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Medical Trust in Pediatric Care in the United States

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Spring 2020

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Abstract

Trust is a critical aspect of the patient-provider dynamic, but in the U.S., its importance is overlooked in many medical settings, especially among those from low socio-economic groups. As the disparities in American healthcare are being recognized on a larger scale, it is necessary to further uncover why this is the case, and how to begin to remedy this disparity. This study presents an original qualitative data set of perspectives from four current health/mental health practitioners, based on their experiences with their pediatric patients, and how the concept of trust is critical to their service provision. Supported by literature, this research illuminates the influence of corporate medicine on the deterioration of medical trust in the U.S. This can be seen in the case of vaccine hesitancy, especially in the age of access to un-vetted information through the Internet. Further, from firsthand accounts, patterns emerge that suggest an increased feeling of betrayal by the medical industry among those from minority groups in the U.S. – often those who have lower incomes and less familiarity with primary care. These results lead to the conclusion that it is imperative to devote extra attention to these communities, including special care to adapting healthcare to their unique culture and needs. By doing this, providers can begin to build honest, reciprocal, ongoing relationships with their patients and their caregivers. While this alone does not solve the fracture between the medical community and the American citizens, it may be a step in the right direction towards repairing the damage.

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1. - Introduction

Modern medicine has revolutionized our lives: it has changed the way we live, how long we live, and how we are treated when we're sick. It has become a pillar that holds our society together, and it saves the lives of millions of people each year in the U.S. alone, while improving the quality of life world over. It is undeniable that quality healthcare has changed the world, but to many it remains inaccessible. In the U.S., specifically, there is a multitude of reasons why this is the case, ranging from lack of transportation, lack of insurance, immigration status, lack of available doctors, insufficient funding, and institutional discrimination, for examples. Further, the factors that prevent individuals from accessing care do not impact all demographics equally. Quality healthcare in the U.S. is often perceived as care reserved for those with money, which, in America, tends to be the white majority. This perception, founded in reality, often causes those in minority groups and those with low incomes to be very wary of the healthcare system, as it has historically not worked in their favor. As a result, the trust between providers and many of their patients is low, especially among caregivers of young patients.

Significant research has focused on the importance of trust in the patient-provider relationship, and why an individual's health depends on their trust in their healthcare provider. Many disenfranchised groups in the U.S. have valid reasons for the distrust they have in the healthcare sector, and as medical professionals who are working in the best interest of their patients' health, they have the responsibility to gain it back. This is an important public and global health issue, as the best-trained medical professionals and first-rate medical equipment do not address the medical needs of a patient if they aren't convinced that their doctor truly cares about them, or worse, if they don't even walk into the office. As the New York Times outlined in a recent article:

“Trust is the cornerstone of the doctor-patient relationship, and patients who trust their doctors are more likely to follow treatment plans. One study found that nearly two-thirds of patients with high levels of trust always take their medications, but only

14 percent of those with low levels of trust do. Another study found that trust is one of the best predictors of whether patients follow a doctor's advice... Trust is also critical for patient satisfaction, and makes it more likely that patients keep seeing the same doctor — which can have other positive effects, like fewer emergency department visits. There are large disparities in trust along socioeconomic and racial lines (often for good reason), and building trust among vulnerable and marginalized patients may be particularly important” (1).

In fact, trust in the U.S. medical industry ranked 24th in a recent study comparing 29 nations, in part due to a perceived lack of accountability of providers to their patients (2). Other studies suggest that only about 34% of Americans trust their medical leaders, and only about 25% trust the health system overall (1). This is the American reality for a myriad of reasons, and while building trust will not make these confounding factors go away, it may help to begin this healing, in tandem with policy change.

This research aims to investigate this issue of trust in medical providers in the U.S., and how its presence, or lack thereof, impacts the patient-provider relationship, specifically in the field of pediatrics. While research has been conducted previously among chronically ill patients, pediatric care provides a different lens as it is often the parents who are trying to make decisions in the best interest of their children. This situation involves a patient who is not autonomous, and parents are often more protective of their child than they are of themselves. This research investigates the perspective of the provider – how they respond when confronted with patients and parents with whom there is no existing trustful relationship, and among which groups of Americans they encounter this most often. Lastly, this research provides starting recommendations of how to begin building back this trust, in an attempt to provide more equitable care to the American population.

