

At the Crossroads: Communication and Vaccination in Pediatric Care: Why communication matters in respect of patient autonomy in neonatal and pediatric vaccination

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As Rosa laid on the tattered hospital bed, she thought about the beautiful baby that she had just given birth to. It was a long painful night. The morning seemed like forever. By break of dawn, the baby had arrived. The attending midwife had been very patient with Rosa, he stayed with her all through the delivery. He held her hand and squeezed it gently. Sarah, the woman on the other bed, was not so lucky. She had been crying in pain for a while, but no one was beside her. There were a few women on the delivery floor and not enough midwives. Rosa peeked across at Sarah as she was pushing. The baby was almost out, she was saying in a loud tone. The floor would have been Sarah's baby resting place, had the nurse not come into the room. Finally, there were screams, of two babies.

Rosa looked at her baby lying on the cot so peacefully. It made her heart satisfied. She was her first. The male nurse who delivered the baby handed the baby to Rosa once again. The soft touch of her hand and gaze of her smile made Rosa feel elated, doubtful, and happy. No sooner had Rosa begun to enjoy the smooth touch of her skin the nurse requested to take the baby. "I am going to clean her up" was all he said. When the nurse brought the baby back to Rosa's room, Rosa could see the visible mark on her tiny upper left arm. It had a little bump, red and swollen. The same one that had been on her own arm and on the arm of every other baby birthed in Guyana. The baby's eyes were glossy. A visible gel-like substance was on both. Rosa wondered how the nurse could have injected the baby without saying anything, {of course she is mine Rosa thought, she just pushed the baby out of her bulging stomach} without telling her about what they were going to do, or placed whatever it was on her eyes. Was this how it was done, to Rosa's baby, to every other baby? There wasn't any communication, nor information provided about the vac-

cine or treatment the baby had received. There is a policy of routine, mandatory vaccination of infants, but neither Rosa's nurses nor doctors communicated to Rosa about the vaccination prior to injecting the baby. Rosa was infuriated. She felt helpless and voiceless all in one breath. Every other visit to the clinic at two months, six months, eight months pregnant had been the same, no mention of vaccination. Rosa felt that her health care practitioners should have been communicating with patients about vaccination.

Almost 15 years after, as a bioethics graduate, Rosa thought about the disparity between her experience and an ideal, informed process regarding vaccination. She felt disrespected, disregarded and detached. Her experience raises the question: In contexts where infant vaccination is routine and mandatory, what responsibilities do healthcare practitioners have to communicate with the infant's parents?

Health care practitioners have an important responsibility to protect patients and others from harm and provide healthcare that is appropriate while respecting patients' autonomy to make medical decisions. I will argue that health care practitioners must find ways to respect autonomy even where vaccination is mandatory, as in Rosa's case.

Respect for autonomy follows the Kantian principle that we should respect others since people have rights to their choices and actions. Reiss et al. concurred with the view that an individual has the right to make decisions regarding his/her body that are free, intentional and based in accurate knowledge about the relevant procedure. Obtaining informed consent ahead of an intervention of procedure is typically treated as the gold standard for respecting autonomy of patients asked to make medical decisions.¹

In the case of pediatric vaccination, decision-making authority lies with a parent or legal guardian who is expected to act in the best interest of the child, expressing their own autonomous choice as parents while caring for their children. In contexts where vaccines are optional, parents are given a choice about vaccinating their children out of respect for their autonomy. Researchers and medical practitioners all agree that the informed consent process for vaccination should combine efforts to respect parental autonomy, protect the child's welfare, and advance public health.² Where mandatory vaccinations are administered, however, the consent process is nonexistent, because parents are not asked to make a choice. The case highlighted above is typical of the realities of many parents whose child has been vaccinated. This essay argues for the importance of communication in the vaccination process, a necessary good in respecting parents' autonomy, even when vaccines are mandatory. It addresses four factors: satisfaction, control, misconceptions and trust as important dimensions in reinforcing ethical practices and ensuring vaccination success.

For the sake of argument, I assume that mandatory vaccination policies, like the one currently operative in Guyana, are justified. Health care practitioners have a duty to protect individual patients from the harm of preventable disease, and to protect others, too. Healthcare providers also have a duty to respect autonomy by obtaining informed consent, thereby acknowledging the right to consent or to refuse medical interventions. While the right to make medical decisions is fundamental, it is not absolute. Compelling public interests can override this right, as in vaccination.

