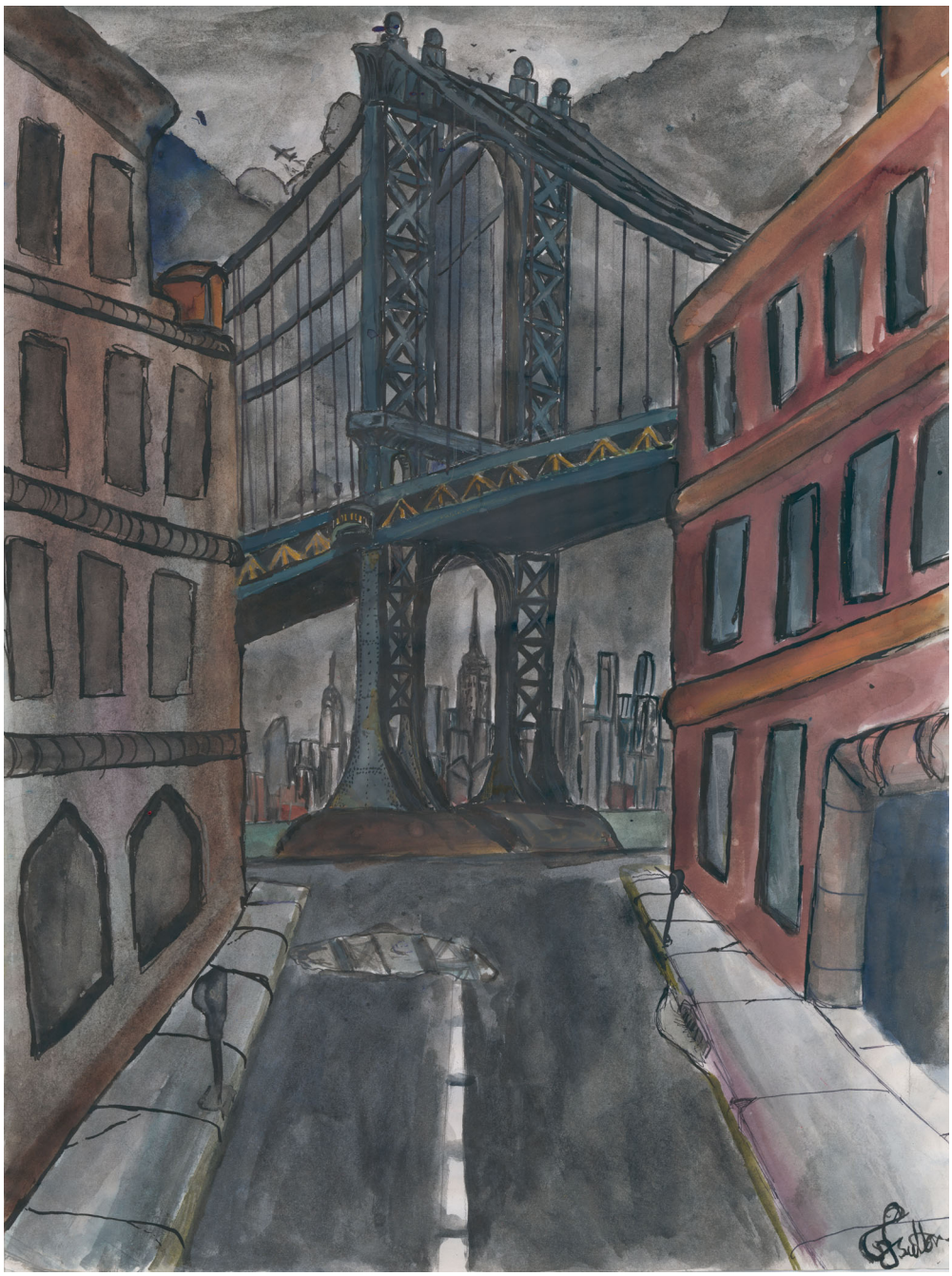

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