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Paradoxes of professional autonomy: a qualitative study of U.S. neonatologists from 1978-2017

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Abstract

The professional autonomy of physicians often requires they take responsibility for life and death decisions, but they must also find ways to avoid bearing the full weight of such decisions. We conducted in-person, semi-structured interviews with neonatologists (n=20) in four waves between 1978 and 2017 in a single Midwestern U.S. city. Using open coding analysis, we found over time that neonatologists described changes in their sense of professional autonomy and responsibility for decisions with life and death consequences. Through the early 1990s, as

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neonatology consolidated as a profession, physicians simultaneously enjoyed high levels of professional discretion and responsibility and were often constrained by bioethics and the law. By 2010s, high involvement of parents and collaboration with multiple subspecialties diffused the burden felt by individual practitioners, but neonatology's professional autonomy was correlatively diminished. Decision-making in the NICU over four decades reveal a complex relationship between the professional autonomy of neonatologist and the burden they bear, with some instances of ceding autonomy as a protective measure and other situations of unwelcomed erosion of professional autonomy that neonatologists see as complicating provision of care.

Keywords: Professionalism; Neonatology; Professional autonomy

Introduction

Like other physicians, neonatologists must negotiate multiple and often conflicting pressures on their provision of care. Among them, constantly expanding technical capacity, forces ongoing reconsideration of what can or should be done in neonatal medical practice. In addition, because neonatologists' patients are always silent about their wishes, providers must give heed to preferences voiced by other interested parties. Chief among these are their patients' primary caregivers, usually parents. Hospital administrators influence provider choices, especially related to matters of finance and public relations. In addition, neonatologists must navigate difficult questions related to law and ethics. Matters of law and ethics can be particularly challenging in the U.S., where any question related to reproduction can quickly become a social controversy far beyond a single practitioner's control. If providers are not able to align their actions with their own sense of right behavior, they may experience moral distress (Daar, 1995). Yet there is an important tension here. We want providers to live with a sense of personal integrity, but we do not want providers to act solely on personal definitions of appropriateness (Mathews and Pronovost, 2008).

To understand neonatologists' decision-making discretion, we must consider the autonomy granted to them as individuals within their profession in theory and in practice (Dingwall, 2006). Bioethicists most often use the term 'autonomy' to refer to the normative principle that patients have the right to make decisions concerning their care. By contrast, medical sociologists have used the concept to refer to *professionals'* control over their work.

Sociologist Eliot Freidson, as part of a broader story of a profession's development (Larson, 1977), argued that the professionals themselves "claim the exclusive right to determine who can legitimately do its work and how the work should be done (p.72)" (Freidson, 1970). To make such a claim, the profession must defend three things. The first is that individual members of the profession possess knowledge and skill needed to do work that non-professionals lack. The second is that professionals can be trusted to work without supervision. The third is that when members of the profession behave unethically or are incompetent, the profession itself can be trusted to address the situation. For several decades, medical doctors were the profession that most convincingly achieved control of work as described by Freidson. Yet in recent decades, physicians' decisions have been subjected to increasing intrusion by external forces. Many contend that at this time, autonomy succumbed to the forces of de-professionalization, corporatization and proletarianization (Haug and Lavin, 1983, McKinlay and Marceau, 2002, McKinlay and Stoeckle, 1988)

The formal history of the profession – its law, organization, and technology – must be linked to the actions taken by individual professionals in their work settings (Bosk, 2003, Bosk, 2008, Heimer, 1999). A framework for doing this was outlined by Bucher and Strauss who rejected the idea that professions are uniform and monolithic. Rather, they are "loose amalgamations of segments pursuing different objectives in different manners and...held together under a common name at a particular period," (Bucher and Strauss, 1961). Segments, including specialties and subspecialties, form initially around shared views of work: its goals, activities, technologies, and identities. To study them, Bucher and Strauss provide a *process* model in which segments, like social movements, appear, make claims of unique expertise and, when successful, attain official recognition as a specialty or subspecialty.

The Bucher and Strauss approach achieved limited uptake in empirical research, probably because of the necessity of longitudinal data. The primary users have been historical sociologists studying macro historical developments for which there is public record (Freidson, 1970, Halpern, 1988). The data we will report here permits consideration of individual experiences as they shape actions and consequent change including changes in work and identity and relationships with other groupings and stakeholders (Abbott, 1988, Light, 2004, Timmermans and Oh, 2010).