This study involved four interviews with pediatric healthcare professionals regarding their experiences practicing medicine in various communities across the United States. One expert informant was a pediatric nurse practitioner; one was a primary care pediatrician; and two were child psychiatrists (one is a national and international lecturer and the other directs a

national group promoting child healthcare). Their responses are analyzed against the backdrop of existing literature regarding medical trust in the U.S.

2. - Research Methodology

The research for this project was qualitative, and is a comparative analysis from responses about Americans with higher socioeconomic status compared to Americans with lower socioeconomic status. The socioeconomic indicators used in this research were income level and racial/ethnic identity. Data for this project were collected through formal, semi-structured, virtual interviews with medical professionals spanning both departments of specialty as well as geographic location within the U.S. Potential expert informants were selected based on their professional experience working with a range of patients from varying socioeconomic statuses. They were also chosen to complement each other, with the intention to hear from multiple specialists within pediatric medicine who might engage in different types of patient-provider relationships. Expert informants were contacted via email and were referred by personal and professional contacts. Academic literature was sourced from various online journals and academic databases (JSTOR, Google Scholar, PubMed-NCBI, etc.). This literature was used as a backdrop against which the interviews were conducted and analyzed.

This approach to data collection was used to solicit the experiences of healthcare providers working in a diversity of contexts in an attempt to represent the interactions in various sectors of healthcare in the U.S., and among different populations. All expert informants work/have worked in the healthcare sector and therefore spoke about their own experiences as providers in the many contexts and among the many populations with whom they've engaged. The literature was gathered to establish the importance of medical trust in these contexts and to assess what research has already been conducted on this subject in the U.S.

In order to maintain patient-provider confidentiality, no questions were asked about specific interactions the expert informants have had with their patients, but rather, trends they have seen throughout their careers as they've interacted with people from different backgrounds. As those being interviewed are speaking generally about experiences in which they have been the authority figure in a professional capacity, there are no serious ethical considerations due to a low likelihood that these interviews took an emotional toll on their well-being or that it jeopardized their reputation in any way. However, it is possible that some of the expert informants may have been reminded of an emotional or difficult experience they had with a patient while participating in the interview.

A limitation to this study is that the sample size was smaller than an ideal scenario due to the fact that not many health providers had the time to be interviewed as this research was conducted during a global pandemic, and practitioners were focused on providing care for their patients. Further, a potential bias of using this sample group is that by interviewing only individuals on the professional side of the patient-provider dynamic, it is possible that the data is one-sided in that it only contains perspectives from one half of the patient-provider relationship. If this project had lent itself to a public survey, it would be beneficial to developing a holistic picture of medical trust in the U.S. to hear from more professionals, as well as directly from patients. This project is focused on the experience of the providers, rather than how they affect the patients. However, if this research were to continue, this would be the next step in developing it further.

Table 1: Expert Informants & Qualifications

| Expert Informants | Qualifications |
|--------------------------|---|
| Elizabeth Pruett | CPNP at School Based Health Alliance, Portland, OR |
| Dr. Kyle Pruett | Clinical Professor of Child Psychiatry at Yale School of Medicine Practicing Child Psychiatrist Pioneering Researcher on Fathers and Children |

| | |
|--------------------|--|
| | Award-Winning Author, International Lecturer |
| Anonymous | Pediatric Primary Care Physician in Philadelphia, PA |
| Dr. Joshua Sparrow | Executive Director of the Brazelton Touchpoints Center, Boston Children’s Hospital Associate Professor of Psychiatry at Harvard Medical School |

Table 1 Legend: Credentials were taken from the professional websites of the experts. Please note that Elizabeth Pruett and Dr. Kyle Pruett are related, however, they practice on opposite coasts of the U.S. and specialize in very different sectors of healthcare. However, this may result in similar mindsets regarding the larger subject of healthcare, and this must be acknowledged as a limitation of this study.

