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# Immunization rejection in southern Alberta: a comparison of the perspectives of mothers and health professionals

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# Immunization Rejection in Southern Alberta: A Comparison of the Perspectives of Mothers and Health Professionals

Shannon Y. Vandenberg, Judith C. Kulig

Qualitative grounded theory was used to compare and contrast the understanding and decision-making process of non-immunizing mothers and health professionals' perceptions of these mothers' understanding and decision-making process. The sample comprised 8 mothers with purposefully unimmunized children under the age of 6 years and 12 health professionals. Semi-structured interviews were conducted and the data generated were analyzed using data immersion, memo-writing, and 3 stages of coding. The mothers and health professionals identified similar, interrelated factors influencing the mothers' decision, categorized into 4 groups: emotions, beliefs, facts, and information. Three primary themes were evident: the health professionals emphasized the influence of religion in decision-making to a greater extent than did the mothers, the meaning of *evidence* appeared to differ for mothers and health professionals, and mothers revealed a mistrust of health professionals. Immunization is a public health issue; collaboration and understanding are necessary to promote positive health outcomes in children.

**Keywords:** decision-making, mothers, public health, nurse relationships/professional issues

## **Le rejet de la vaccination dans le sud de l'Alberta : une comparaison des points de vue des mères et des professionnels de la santé**

**Shannon Y. Vandenberg, Judith C. Kulig**

Les auteures se sont fondées sur une théorie qualitative à base empirique pour comparer l'analyse et la démarche des mères qui décident de ne pas faire vacciner leurs enfants, à l'idée que s'en font les professionnels de la santé. L'échantillon comprend 8 mères ayant délibérément omis de faire vacciner leurs enfants de moins de six ans et 12 professionnels de la santé. Les auteures ont mené des entrevues semi-directives dont les données ont été analysées suivant une méthode fondée sur l'immersion, la prise de notes et trois étapes de codage. Les deux groupes évoquent des facteurs semblables et interdépendants pour expliquer la décision des mères, qu'on peut répartir en quatre catégories : émotions, convictions, faits et information. Trois grands thèmes en ressortent : les professionnels de la santé insistent davantage que les mères sur l'influence de la religion dans la prise de décision; les mères et les professionnels de la santé semblent accorder un sens différent aux *données probantes*; les mères expriment une certaine méfiance à l'égard des professionnels de la santé. La vaccination est un enjeu de santé publique; la promotion de résultats de santé positifs chez les enfants doit reposer sur la collaboration et la compréhension des enjeux.

**Mots clés :** prise de décision, mères, santé publique, rapports/enjeux professionnels

The introduction of vaccines is considered a marvel of modern science and one of the most remarkable successes of public health. According to the World Health Organization (WHO) (2013), two to three million lives are spared annually as a result of immunization, and rates of diseases such as measles, rubella, and polio have decreased by over 95% in Canada since the introduction of vaccines (Gold, 2006). Smallpox, which historically plagued millions of children globally, is now eradicated (Public Health Agency of Canada [PHAC], 2005). Despite the success of immunization, the WHO (2011) specifies that 23 million infants worldwide are not routinely immunized, raising fears that nearly eliminated vaccine-preventable diseases, such as polio, will re-emerge. Currently, measles outbreaks around the globe have highlighted the importance of vaccination. Poor vaccine coverage has led to the resurgence, with 147 reported cases as of February 2015 in the Americas alone (WHO, 2015).

### **To Immunize or Not to Immunize?**

One of the most significant decisions parents make in terms of their child's health is whether to participate in childhood immunization. Austin, Campion-Smith, Thomas, and Ward (2008) and Sturm, Mays, and Zimet (2005) identify factors that influence immunization decision-making: concerns about vaccine safety, risk versus benefit of vaccines, guilt, confusion due to conflicting information, health-care provider attitudes, mistrust of government and health professionals, personal attitudes and beliefs, social norms, media reports, inexperience with vaccine-preventable diseases, and lack of knowledge about immunization. The current literature uses the term *vaccine-hesitant parents* (Sadaf, Richards, Glanz, Salmon, & Omer, 2013), while in this study we also use the term *non-immunizing parents*.