Historical Context

When Louis Gluck opened the first Neonatal Intensive Care Unit (NICU) in 1960 at Yale-New Haven Hospital, the neonatal mortality rate was 19/1000 live births (United Nations Interagency Group for Child Mortality Estimation, 2018). Public attention to the plight of imperiled newborns in the United States increased in 1963 after the death of President John F. Kennedy's infant son, born at about 37 weeks, 39 hours after his birth (Lussky et al., 2005, Placencia and McCullough, 2011). Yet the increase in resources devoted to neonatal care over the following decade, including the expansion of NICUs, was accompanied by concern for insufficient expertise to properly care for such unique, complex patients. Informal conferences of neonatologists, not directly connected to a professional association, began in the 1960s, the first of which appears to be a 1968 gathering hosted by Jerold Lucey (Lantos and Meadow, 2008), longtime editor of *Pediatrics* (Belluck, 2017). In 1974, the American Board of Pediatrics established a subspecialty board in neonatology (American Board of Pediatrics, 2018). Also in 1974, four major organizations of medical doctors along with the National Foundation for Infantile Paralysis (now the March of Dimes,) proposed regionalization of perinatal health services as the best way to optimize scarce resources and to assure quality (Ryan, 1975, National Institutes of Health, 1992).

Nonetheless, expansion continued. By the early 1980s, 351 hospitals, or about 5% of all U.S. hospitals, had NICUs. By 1995, the number with NICUs had nearly doubled again to 698 (Howell et al., 2002) and mortality rates for neonates had leveled off at about 4/1000 live births (United Nations Interagency Group for Child Mortality Estimation, 2018). During this same time period, the 50% survival rate of newborns fell from 26 weeks to 24 weeks (Philip, 1995). By the late 2000s, the survival of an infant born at 29 weeks was not remarkable (Mercurio, 2008) and some born at 22 weeks now survive (Younge et al., 2016). In addition, the physical setups of the NICUs have changed. Until recently NICUs were large wards where physicians and nurses could observe many newborns at once but that afforded little privacy to families. NICUs have now shifted primarily to single rooms.

The history of neonatology is woven tightly with advances in technology and the rise of medical ethics. Incubators were used for decades before the first NICU, but it was not until a randomized trial in 1950s that thermoregulation was shown to be important for survival (Silverman et al., 1958). In the 1960s, the use of intermittent positive pressure respiration, the

application of corticosteroids, and the introduction of apnea monitors increased newborn survival (Lantos and Meadow, 2008). The 1980s saw the introduction of surfactants (Landzelius, 2006), and the past two decades witnessed new tools for genetic screening and the introduction of complex surgical procedures both in utero and immediately after birth. At the same time, although new thresholds for viability meant that newborns who would previously have died could now survive, these changes brought concerns about their long-term quality of life (Landzelius, 2006).

The field of bioethics came of age over the same period of time as neonatology. Modern bioethics, dating to the Nuremberg Code, was originally mostly concerned with medical research. The World Medical Association's Declaration of Helsinki, outlining ethical principles for human subject research, was first published in 1964 (McWhirter, 2012). Ethically questionable studies on hepatitis took place at Willowbrook State School from 1956-70, and the infamous Tuskegee syphilis study became widely known in 1972. During this same period, several high-profile ethical dilemmas arose specific to the field of neonatology, nearly all of which came down to the central question: "whom should we try to save and whom should we let die?" Two infants with Trisomy-21 and duodenal atresia, one born in 1963 and the other in 1971, became the composite "Johns Hopkins Case" (Placencia and McCullough, 2011). Parents requested that the infant not be surgically treated, a decision that would lead to the death of the infant. In 1970 the Joint Commission promulgated the first Patients' Bill of Rights (Schyve, 1996). These principles were adopted by the American Hospital Association in 1972 (Schyve, 1996). In 1974, Congress established a commission led by Walter Mondale and Edward Kennedy to explore issues of medical ethics (Brian and Cook-Deegan, 2017). Major ethical debates continued in the public square through the 1980s. After several cases in 1982 in which parents again opted against life-saving treatment, known as Baby Jane Doe and Baby John Doe, the Reagan Administration issued rules that made it illegal to withhold such care on the basis of Section 504 of the Rehabilitation Act (Mercurio, 2008). In 1980, only 1% of hospitals had ethics committees, but by the end of the decades that figure had risen to 40% and by the end of the 1990s, over 90% had formal ethics consultation (Aulisio, 2016).