3. - Literature Review

There is already significant research documenting the importance of trust in the patient-provider relationship, as well as the medical field more generally, with respect to health outcomes and satisfaction with treatment. Trust in this field is vital to patient care because there is an “implicit imbalance of power due to a high level of information asymmetry” and as a result the patients are put in a “vulnerable position” when they trust a medical professional (3). Medicine is a field uniquely focused on prioritizing the well-being of the client, and this extends further than just the well-being most often associated with healthcare. By ensuring that patients feel secure in their relationship to their provider, and that they trust that the provider truly has their best interests in mind, they are more likely to leave their visit feeling satisfied, and therefore, in a healthier state. There is even evidence to suggest that increased trust in one’s doctor improves outcomes for the condition being treated, as it often is associated with continuity on the part of both the provider and the patient (4, 5). Further, studies suggest that increased trust in medical professionals not only improves patient outcomes but also decreases healthcare costs (6). Many U.S. residents, especially those who are un- or under-insured (often in combination with other low socioeconomic indicators), perceive hospital providers to be more trustworthy (and more knowledgeable) than providers in ambulatory care; it is also more affordable for those without sufficient insurance (6). For this reason, many seek emergency

care for all health needs, which is costly to the healthcare system, and uses resources best reserved for true emergencies.

The relative ease and efficiency with which one can be treated through emergency services compared to challenges often faced in ambulatory care, especially regarding specialists, acts as a deterrent from the latter. As a result, many patients do not trust that ambulatory care can provide them with affordable, quality, and timely services (6). In the U.S., this trend may potentially be correlated to the lack of universal health insurance, which may act as a barrier to non-emergency care. However, this same pattern is seen in countries with universal coverage, suggesting that those coming from low socioeconomic backgrounds in general feel that their healthcare providers are not effectively caring for their needs (5). Therefore, in order to relieve this unnecessary burden on the resources of emergency care, evidence recommends that ambulatory care increase their perceived ability to provide quality care for their patients, rather than increasing hospital capacity (6).

While some studies have begun to investigate which groups have reported mistrust and dissatisfaction with primary care, there are still large gaps in the research, and very little has been done to investigate this phenomenon in pediatric care. Preliminary studies show that African Americans are one demographic that experiences high levels of distrust, arguing that “socioeconomic status is not just a confounder of racial differences in health but part of the causal pathway by which race affects health” (7). Additional research indicates that “physicians tend to perceive African Americans and members of low- and middle-socioeconomic groups more negatively than they do Whites and upper-[socioeconomic status] patients” (7). People with low income in the U.S. are more likely to be a member of a minority race/ethnic group, and are more likely to “be Medicaid recipients or uninsured, have poor-quality healthcare, and seek healthcare less often” (7). As a result, many individuals among these groups have valid reasons to mistrust their health system.

Another facet that has been studied around the globe is the perception of healthcare as being commodified, and the effects that this has on public trust. There is concern that as a result of consumerism, the physician-patient relationship is turning into a provider-consumer relationship based on “self-interest” and a “market ethic” compared to a “professional ethic” (8). This is corroborated by studies showing that those with “high medical cost burdens” were more likely to view their interactions with medical professionals as “financial transactions,” and were therefore less likely to trust their providers (8). In an international assessment of healthcare commodification globally, the U.S. ranked number one, thereby suggesting that this issue is likely to seriously impact the perceptions of the American public regarding their healthcare (8). However, even with this mindset of healthcare as transactional, it is important that questioning continue to be a component of the patient-provider dynamic (from both sides), both for the peace-of-mind of the patient, as well as to maintain a critical lens and in many cases, seek out second opinions regarding treatment plans. Asking questions decreases the information imbalance inherent to the patient-provider dynamic that facilitates this transactional experience, and helps build a relationship between these two parties in which both know what to expect from the other (9).

4. - Evolution of Healthcare

When thinking about the dynamics of relationships in healthcare, it is necessary to analyze the current American healthcare industry, and how it came to be. While investigating this, it became clear through interviews with expert informants, Dr. Pruett and Dr. Sparrow, that healthcare in America has changed drastically over the past 50 years – specifically, it has become a corporation (10, 11). They argue that this is a new phenomenon that significantly impacts how care is provided, and consequently, impacts trust in medical settings (10, 11). As a child psychiatrist who has been practicing for many decades, Dr. Pruett stated that medicine has more recently become a “business” that operates “for profit,” and that as a result, “the