One ongoing challenge is the diversity of populations and their acceptance or rejection of immunization. At the site of the present study in southern Alberta, Canada, there exist non-immunizing individuals within cultural or religious groups, including Hutterites, Mennonites, Dutch Reformed, and people adhering to alternative health beliefs (Kulig et al., 2002). According to Matkin, Simmonds, and Suttorp (2014), cultural and religious norms and expectations make it challenging for group members to make informed decisions about immunization.

Over the last decade, southern Alberta has dealt with significant vaccine-preventable disease outbreaks. Pertussis outbreaks have occurred every 3 to 5 years, the most recent outbreaks being in 2009 and 2012 (Matkin et al., 2014). In 2014, outbreaks of measles and pertussis affected a number of communities in Alberta (Matkin et al.), placing avoidable pressure on the health-care system and the economy (Alberta Health and Wellness [AHW], 2007).

## *Immunization Rejection in Southern Alberta*

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According to the Government of Alberta (2012), childhood immunization rates in southern Alberta are slightly lower than in the province as a whole. For instance, in 2010 the percentage of children fully immunized with the measles-mumps-rubella (MMR) vaccine by age 2 was 85.68% for all of Alberta, compared to 83.93% for southern Alberta (Government of Alberta); to achieve effective herd immunity for measles in Alberta, the target is 98% for 2-year-old children to have received one dose of MMR vaccine (Matkin et al., 2014). The immunization rates for all childhood vaccines for 2-year-old children varied among communities in southern Alberta; however, 42.8% of 2-year-olds were unimmunized as of June 2013 (Matkin et al.).

Global, national, and provincial immunization strategies have been drawn up in response to the challenges of low immunization rates, aimed at addressing immunization issues, promoting immunization, and ultimately improving immunization rates (AHW, 2007; PHAC, 2005; WHO, 2010). On the whole, health-care professionals (HCPs) have welcomed these strategies as a means to promote health and prevent disease, which is necessary to curb rising health-care costs around the globe (Khorsan, Smith, Hawk, & Haas, 2009).

HCPs, such as physicians, public health nurses (PHNs), and chiropractors, in southern Alberta are impacted by the unique immunization situation there and may be sought for support and advice on the topic of immunization by their patients. Bedford and Lansley (2006) found that 59% of participants in their study in the United Kingdom obtained immunization advice from HCPs. They also found that a trusting relationship with HCPs is crucial in parents' decision whether or not to immunize their children. Similarly, Leask et al. (2008) found that HCPs influence parents in their decision whether or not to immunize their children.

According to Plastow (2006), HCPs are responsible for promoting childhood immunization as well as for providing accurate, evidence-based information to their patients and the general public, while respecting the autonomy and freedom of choice of individuals, as stated in the 2011 *Canadian Charter of Rights and Freedoms*. Childhood immunization falls under public health in Canada (Health Canada, 2009); therefore in many provinces, including Alberta, PHNs deliver the publicly funded immunization programs. The scope of practice of a PHN in Canada involves communicable disease prevention, which consists of planning, coordinating, delivering, and evaluating immunization programs, in addition to being accountable for current knowledge on immunization, skills in administering vaccines, and appropriate therapeutic communication skills (Community Health Nurses of Canada, 2009; Manitoba Health, 1998).

## **Purpose**

The purpose of this study was to explore and compare the understanding and decision-making of non-immunizing mothers with the perceptions of HCPs regarding non-immunizing mothers' understanding and decision-making concerning childhood immunization. The study was part of a larger investigation of the topic (Vandenberg, 2013) guided by four research questions: (1) How do mothers develop an understanding of immunization? (2) How does mothers' understanding of immunization influence their decision not to participate in childhood immunization? (3) How do HCPs perceive non-immunizing mothers' understanding of immunization and their decision not to immunize their children? (4) How do the understanding and decision-making process of mothers compare with the perceptions of HCPs regarding childhood immunization?

## **Method**

### *Design*

This study took place in southern Alberta with mothers from both rural and urban settings. A qualitative research approach was used, with Straussian grounded theory (Corbin & Strauss, 2008; Glaser & Strauss, 1967) as the research design and symbolic interactionism (Mead, 1934) as the theoretical framework, to explore and compare the perceptions of non-immunizing mothers and HCPs regarding immunization. The selected research design and research questions enabled the participants to openly share their feelings, beliefs, and worldviews.