Our study attempts to understand how, over the past several decades, neonatologists negotiated the complex pressures associated with life-and-death decisions for their patients. To put it more personally, in a field where providers must often choose between several poor

options, how do neonatologists decide which infants to treat and which to let die? What assists them in their decisions and what constrains them? First, we place these questions within the existing scholarship on the history and sociology of neonatology (Anspach, 1993, Lantos and Meadow, 2008, Guillemin and Holmstrom, 1986, Heimer and Staffen, 1998, Lussky et al., 2005, Mesman, 2008, Placencia and McCullough, 2011). We then explore the changing professional autonomy of neonatologists as it emerges in interviews between 1978 and 2017. Much of the literature on professional autonomy focuses on the organized profession and its autonomy (Greer, 2008) and has been rightly criticized for formalism (Abbott, 1988). Our concern is, rather, the experience of neonatologists within the context of complex technological, organizational, and ethical pressures.

Methods

Our analysis employs qualitative research methods to explore a unique data set of longitudinal interviews with neonatologists conducted between 1978-2017. The first wave of interviews (1978-81) included 204 interviews of physicians in twelve specialties, one of which was neonatology. With an additional round of 288 interviews between 1986-1991, these physician interviews reached a total of 492. These first two rounds of interviews were conducted by a sociologist who then served as an advisor for the third round of interviews. The third set of interviews were organized by a larger team, including sociologists, an historian, a physician, and others in the field of health policy.

The interviewees were affiliated with hospitals in a single Midwestern U.S. metropolitan area with a population of about 1.2 million. In 1978 this region included 25 independent hospitals. Over the years of the study, due to closures and mergers, this number reduced to four hospital systems in 2010. This level of consolidation, and possibly homogenization, is in line with larger national trends.

This analysis examines interviews with neonatologists working in hospital NICUs. They include 1978-81 (n=3); 1989-91 (n=8, including two interviews with physicians interviewed in wave 1); 2016-17 (n=9, including one physician who was interviewed in wave 2).

Our sampling strategy offers no claim to statistical representation of practicing neonatologists, but we did seek ‘representation’ of practice in the sense that the study included doctors from the range of practice settings that existed in the region at the time. We thus

interviewed in each of the NICUs that offered services in the region. In 1978, there was only one NICU with one neonatologist. Fortunately, the sample includes two interviews with neonatologists who identify as ‘first generation neonatologists.’ This means that they were trained by pediatricians whose vision shaped the creation of subspecialty defined by its emphasis on vulnerable infants. We did not interview medical students or residents. We also did not seek out formal office holders within the hospital, community, or profession. To identify interviewees without these aids, we extracted names from public or semi-public membership lists—hospital medical staffs, medical society members, and the yellow pages. In the final wave of interviews, we relied on snowball sampling from an index respondent.

The interviews were semi-structured with a short list of ten questions guiding interviewees to describe their sense of their work: reflections on larger professional developments, personal clinical encounters, and what was fulfilling or what was challenging. Interviews took place in the hospitals where the physicians worked and interviewees were not given the questions in advance. In all three waves, interviews were long, averaging over 90 minutes. We audiotaped the interviews, transcribed them verbatim, and coded them by themes. We loaded the transcribed interviews into Folio Views, a text retrieval software.

Results

Across all three waves of interviews, the neonatologists interviewed described three main challenges to their professional practice: pressures from their own professional specialty; pressures from technology; and pressures from parents. However, these pressures are not constant. The three types of pressures exerted on neonatologists ebb and flow across the three waves of interviews, influencing how providers perceived challenges to their care for fragile and dying infants. The results illustrate a strong sense of professional autonomy through the first two waves of interviews that is enhanced by pressures related to specialization and technology. Simultaneously, that strong sense of professional autonomy comes with responsibility, which often becomes a burden. By the third wave in 2016, as the pressures shift, neonatologists expressed a decreased sense of control over their professional lives. This decreased sense of autonomy was paired with a reduction in professional responsibility for their patients, as the responsibility was now diffused across multiple actors, including parents. While law and government receive much attention in the literature on neonatology and reproduction in general,

interviewees very infrequently discussed the role of these external forces in shaping their perceived challenges related to the practice of care. Instead, they spoke of the more immediate influences such as other medical providers, parents, and their own sense of right behavior, even though these things were certainly shaped by the broader legal, political, or economic environment.