stakeholders are the stockholders, not the patients” (10). This is often a significant factor in “eroding the trust of the doctor-patient relationship,” as many patients feel that the doctor has obligations outside of just providing quality, affordable care, and doctors may feel that they cannot always provide the level of care they would like, due to these necessary monetary motivators (10). Dr. Sparrow adds that “insurers, pharmaceutical industries, and hospital chains have much bigger roles, so that the individual physician is in a position of knowing things, having to say things, and doing things that actually go against their clinical wisdom” (11). This is an important distinction, as it is the physician who becomes the face of this industry, being the one who interacts personally with the patient, yet they are bound by these institutions and therefore not always entirely autonomous. While this was something that was not widely known for many years, it has recently become something about which more individuals are aware. As a result, they can feel betrayed by both the institutions and their physicians, thus casting doubt on a doctor’s ability to provide them with unbiased medical advice. Dr. Sparrow states that many of his medical students struggle with this fact, as they understand that continuing into the medical field requires a certain level of “professional socialization” that leads them towards a “Euro-American transactional, linear monetary” model (11). They struggle with how to “[retain] their humanity” in the face of this socialization, as well as in the face of “burnout” and “compassion fatigue” (11). As a result, in most cases, medical professionals want to be empathetic to their patients, but there may be institutional barriers in the way.

Along with this corporate shift, Dr. Sparrow adds that there has also been a change in the way individuals interact with the healthcare sector, as he argues that there has been a “cultural shift” that affects “what is expected of physicians” (11). A large part of this shift is a result of increased access to resources like the Internet, which allow information to be rapidly democratized. In the past, citizens have relied on their physicians, and often one singular renowned physician, to provide them with medical information. However, the Internet

provides “such easy access to generating and obtaining information that you're not going to have one or a couple of big voices, you're going to have lots and lots of smaller niches” (11). While in general this is beneficial, as it elevates new voices, it can also give a platform to those unqualified to be advising in a medical capacity. Whether or not this is the case in a digital context can be hard to verify, as much of the information that exists on the Internet is “unvetted and un-curated” (11). Previously, individuals sought medical attention because “you want them to tell you what to do” because “the doctor knows more than you do” (11). Now there is a growing mindset of “the individual owning their own health” (11). This model has gone a long way in changing the reputation of the medical field from one that stands on a pedestal to one in which everyone has a right to participate. However, this may be a positive change, as it is important to understand that medical professionals, and medicine in general, is flawed in many ways, and this democratization of health knowledge empowers individuals to take control of their health in unprecedented ways, for better and for worse.

As illustrated above, there is a lot of distrust in today’s American healthcare system, perhaps in part because individuals feel that they have been burned and abused by the system as it exists today. This is a uniquely American problem, as many countries comparable to the U.S. – such as Canada -- have socialized healthcare systems that are not operated for a profit. While there are downsides to every type of system, as a result of this socialization, citizens of countries like Canada, and many European nations as well, do not exhibit the same distrust as a result of feeling betrayed by the system., especially as the concept, and reality, of an uninsured citizen does not exist (10).

5. - Socioeconomic Status

The four expert informants that participated in this research all work in vastly different communities across the U.S. Because of this, this investigation elicited information about patient-provider interactions among differing socioeconomic groups, that supports the data

provided by the literature review. However, it is important to note that even though the expert informants questioned in this research were able to speak to a wide diversity of American communities, there are still many that are left out of this conversation, and it is important to refrain from generalizing the experiences of these medical professionals to the entire medical community. Instead, these accounts are meant to provide a window into a few of the ways that trust plays out in the different communities in which the expert informants practice. This intends to highlight that differences exist, while avoiding generalizations. As such, this is not meant to provide a comprehensive analysis of the experience of any group mentioned, and readers are warned from making any unfounded extrapolations.

5.1 - Higher Income Communities

This analysis will start with a discussion about the experiences of physicians who practice in middle- to high-income communities. Theoretically, the healthcare system is built to function for those with insurance and a style of living/culture closest to what the doctors themselves experience, and therefore these accounts will be used as a baseline. By speaking with practitioners in these communities, the goal was to establish a standard by which to compare the practice and experiences of practitioners in lower income communities. However, it is important to acknowledge that no community is perfect, and therefore there may be limits to this approach. This population of people, typically being able to afford healthcare services, and likely having access to quality care, often do not enter a doctor's office feeling defensive due to previous healthcare trauma. However, what many of the expert informants mentioned, is that this group of individuals is more likely to feel that as educated individuals – often with connections to other doctors or medical institutions – they are more empowered to ask questions and come to an appointment having done their own research already (10, 12, 13). While they may not be notably distrustful of their providers, they do feel that they have a high level of autonomy over their own care. Further, those with exceptionally good networks often look for shortcuts or fast-tracks regarding their medical care, relying on the previously

established idea of healthcare as transactional (10). This presents a unique trust dynamic, which often falls somewhere between what existing literature names as “Consumerism,” where a patient has very little trust for their provider but a high level of trust in themselves, and “Team Playing,” where there is a high trust in both the provider’s competences as well as one’s own (14).