Symbolic interactionism is a useful perspective for understanding human beings and their behaviours in the world they inhabit and for according their words the greatest importance, which allows for close association with qualitative research (Mead, 1934). Grounded theory is a useful methodology for conceptualizing dimensions of social processes and for considering participants' views, intentions, and actions (Glaser & Strauss, 1967). Straussian grounded theory was chosen because it compels the researcher to assume a position of objective external reality while giving voice to the participants and acknowledging their worldviews (Corbin & Strauss, 2008).

The main features of grounded theory are theoretical sampling, simultaneous data collection and analysis, comparative methods, three phases of data coding, memo-writing, and theory generation (Ghezjeljeh & Emami, 2009; Jeon, 2004), all of which were adhered to in this study. Ethical approval was obtained from the authors' affiliated academic institution and the relevant health-services agency. The *Tri-Council Policy*

*Statement: Ethical Conduct for Research Involving Humans* was followed and hence principles such as confidentiality of documents and information were upheld.

### **Sample**

Eight mothers of children under the age of 6 years who purposefully had not immunized them with routine recommended childhood immunizations according to the Alberta Immunization Schedule were recruited using posters placed at locations frequented by mothers and children, such as health clinics, libraries, and family centres. Also, a notice was placed in a faith-based newsletter outlining the study and inviting interested mothers to contact the first author. Once contact was made with four mothers, snowball sampling was used to make contact with four others. Mothers were specifically chosen, rather than parents, given mothers' intimate, emotional relationship with their children and their involvement in health decision-making.

Twelve HCPs, comprising four PHNs, five chiropractors, two pediatricians, and one specialist physician who had a professional relationship with families, were recruited via formal letter of invitation. Letters were mailed to a wide variety of chiropractors in both rural and urban settings in southern Alberta. A fifth chiropractor was interviewed as a result of one chiropractor in the initial group of four expressing a non-supportive view of immunization; this additional interview allowed for the generation of further information from this perspective.

Although they do not administer vaccines, chiropractors were chosen for the study because the literature suggests that they are consulted by parents for information on childhood immunization (Medd & Russell, 2009; Page, Russell, Verhoef, & Injeyan, 2006). Furthermore, in their study with Alberta chiropractors, Medd and Russell (2009) found that chiropractors did not have a positive view of immunization, and, in another study, Russell, Injeyan, Verhoef, and Eliasziw (2004) found that only 25% of chiropractors advised their patients to immunize and 27% were opposed to immunization.

Letters were mailed to all practising pediatricians in southern Alberta and telephone calls were used to enhance recruitment. PHNs were recruited from both urban and rural settings in southern Alberta. PHNs were chosen because of their direct involvement in delivering the childhood immunization program in Alberta and pediatricians were chosen based on their expert knowledge of pediatric health issues. Additional HCPs who have a role in childhood immunization, such as family physicians, were not recruited because a sufficient sample size was achieved using other groups of providers.

### ***Data Collection and Analysis***

Data collection consisted of individual semi-structured interviewing of mothers and HCPs. Interviews were conducted by the first author in a location convenient for the participants. The interviews with mothers focused on knowledge about childhood immunization, experience with HCPs, beliefs and feelings about immunization, sources of information on the subject, and the decision-making process around childhood immunization. Interviews with HCPs concentrated on perceptions of childhood immunization, sources of information on the subject, role in immunization, relationship with non-immunizing mothers, and perceptions about mothers' immunization decision-making process.

Written and oral informed consent was obtained from all participants. Interviews were audiorecorded and transcribed verbatim by the first author.

In accordance with grounded theory research, data collection and analysis were carried out concurrently (Strauss & Corbin, 1998). The first author analyzed the data from all of the interview transcripts, field notes, and memos, while the second author analyzed the data from several transcripts. The authors met on several occasions to review the findings and discuss themes and factors. The components of rigour as prescribed by Liamputtong (2013) were ensured in the following ways: credibility was established through the data collection and analysis processes; transferability was achieved by making sure that participants' ideas and perceptions were outlined in considerable detail in the findings; dependability was ensured via proper data management and including details of the data analysis; and confirmability was achieved by means of the two authors independently analyzing and confirming the findings. NVivo software was used in the storing, managing, and analyzing of the data.