Specialization as Building Autonomy: 1978-81 and 1989-91

The profession of neonatology first defined itself in the 1970s and 1980s. In the first two waves of interviews, as the neonatologists reflect on that newness, an overarching theme was their ability to define how they practiced and the excitement of using new technologies available to the emerging profession. A lack of external constraints on care and the near exclusive authority over medical decision-making supports the notion that the practitioners' autonomy largely went unchallenged as the domain grew. The neonatologists describe themselves as having primary discretion over the care of their patients, and the use of technology. The technological knowledge often stayed within neonatology as a specialization and acted as another tool of the trade and a marker of the autonomy of neonatologists in their practice.

“Once we brought [intensive care nurseries] into existence, then specialists in various aspects of infant care began to proliferate and demand [fetal] monitors. The concentration of skills, expertise, and the interaction among the experts themselves was perhaps as important for the field’s development as the concentration of sick babies.” [1978-81, 262608]

“...the cost of obtaining marginal benefit may be excessive...in private hospitals it’s easier, [to find money] they trust our judgment and don’t ask a lot of questions” [1978-81, 262608]

The neonatologists in the second wave of interviews (1989-91) did not discuss being involved with any other specialties, decision-makers or hospital administration. The seemingly exclusive authority perceived by neonatologists is similar to the generally high level of professional autonomy described in the first wave of interviews.

“One thing I think is going to have to come under scrutiny by somebody sooner or later...we keep coming up with this question of how small is too small and is there a cut off

below which we will say, this is not a candidate for ___...they have done this in some other areas that are really high tech, high cost sorts of things...we [neonatology] have not made any attempt to do that.” [1989-91, 070715]

Funding allowed neonatology to grow and develop as a subspecialty. This growth in autonomy aligns with the relative lack of constraints physicians as professionals faced prior to the inception of managed care in the 1990s. Neonatologists described greater autonomy prior to the 1990s than did members of other specialties and subspecialties because, unlike other medical specialties, there were no Diagnostic-Related Groups (DRGs) for neonatology (even today there are only 7 Medicare DRG codes for NICU care).

Neonatologists in the first two waves of interviews reflected on how much money was spent to support their practice. They were uncertain about where this money came from. They were also surprised at the unbridled authority they had in using the tools purchased with that money. Discussions of money, and the lack of restraints on that money are persistent themes throughout the first two waves of interviews. The money is often discussed in the context of expanding neonatal wards, building new wards, and purchasing technology. The neonatologists are generally in awe of the amount of money that is being spent on the NICU.

“...confusing how people get appointed and where the money comes from...” [1978-81, 310001]

“...It’s a new business [neonatology], it’s a new money-making business for the hospital and the babies are popular, it’s all part of it.” [1978-81, 070715]

Some were critical of the priorities that would produce the level of support they enjoyed while other health needs were unmet.

“[there are] plenty of neonatologists, plenty of equipment, plenty of money... your money ought to go to care for ladies using cocaine, not 500-gram prenatal babies. Everybody knows that.” [1989-91, 070715]

From the point of view of the neonatologists, those outside of the field did not seem to question the amount of money given to neonatology, or how neonatology as a profession used the money.

“When neonatal wards renovate, with beds and big TVs, it forces every obstetrics ward in the city to renovate. Getting their money from big businesses. And they don’t have a clue what they just did by encouraging [hospital] to develop an obstetrics suite, was to cost millions from everybody else. Millions for the sake of 80 babies a year, out of 1600 in the city. It’s crazy. I mean, are all these big corporations stupid?” [1989-91, 100022]

Technology as Protecting Autonomy: 1978-81 and 1989-91

One of the most common themes that arose from the first decades of interviews was the professionalization of neonatology through the use of new technology. The first waves of neonatologists frequently discussed technology as something intrinsic to their profession. It was as though the profession was defined in large part through the use of technology and it was thus something that they *must* use in their medical practice. Here, the neonatologists describe technology as a crucial component in defining and directing their practice, both giving them autonomy by evolving the specialty while simultaneously shaping the direction of treatment.