“Consumerism” fosters the idea that the patient must take responsibility for their own care, and they can often be “manipulative and noncompliant” in their interactions with providers to get what they want, often without the provider noticing (14). However, “Team Playing” is the ideal relationship type, which requires cooperation and mutual understanding and respect on both sides, and all parties are viewed as “equal partners,” with decisions being “collaborative and negotiated” (14). The difference between these two categories is how much trust the patient has in their doctor – if a patient enters the office as a consumer, it is the responsibility of the doctor to work with the patient to turn them into a team player, in which their need to participate in their own health is respected and is understood as a shared partnership, rather than an imbalance of power. This can be accomplished in a few ways – some effective methods utilized by the expert informants include proving their knowledge and care by doing their job well and following up with patients, and paying extra attention to avoiding mistakes (12). In the experience of one expert informant, this demographic tends to respond well to the doctor proving their worth through their medical expertise (12). Another approach is to listen to the patient’s concerns, and what they believe the resolution may be, and start an ongoing conversation where the patient understands that their contribution is valid, and so is the doctor’s (10, 12, 13). This method finds success in all populations and is an important tool when beginning a relationship with any patient (10, 12, 13).

5.2 - Lower Income Communities

In lower-income communities, particularly those without health insurance, many patients are quite wary of the medical system and its ability to help them (10, 13). Further, it is

important to acknowledge that in the experiences of this study's expert informants, those of ethnic and racial minority groups tend to fall into this category more often than white Americans. This indicates that minorities in the U.S. may be disproportionately excluded from access to a healthy relationship with their medical providers, and therefore, a trustworthy place to access care safely (10, 13). Dr. Kyle Pruett speaks about how individuals who are uninsured are "basically terrified" upon entering his office, as they know it is a possibility that they will not be able to afford the visit or the treatment prescribed – a particularly devastating situation when a parent is worried about the well-being of their child (10). As a result, many opt instead for the emergency room to avoid private practice rates or follow-up appointments (10). Dr. Pruett argues that many people view the medical system as a big institution, and thus associate it with other big institutions, like those run by the government, due to mandated reporting laws (10). For undocumented immigrants or those concerned about keeping custody of their children, this (very real) association may be a significant deterrent from seeking care. However, this prevents these families from forming a meaningful relationship with a medical provider, therefore being less likely to receive tailored, comprehensive care, and potentially causing a more serious (and expensive) medical concern down the road.

Especially for those with ongoing medical needs, studies have shown that "routine checkups are a primary teaching vehicle for helping patients to understand and manage their chronic illnesses," as "they facilitate the building of rapport between patient and practitioner," which in turn, builds trust that a medical professional genuinely cares about their challenges and is able to help (7). When this happens less frequently, and patients only seek care in emergencies, the opportunities for trust building are few and far between. This frustration often leads to individuals in this situation viewing themselves as "receiving second-rate healthcare, and this leads them to be more suspicious of practitioners' skills and intentions," as they expect that they will not see this doctor again once they leave the office (7). Other studies show that "being in a lower income bracket and belonging to ethnic minority" are both factors

that are associated with decreased trust in the healthcare system (3). Further, while subjects were grateful to have access to care, they felt that their treatment based on their socioeconomic status caused them to feel that their concerns were not being taken seriously or given the respect they deserved (5).

This then categorizes this relationship between the provider and the patient somewhere between the aforementioned “Consumerism,” and “Resignation” where one neither trusts their own abilities nor the abilities of their provider to manage their illness (14). The latter relationship type is often seen in cases where patients withdraw from care, having resigned themselves to the idea that there is no way to make a positive difference in their situation (14). Ideally, the desired relationship is “Team Playing,” where both parties are partners in the discussion of the patient’s health (14). Therefore, it is important not to underestimate the power of consistency and personal relationships in the healthcare sector, as patients who feel that their provider knows and respects them are more receptive to care and are often more open about their health (14). In previous research, respondents reported that because of their infrequent visits, often with a new provider each time, they were not able to form a relationship with their doctors (7). As a result, it is all the more important that this be acknowledged, and the barriers to consistent, quality care for all be torn down in the name of equal treatment, the well-being of patients, and the relationships between patients of lower income and their providers. Through this, it may be possible to achieve this ideal relationship type, which requires cooperation, mutual understanding, and respect on both sides, where all parties are viewed as “equal partners” and decisions were “collaborative and negotiated” (14). This two-way relationship is both “affirming and validating” on both sides, and fosters the kind of trust that is ideal in a patient-provider dynamic - however, both sides must step to the plate in order to realize it (14).