### ***Findings***

Eight non-immunizing mothers in southern Alberta were interviewed, of whom four were rural residents and four urban. Their ages ranged from 25 to 37 years with a mean age of 30. All but one were married. Their education varied from partial high school to bachelor's degree. Their number of children ranged from two to six. All indicated that they were of Caucasian ethnicity. All mothers specified a religious faith, described as either Christian or Latter Day Saints (Mormon). The first author attempted to recruit mothers from a variety of cultural and religious backgrounds, given the unique demographic situation in southern Alberta; however, mothers of Mennonite, Hutterite, and First Nations backgrounds did not respond to recruitment efforts.



Twelve HCPs were recruited for the study. Their ages ranged from 29 to 61 years, and there was an even representation of women and men. Length of time as an HCP ranged from less than 1 year to more than 20 years, with a mode length of greater than 20 years. Ten HCPs indicated that they were Caucasian and two identified as of another race.

Mothers described the immunization decision-making process as lengthy, difficult, and complex and indicated that the decision was reached not carelessly but purposefully. They considered the health of their children to be one of the most important matters to them and felt that they were making the decision that was best for their children. Similarly, HCPs realized the difficulty in making decisions regarding the health of children and understood that non-immunizing mothers were doing what they believed would ensure the health of their children. Professionals also acknowledged the importance of the risk-versus-benefit analysis. They knew that mothers weighed the risks of immunization against the risk of disease but felt that the success of immunization programs in keeping vaccine-preventable diseases at bay was not fully appreciated.

Both mothers and HCPs identified a number of interrelated factors that contribute to immunization decision-making, which fall under four themes — *emotions, beliefs, facts, and information* — although the authors acknowledge that the factors discussed below could debatably be placed under multiple themes.

### ***Emotions***

Mothers explored a number of emotional factors that had led them to not take part in the universal childhood immunization program. These included fear, negative experiences, guilt, indifference, and social belonging. Comparably, HCPs identified fear and social inclusion as emotional factors in decision-making. HCPs clearly recognized emotional motivation as an important factor.

Mothers discussed fear of the unknown and fear of vaccine effects, in addition to fear resulting from negative experiences with immunization: “I didn’t feel secure doing it. To me it was kind of a scary thing.” HCPs also found fear to be an integral paralyzing factor that forced mothers to defer to a passive decision, which was to refuse to immunize their children. One PHN said, “They are hearing all these different things — it influences them, because it scares them and it almost paralyzes them to not know what to do . . . they are really quite fearful for their own children.”

Mothers also discussed feelings of guilt and the inability to forgive themselves should harm result from immunization: “I think that if I went along with it and something happened, that [it] was my responsibility,

just the guilt would be huge.” There were feelings of indifference due to the belief that diseases are not as serious as they are thought to be, as a result of tolerable personal experiences with vaccine-preventable diseases. One mother described her experience with chickenpox: “I mean, you go through a couple of days, but it’s no big deal really.”

Mothers indicated that they felt pressure from family, friends, and religious or cultural groups regarding childhood immunization: “We asked quite a few different people when we were trying to decide whether to immunize or not, like, our friends . . . probably [it was] how the people around me think about immunizations that led to [my] being okay with the decision not to immunize.”

HCPs similarly identified social inclusion as an important emotional factor for mothers, who might have grown up in cultural or religious groups where, generationally, immunization was not adhered to and consequently refusing vaccines had become a matter of social or familial inclusion. One PHN said, “Sometimes that informed choice is peer pressure . . . they want to keep their cultural identity . . . there’s a tremendous amount of peer pressure.”

### ***Beliefs***

Mothers identified a combination of religion, natural health beliefs, and mistrust as factors in their decision about immunization. Clearly, religion was a factor: “If my children [were to] get sick, I would consider that . . . God’s hand.” While all the mothers mentioned a religious affiliation, their affiliations differed. Furthermore, religion was not a predisposing factor in the decision-making process. In contrast, HCPs perceived religious beliefs to be a central influence in southern Alberta for mothers not to immunize their children. However, they generalized non-immunizing mothers into what they viewed as the non-immunizing groups in the region, namely the Hutterites, Mennonites, and Dutch Reformed.