In Guyana, Public Health (School Children) Immunization Act 1974 delineates that no person should be admitted to school or day-care centre unless that person produces a certification of immunization to the Head Teacher or Principal of that school or the supervisor. Subject to the law, infants are vaccinated from birth and continue to be vaccinated following a schedule for infectious and vaccine preventable diseases which can lead to compromised health (Government of Guyana, 2016). Vaccination cards or certificates signed by a medical practitioner are required as proof of vaccination at the point of entry of all schools (Government of Guyana, 1974; Vanderslott & Marks, 2021). Alternatively, regular school vaccination campaigns are scheduled which takes the process into the schools and away from the Health Centres and hospitals. Students who cannot produce a card or show evidence of vaccination are administered the missing dosage of the vaccines. If unvaccinated children are found in school following a school vaccination campaign, the head teacher or principal of the school who enforces the provision is liable on summary conviction to a fine of \$19,500 Guyana dollars (\$94USD) as a penalty for failure to ensure compliance (Public Health (School Children) Immunization Act 1974). This is a significant penalty in a country where monthly salaries for staff nurses and midwives is \$195,000 Guyana dollars

the equivalent of USD \$928 (2023 salary adjustment).

As the legal custodian of a child, parents normally make decisions for the child after having received vital information. Their decision reflects their role in ensuring the interest of the child is considered, and their authority as parents or legal guardians to raise their child as they wish. Parents speak for their children because infants are incapable of speaking for themselves adequately, and because they take responsibility for their child's well-being. In a health care setting, this voice is heard and acknowledged in the consent process, in the dialog and transaction between the practitioner and patient. In the case of mandatory vaccination procedures, parental informed consent is no longer the guiding construct for medical decision-making. The public interest first is the priority. Research studies show that parents worldwide generally support mandatory vaccination policies.³ Notwithstanding the limited voice parents have in mandatory vaccination; they often derive a feeling, a sense of satisfaction from their participation in the process. Even when informed consent is not the most important concern, however, parental autonomy is still important and relevant. Satisfaction is derived from both respect for parents' autonomy and trust in the medical system. Both are necessary in any effective health care interaction and poor communication about vaccination can result in vaccine hesitancy and dissatisfaction.⁴

Parents should feel satisfied with the process, and practitioners have a moral obligation to ensure that adequate information is provided in the process about vaccination. This reciprocal exchange cements the respectful relationship and trust that each have of the other as it quells the power imbalance already created between professionals and patients in the health care setting. Effective communication allows for the transmission of related, relevant, and meaningful information from patient to practitioner and vice versa. When parents assent to their children to be vaccinated, this effectively protects everyone, as infant vaccination protects the individual as well as the community.⁵ Simply, adequate information and necessary guidance should be freely provided. A patient may ask what is the vaccine being administered or why is it important that I take it or what are the visible side effects? This is important information that should be communicated to a patient. In the case highlighted, the parent could have been told that the newborn was going to be administered a vaccine and the side effect, a mark on the left upper arm, would be the result. Providing information would clearly demonstrate respect and care for the child and the parent. Parents rely on practitioners as the main source of information regarding vaccination. In fact, if even the most basic information were communicated, the provider could have resolved the tension and lessened the perception of absolute control by the medical team over Rosa's daughter.

The policy in Guyana regarding pediatric vaccination information dictates that gestational mothers' physicians inform parents about the vaccines expected to be administered

to the infant after birth. This information is to be shared during their prenatal clinic visits. This policy makes conversations about newborn vaccination different than most conversations about upcoming medical decisions or procedures. Generally, the consent process occurs immediately before a procedure is done. This raises the question: Should information about newborn vaccination be provided long before vaccination takes place? Fundamentally, this process in Guyana is seemingly flawed since it takes the dialog between parents and practitioner, when it does occur, away from the process at the time the vaccine is being administered. A possible scenario could unfold when the vaccine is eventually administered that parents forget the information provided because they were preoccupied with the pregnancy and myriad of pregnancy-related issues and delivery. Most medical procedures and practices require that the consent process occur before the procedure is administered. This process should also apply for pediatric and neonatal vaccination.

When a physician provides a patient with information and feedback about the patient's condition, surgery, state of well-being, or vaccination it shows sensitivity to and empathy for the health needs of the patients. In the same way, answering patients' questions, providing feedback, and ensuring that each patient or parent understands the vaccination process demonstrates the practitioner's respect for the patients' dignity and autonomy. It is good ethical practice. It may not change the outcome of the vaccine or the side effects, nor the fact that the vaccine must be administered, but it can change a patient's reaction to it as well as how the patient feels about the process and vaccination. Done right, this two-way dialog can calm the environment and quell fear, misconceptions, or hesitancy parents may have about mandatory vaccination and vaccination in general.

Poor communication by physicians and nurses is a hindrance to vaccination efforts. Communication sets the tone for respectful and successful vaccination campaigns where the practitioner becomes the supportive point of reference. Reiss and Karako-Eyal suggest that providing full, accurate and clear information to parents from an authoritative, trusted source reduces misconceptions and uncertainties and influences parents' positive attitudes towards vaccination.⁶ This is a positive indication of how crucial it is for practitioners to speak with their patients.