6. - Patient-Provider Dynamics

There is also evidence to suggest that in untrusting patient-provider relationships, doctors are more likely to prescribe medication in response to patient concerns in an attempt to convince the patient that they are taking their situation seriously (9). As a result of this, some argue that patients are being prescribed medicine at rates that are too high for minor conditions, which not only raises healthcare costs but also increases levels of potentially unnecessary medication in the population (9). Those of this mindset hypothesize that if providers feel secure in their relationships with their patients, and believe that their patients will trust and accept their recommendations, they are more likely to delay prescribing medicine and procedures in situations where they truly believe the patient will recover on their own (9). As mentioned earlier, a large component of this relationship is that if a doctor does not prescribe medication or a procedure, that they will follow up with “active surveillance” in order to monitor the patient’s condition in case it deteriorates (9). However, this relies on the assumption that a consistent doctor is present in the patient’s healthcare and that both the provider and the patient have the resources to maintain contact – something that is often not the case for those without sufficient medical insurance, or for whom the emergency room or urgent care is their sole interaction with the healthcare system.

Another issue, mentioned by all of the expert informants, was the challenge of understanding the nuances of the experiences of individuals from communities different from their own (10-13). Respondents from previous research also noted that a shared racial/ethnic identity with their patient seems to increase patient trust (10, 12). Although expert informants voiced their dedication to working with their patients to try to bridge this gap, one noted that their “biggest challenge is making those connections the same way” as they would with a patient from their own community (12). Dr. Pruett responded that he “realize[d] it's a part of our discussion,” and asks what the patient believes he will miss about their situation, having not come from the same environment (10). By doing this, he acknowledges that there may be gaps in his understanding about the complexities of their health and validates their concerns.

He then opens a dialogue about these issues, and encourages a two-way dynamic where the patient is encouraged to speak up if he is missing something (10). He is giving the patient permission to correct him and promoting a two-way dialogue about an individual's health, and the many factors that might impact it (10). His philosophy is that "there's no right answer, but... there is a right conversation" (10). This mirrors the characteristics many patient respondents from previous research have described as being beneficial in creating the "Team Playing" relationship – "curious listener, compassionate stranger, nonjudgmental collaborator, and mirror for family strengths" (14). Of the expert informants questioned for this study, two explicitly stated that when a patient comes to their office already wary of their ability to help, it is often a result of a previous encounter in which they felt they were not being listened to and "their concerns were not being addressed" (12). Therefore, expert informants suggest that one successful method is to show the patient that they truly are listening and honoring their concerns as valid and important, and are honest with them about what their own thoughts are as well – especially as it is often difficult to acknowledge one's own implicit biases (10, 12).

Dr. Joshua Sparrow argues another angle to this point, specifically from his experience working with Native American communities. Dr. Sparrow posits that "part of trust is being really aware of the limits of what we know and where our assumptions and biases are, and being really humble about our ignorance" (11). Like those mentioned above, he emphasizes the importance of recognizing one's own limitations in truly understanding the context of people's lives, but he then goes further by saying it's not enough to just "pay lip service" to this concept:

"[one must] embody or enact the awareness of one's own ignorance... not knowing what one doesn't even know, knowing that one will make mistakes, and some of them may end up being hurtful and people may never tell you... It's not so much about talking the talk, it's about walking the walk. I also think among people who identify themselves as white, who desperately want to be trusted as quote-unquote white allies, I think they often are asking for other people to actually take care of their need to have their guilt absolved or that they don't have to carry that load. And I think all that stuff gets in the way, because I think people who identify as white, when they bring those kinds of things to relationships, it's hard to really be there

together or get to know each other. Because there's this agenda of 'please tell me that I'm actually the white person who's okay.' But no, please that's your problem, you need to take care of that on your own time." (11).