A preference for a natural body free of unnatural substances, such as vaccines, was explored with the mothers. One mother said, “It’s more important for me to build up the immune system rather than bombard it with something that could be prevented just by having a stronger immune system.” Mothers believed that the body’s immune system is designed to ward off vaccine-preventable diseases, a belief that was also held by two HCPs who were unsupportive of childhood immunization.

Mothers openly acknowledged a mistrust of HCPs, pharmaceutical companies, and government, derived from anecdotal information and personal experiences. They believed that HCPs provide biased information, given the role of HCPs in health care, and described government and pharmaceutical companies as being financially motivated to promote vaccines. Comments by two different mothers highlight this perception:

“I think HCPs are seen as, well, of course, they are for that [immunization] because that is what HCPs are taught to think, so maybe you discredit it a little bit”; “There’s a lot of literature out there how the pharmaceutical companies really push the doctors into pushing vaccines, and they get their perks and their trips.”

HCPs knew that the mothers had little trust in them and were aware of the perception that they were financially associated with government and pharmaceutical companies. One chiropractor said, “. . . especially nowadays, distrust of the government and of pharmaceutical companies, and of anyone who has a financial backing in the sales and production of medicine, so that’s definitely some powerful, persuasive forces for people to weed through.”

### ***Facts***

The third theme identified was facts — information that is true or certain. Four factors were placed under this theme: lack of exposure to vaccine-preventable disease, vaccine ingredients, multiple vaccines/antigens, and vaccine ineffectiveness.

Mothers and HCPs acknowledged that immunization programs, on the whole, have been successful at preventing vaccine-preventable diseases and that, consequently, these diseases are no longer considered a threat, making it difficult to appreciate immunization. “It’s so easy to forget about it, not think about it,” said one mother, “because most of these diseases aren’t really a threat immediately . . . it’s so easy to put it off, because there’s no threat, really. If there is, you don’t see it.” According to the HCPs, the perceived risk of disease was lower than the perceived risk of vaccine side effects: “Weighing . . . the difference between which one is going to cause harm is sometimes difficult for a parent when you don’t see disease.”

Vaccine ingredients were a significant obstacle for the mothers, because these were mistakenly associated with harmful chemicals, including mercury, formaldehyde, and animal DNA. Mothers also made reference to the alleged presence of human diploid tissue in vaccines. One mother said, “Over time, all the chemicals and things that have been added, that’s what kept us from doing it.” HCPs also considered vaccine ingredients to be an impediment to immunization. They expressed concern that mothers believed that vaccines contain various metals and fetal tissue.

The mothers were concerned about the number of recommended childhood vaccines as well as the number of antigens in a specific vaccine, believing that multiple vaccines and/or antigens bombard a child’s immature immune system. For instance, they disapproved

of vaccines containing multiple antigens, such as the MMR vaccine: “I remember thinking there were an awful lot in the first 2 years . . . it seems like an awful lot to bombard . . . especially because their immune system isn’t fully mature yet.” Furthermore, mothers were aware of the fact that natural infection with disease provides lifelong immunity whereas immunized children remain susceptible to diseases, as vaccines do not offer absolute protection. In addition, mothers believed that the decline in vaccine-preventable diseases is a result of improvements in personal health and hygiene rather than the introduction of vaccines.

### **Information**

Not knowing and information sources are the two factors included under the final theme. Mothers confessed to having a lack of knowledge about and understanding of vaccines. The mothers admitted that, based on their decision to not immunize their children, they subsequently had not conducted a thorough inquiry into immunization. For this group, information was not viewed as important, as one mother confessed: “I don’t really know, because . . . we are flat-out, like, we aren’t immunizing, so I’ve always kind of just pushed it out as fast as they try to give it to me.” Comparably, HCPs viewed mothers’ understanding across a spectrum, varying from limited understanding to very well informed and educated on the topic.

Mothers indicated they used a variety of information sources for their decision-making, including books, journals, anecdotes, and HCPs, with media and the Internet identified as a key source. Family and friends were seen as an important source. HCPs also indicated that the mothers were a close-knit group and hearsay or informal talk was prevalent. Interestingly, mothers felt that they received conflicting or biased information from HCPs.