Providing information about vaccination would help to strengthen trust in the process and the medical system, which is critical in Guyana as a post-colonial ethnically diverse state.⁷ Trust in institutions, including medicine, that once were used to oppress indigenous people as well as enslaved persons, is low. As a post-colonial state, Guyana has inherited decades of distrust from a system that transported its people to the Caribbean shores and subjected them to webs of cruelty, places of despair and markers of despotic slavery and human waste.⁸ Widespread ill health and chronic malnutrition were characteristic of the plantocracy (a sys-

tem of governance where the population divided into two classes, planters, and owners). Historical studies suggest that medicine represented a wider social and political force and added to a sense of superiority among colonists and helped to fuel the colonial complex. Among its many influences was its ability to broker relationships with non-Europeans, bolster political institutions, give force to administrative decisions, and provide a measure of self-justification for British presence in foreign lands. In Guyana, the health care of the plantation workers was considered important only to the maintenance of a steady supply of labour, although they were not the primary beneficiary of medicine. The physician had overarching authority to administer medicine to enslaved plantation workers on the request of the colonial rulers. The plantation workers were systematically categorized by race, into hierarchies of bodies on which colonial rulers rest. Researchers noted that plantations were about the exercise of power, and medicine directly helped to maintain the institutional stability of plantations and reproduce and strengthen the fabric of the government, the colonial rulers, in the then British Guiana. Medicine was used as a tool of social control imposed from the outside and exercised by individuals through its use to care for their body and hygiene. After independence, planters resisted government interference and resisted attempts to impose health services provided as another form of institutionalization which was viewed as an unwarranted threat to their independence.⁹ The freed people distrusted the intention of the medical services provided.

The culture of distrust and fear of medicine as an institution is still prevalent, also influencing attitudes towards vaccination. Weak enforcement of the rule of law, and political and social tension further eroded the trust in medical care and in particular vaccination processes because it was viewed as government imposition of their agenda. The heightened struggle over political power resulted in Guyana being a multi-racial multiethnic society split down ethnic lines and influence by political leaders who ruled by playing on the fears of the masses to gain support at the polls. No doubt this has led to the inability to trust the motives of a government other than those of one's own race or ethnic group causing a trickling down effect to all sectors including health care.

This history of medical authoritarianism recalls the one-sided relationship of the colonial and early post-independence eras, rather than what ought to be the two-way relationship between doctor and patient that ought to be the norm today. Trust is built when there is a two-way relationship in which both parties are allowed the right to know, understand, and be comfortable with a procedure or process in medical practice. On the other hand, patients are reluctant to ask questions because of the "shut ya mouth" culture (do not speak). If a patient asks too many questions, they tend to be treated with apprehension and appear arrogant. During the colonial era, the planters were not expected to talk back but

followed orders. Those who showed opposition were seen as hostile and rebellious. Ironically, hospitals were used as institutions of solitary confinement where the doctors were the expert attending practitioners.¹⁰ In this context, doctors reinforced the already engrained submissive culture. Given Guyana's history of distrust of the people towards those in authority, trustworthiness and trust-building should be the priority of the medical profession. More effective communication about vaccination could help to improve trustworthiness, promote satisfaction and a feeling of respect and control. Empirical research is needed but the hypothesis seems plausible.

What should and should not be communicated?

To ensure respect is continually interwoven into the medical system, continual training of healthcare practitioners is needed to improve their communication with patients. Further research is needed to assess the content and format of such training, and this is beyond the scope of this paper. This would support Guyana's Medical Council Act (2008) which specifies the need for practitioners to develop effective communication skills to allow them to successfully relate to patients, regardless of the education or socioeconomic level. Guyana's cultural blend of British English and the continuum of local creole are the current languages of use. The practitioner's ability to communicate with the patient, in his/her vernacular and culture, is therefore essential to this process.

Additionally, given the sociocultural context of health care services and vaccination, a one size fits all communication style may not be appropriate. The exchange of information between practitioner and patient should not be perceived as difficult, dismissive, or of inadequate depth and length. Instead, communication that is adaptive, tailored, and to the unique concerns and desires for information of each patient or parent should be the norm. Effective communication has been found to enhance the success of vaccination programs, to foster trust, respect patients' autonomy, and ensure a balanced and reciprocal relationship between

patient and practitioner.

Respect for autonomy in newborn and pediatric vaccination should ensure communication of information that satisfies each parents' unique needs, and builds trust that helps to ensure the success of vaccination programs whether or not these are mandatory.

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