Through this statement, Dr. Sparrow asks medical professionals, and others working in cultural contexts different from their own, to critically look at their own behavior and think about the burden that is put on the patient when they are asked to explain themselves. He argues that it is not the responsibility of the patient to teach the provider how to take care of them respectfully and consciously, and even if the intentions of the provider are in the right place, it can still cause undue trauma to the patient to have this burden placed on them (11). It is also important to recognize, especially in Native American communities, that conceptions of medicine and health may be different from the Western standard. In working with communities that have built cultures without Western medicine due to past lack of necessity or inaccessibility, implementing health interventions is an endeavor which requires significant conversation with those in the community about what they need, how they need it, how outsiders can help, and what their role will be (11). As Dr. Sparrow attests to from his years of experience working in this capacity, Western health interventions rarely resemble their starting form after they have been adapted to the needs of any given community (11). However, it is imperative that the specifications of this adaptation come from the community itself, and not from an observer deciding what is needed (11). To corroborate this, all expert informants noted that an ongoing, honest dialogue explaining the thoughts and concerns of both parties is the most important tool for building trust (10-13).

7. - Vaccination

An interesting facet of medical trust plays out in the context of pediatric vaccination. This medical procedure is separated out from the larger topic because of the disconnect that many providers perceive between vaccination and other types of Western medical interventions. One expert informant, who preferred to remain anonymous, stated that even if a parent trusted them

with everything else, “it seems that there's a guttural feeling about injecting something, and what that could mean, and wherever the thought process goes of what happens when you inject something into a child” (12). Elizabeth Pruett, CPNP, corroborated this, adding that in her practice, parents tend to be “vaccine hesitant as a feature of their anti-government, anti-establishment position, and tend to not present for much in the way of what is normally considered invasive medical treatment, in general” (13). Many associate vaccines with “Big Pharma,” another arm of the for-profit medical sector, and are concerned over its lack of accountability (15). It seems that vaccines tend to be the exception to otherwise strong relationships between the provider and the patient, which begs the question about whether this is a reflection on the efforts of the provider, or whether vaccination deserves its own separate consideration based on its nature. It is also important to note here the importance that the Internet has played in causing this hesitancy in vaccination. As mentioned in previous sections, the rise of the Internet has provided a platform for unverified information to present as fact. While there may be sound reasons to be wary about vaccination, the addition of misleading or fabricated data being published by those without medical or scientific education can be a dangerous propagator of information. This is particularly relevant as people are encouraged to do their own research when it comes to their health and the health of their children.

The reasons that a family is vaccine hesitant may be partially independent of their relationship to their healthcare provider. The way that this topic is approached by both sides can have significant repercussions on the future of their relationship regarding all medical concerns. This vaccine hesitancy has been observed to be particularly relevant regarding the HPV vaccine, as many associate it with teenage sexual activity (12, 13). Another vaccine that raises significant discussion is the flu vaccine, as many parents find difficulty associating it with positive outcomes (12). Of the two expert informants interviewed who administer vaccines, both said that when faced with a family who is vaccine hesitant, they will work with the family to the extent that they believe is reasonable within their role, although the two had

different ways of going about this. The CPNP informant takes the more scientific approach, providing families with materials to educate them on the science behind vaccination, while the primary care physician uses logic and a “sense of reason,” recounting situations where vaccines have changed our society in the past (12, 13). However, the primary care provider said that if their attempts at convincing the family to follow some level of a vaccination schedule failed, they would suggest they find a new provider, while the CPNP said that they would continue seeing the family (12, 13). Both of these reactions have positive and negative consequences for this family’s relationship to their provider (or perhaps a new provider if they are recommended to leave the practice). In the case of the provider who follows a stricter vaccination policy, the family that is asked to leave may develop a distrust for medical professionals in general, even when they move onto a new practice. However, this provider used the tool of logic in their attempt to convince the family to vaccinate, and so when they are subsequently asked to leave, they may understand the weight of their decision, as their access to other medical treatment is more contingent on vaccination than they originally believed. Thinking about the provider who allowed a more flexible vaccination regimen, encouraging families to stay in the practice who aren’t vaccinated may improve the patient-provider relationship and allow a safe place for them to continue to receive care, but may reinforce their own beliefs that vaccination is an optional public health measure, which paves the way for others to follow suit. This is a tricky balance, and there is no clear solution. Following Dr. Sparrow’s recommendation, it is likely that each response should be tailored to the culture and beliefs of the community in which they exist, with no clear one-size-fits-all method (11).