Overall, HCPs perceived mothers’ sources of information as inaccurate or not evidence-based. However, they acknowledged that it is difficult to locate accurate information given the abundance of information available on the Internet. One chiropractor summarized this view: “It is tough to really sit down and objectively weed through all of it and find the good stuff, so it’s . . . a losing situation right from the get-go.” The HCPs felt that mothers accessed information that resonated with their emotions on the topic, including sensational media stories, rather than scientific sources, but acknowledged that it is difficult to distinguish between evidence and opinion. In addition, professionals realized that they were only one source of information and that mothers obtained advice from a variety of sources, including other HCPs.

## Discussion

This study was limited to a specific geographic area that is home to a number of diverse religious groups. Despite this limitation there are three points worth elaborating on: HCPs and mothers outlined similar factors influencing immunization decision-making, mothers and HCPs understand and define the word “evidence” differently, and the apparent mistrust of HCPs signals a need for greater collaboration among HCPs.

HCPs and mothers outlined a variety of similar, interrelated factors influencing the childhood immunization decision-making process, demonstrating that, overall, HCPs have appropriate insight into non-immunizing mothers’ understanding and decision-making process. However, HCPs placed greater emphasis on religious beliefs as a factor in immunization decision-making, expressing the view that mothers are rejecting immunization for religious reasons, whereas the mothers felt that religiosity was only one factor in their decision. The findings might have been different if mothers had been recruited from a wider range of cultural and religious backgrounds. Downs, de Bruin, and Fischhoff (2008) and Kennedy and Gust (2008) found a similar association between religion and immunization refusal in their studies of parental decision-making around immunization. Additional research may be helpful in exploring the issue among mothers, parents, and HCPs in a larger geographical area with participants from a wider variety of cultural, social, and religious backgrounds.

HCPs indicated that, although the mothers may have appeared to be and considered themselves to be well informed, they were rather misinformed as a result of the unreliable information accessed. The findings suggest that the meaning of *evidence* can be understood very differently by mothers and HCPs. The HCPs acknowledged the difficulty in accessing evidence-based information, particularly on the Internet, as well as the challenges in understanding the material accessed. This finding is consistent with those from previous studies (Betsch, Renkewitz, Betsch, & Ulshofer, 2010; Davies, Chapman, & Leask, 2002; Diekema, 2005; Levi, 2007). HCPs should ensure that their practice offers current, evidence-based knowledge about immunization in order to promote informed decision-making among vaccine-hesitant parents (Macdonald, McIntyre, & Barry, 2014), who need to be educated in the importance of immunization and provided with appropriate resources and information.

Research that explores the effectiveness of current immunization campaigns may be fruitful and may help shape the development of more effective education strategies. It would be beneficial to determine if current immunization delivery methods are conducive to positive health outcomes. Trialing of innovative delivery methods would be advanta-

geous and could provide opportunities for evaluation research. For instance, PHNs could administer vaccines in physician clinics and hospitals, as well as in the traditional public health clinic. This could serve to increase immunization uptake and could also yield opportunities to communicate with vaccine-hesitant families who do not access traditional public health clinics.

The mothers' mistrust of HCPs was apparent. Ropeik and Slovic (2003) also found that trust in HCPs was minimal because of HCPs' concern about public protection. Mills, Jadad, Ross, and Wilson (2005) found high levels of public distrust of HCPs. HCPs in the present study were aware of the lack of trust, acknowledging that this could be the result of misperceptions concerning financial motivation for immunization and the information about vaccines that was provided. Immunization is a public health issue, and HCPs across disciplines need to collaborate to address the issue and promote credibility. Furthermore, increased cooperation between mothers and HCPs is necessary to reduce mistrust of HCPs and the information provided by HCPs regarding immunization.

### **Limitations**

There were several limitations to the study. The mothers represented a homogeneous sample from a limited number of cultural and religious groups. Other HCPs, such as family physicians, who also have a role in childhood immunization were not included in the study. Furthermore, the sample size was small and hence the findings may not be generalizable to other geographic areas or to other groups of mothers and HCPs.

### **Conclusion**

In this grounded theory study, a number of key themes were constructed from the data, demonstrating that both mothers and HCPs were concerned about the health of children, although there were different conclusions about the meaning of health. Given the current attention centred on vaccine-hesitant parents, understanding their alternative perspectives is becoming increasingly important for both HCPs and the public. Greater understanding will lead to greater collaboration, which can serve to promote positive health outcomes in children now and into the future.

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