8. - Conclusion

These firsthand accounts of medical providers working with varying communities across the U.S., combined with existing literature focusing on medical trust, illuminate a few key takeaways from this investigation. First, one cannot understand the complex way that patients

and providers interact without looking at the healthcare institution itself, and the ways it has changed over the past half century. The for-profit medical industry is a uniquely American construction in many ways, and it is a vital part of the discussion of who gets quality care, and who gets left behind by this system. This is the basis for much of the distrust in American medicine today. Therefore in order to begin to rebuild that trust, we must understand how it was broken and acknowledge the trauma that this industry has caused to so many Americans, especially those without adequate economic and social resources. We also must acknowledge the ways that the medical industry restricts the provider's ability to freely provide care for their patients, as many have undisclosed conflicts of interest. This is something that patients notice, and further contributes to the breakdown of trust. Therefore, honesty from both parties is a necessary component of the foundation of patient-provider relationships.

Compounding the corporate shift in the medical industry is the monolithic way that it operates; Western medicine preaches a gold standard of care that will resolve health issues for all. Even if one is introducing a method of care that truly will improve people's lives, it cannot be implemented without consideration of the local community. There is no universal, scalable model for care, and all expert informants for this research corroborated that patients are much more willing to form a trusting relationship with them when they are adaptable, flexible, and open to suggestions that are brought to the table by the patient themselves. In this vein, Dr. Sparrow argues for "deep adaptation" of medical interventions, where the two parties form a truly collaborative and long-lasting partnership towards their common goal of improved health, rather than just surface level consideration (11). To this end, he suggests that this often involves a shift from "reducing people to their diagnosis" to instead thinking about "the whole person and the strengths that they have to heal, including their culture as well as their families and communities" (11).

From this, we begin to understand the importance of the patient-provider relationship being a "two-way street" (13). In all forms of medicine, and especially in pediatrics, it is

important for the patient and their caregiver(s) “to feel comfortable asking questions” and to feel that they can be “honest” with their provider, with the expectation that the provider will ask questions, be honest, and be transparent in return (13). However, a key factor in being able to form this type of relationship is being able to have “the luxury of time” – it often takes multiple conversations over an extended period of time in order to cultivate this dynamic (13). This not only assures the patient that their provider truly cares about their well-being, it also allows the provider to get to know the patient, potentially reducing the premature dismissal that many patients feel occurs, especially as members of minority groups (16). This underscores the importance of having a consistent primary care provider who knows the patient personally, can follow their health, and act as a trusted portal to the medical world. While many in the U.S. remain un- or under-insured, having a primary care provider is a privilege that remains out of reach, but studies show that this is truly the best way to build these relationships (4-6). As a result, if the medical field aims to increase its trustworthiness, a major step would be to break down the barriers that prevent many Americans from accessing an affordable, consistent, primary care provider. There are many organizations already working on this, including the school-based health center where expert informant Elizabeth Pruet works. She reports that families are “really grateful when an organization like mine exists to be able to provide a safety net for them where none has existed before, and they can't believe that it's really real” (13). This stands as just one example of how accessible, adaptable care can make a difference in people's lives, while at the same time showing how seriously the current system has failed many Americans.

Recently, academia and the medical field have begun to realize the importance of trust: it has become a new buzzword and many providers do prioritize (re)building it (10, 12, 13). However, in adapting the medical industry to focus more on building trusting relationships, it is absolutely crucial to recognize the need for meaningful cultural adaptation. In tandem with this, we must also recognize the need to shift corporate medicine away from systemically

pushing away those who could benefit most from a trusting, long-term relationship with a medical provider. Looking to pediatrics, it is important to include this field of medicine in the conversation, as it relies on many of the same trust indicators as adult medicine – after all, those making decisions for the children are most often adults who participate in the medical system themselves. This is compounded by the fact that pediatric medicine often involves frequent semi-invasive treatments such as vaccination, and therefore it is all the more important to recognize the importance of trust in these settings.

Trust is a “fraught” and “problematic” concept in many ways, and has different meanings depending on the context and individuals involved (11). It must be earned by all parties in every interaction, and it is not something to take for granted. It may even involve breaking down some of the learned roles of “patient” and “doctor” and instead focusing on shared “humanity” (11). It is especially important to prioritize this in the case of pediatrics, as it is equally important to form a trusting relationship with the child as well as the parents – if one does not have the trust of the parents, “then there is not an ethical way to proceed” (10). The concern of this research is just a small aspect of the complex dynamic between the healthcare industry and American citizens, and it definitely does not show the whole picture. However, this investigation does uncover some important aspects of this issue of medical trust that must be recognized before the healthcare sector can move forward in improving the quality of care for all Americans.

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