“All of the neonatologists I talk to have some concerns. For what we’re doing this [using technology to prolong life]? And while we have concerns... it’s what we’ve been trained to do. It’s the only thing we know so we go ahead and do it.” [1989-91, 070715]

Nonetheless, neonatologists interviewed expressed concerns about that technology. The concerns were almost always discussed in the context of the quality of the technology, or the uncertainty of the efficacy of the technology for improving patient outcomes.

“We have all of this technology, and we’re saving babies at what costs?” [1989-91, 100022]

“We do the best to keep them alive. Unfortunately, we can’t guarantee every one of them. How good they will be alive. That’s the problem. And we can keep them alive. At least on paper...” [1989-91, 090906]

The feelings of uncertainty about the limits of the technology for their patients, frequently raised ethical questions for the neonatologists. The immense pressure to use the technology was often paired with questions about the limited benefits of that technology. This tension that the neonatologists discussed brings us to the first pressure the neonatologists describe in their practice. This is the pressure to use technology, despite the concern about the efficacy of that technology.

"...[we] can't predict who will be fine and who won't when they are born, so you can't set a cut-off [for receiving treatment]." [1989-91, 070715]

"[improving survival rates with technology] ... we had good outcomes with the technology, so we marched on" [1989-91, 070715]

"Uh, neonatologist is one very, very...traumatic, both physically, psychologically, socially, family and what not. So that's where the burnout is more frequent, and of course the more unstable your client...the more probability you have [of burnout] ... And these are very small children...And they can die one day or the other. And you do not know what the outcome would be...That's how bad it is." [1989-91, 090906]

This pressure may not have directly reduced provider autonomy, since technology undergirded the practice and professionalization of neonatology, but the pressure to use technology certainly raised feelings of discomfort. Technology, at this point in the interviews, came with many challenges for providers. In many ways, technology appeared to raise the salience of their responsibility as practitioners, as the weight of the success of their practice for their patients depends on the success of the technology.

Parents: 1978-81 and 1989-1991

At this point in the interviews, parents are rarely discussed. If they are discussed, it is not as people sharing the responsibility of making a decision. Later periods show how this changes significantly. This is most clearly observed when comparing the interviews from a single physician who was interviewed in both the second and third waves. When discussing how

complex decisions were made, parents were hardly mentioned in the second wave, but were at the center of the interviewee's reflection during the third wave.

Collaboration as Reducing Autonomy: 2016-17

As we enter the third wave of interviews, it is striking how often neonatologists bring up other medical specialists. As neonatologists talked about the way their practice changed, or the way they currently practice, they consistently placed their role as a member of a team amidst many other practitioners. Across the final wave of interviews, neonatologists consistently discussed how they are not the primary decision-makers. Where older waves of interviews constantly presented cases of neonatologists making ethically fraught decisions more or less on their own, in this last wave, they consult with other specialists, and generally arrive at decisions together.

"...care conferences sometimes are good because we can bring in other specialists, too...So whoever is involved, so sometimes, suppose this is a kid who has multiple problems like gastroenterology problem, neurology problem, so we call a neurologist, gastroenterologist, and also, of course, the opinion of a cardiologist and whoever else is involved. Sometimes social workers..." [2016, Interview 4]

Younger practitioners in the final wave talked about team-based care as the status quo, with shared decision-making as the standard model for their and not as a challenge. The integration of the different specialist views was not always easy, as specialist frameworks may not align without effort and maybe irritation.

"It's fun to watch the invasion of newborn intensive care by other sub-specialists now. Well, invasion's probably a word that's a giveaway, and I shouldn't use it...It's frustrating when someone tries to apply adult medical values, or adult learning, physiology, to a smaller baby who doesn't play by those rules. So, you spend a great deal of time saying, "I know what your saying's right for a taller person, but I don't think it's right for the baby." [2016, Interview 1]

The way that neonatologists discussed the involvement of other practitioners in their decision-making has implications for physician autonomy. As the practitioners stated, they do

not make the medical decisions by themselves; they are one of many individuals involved. This group-based dynamic to medical decision-making is the most direct effect on autonomy we observe over the course of the interviews. The team-based, standard operating procedure removes sole authority from neonatologists. At the same time, even though some neonatologists described frustration regarding the loss of autonomy over medical practice decision-making, many practitioners specifically mentioned consultation with other medical specialists and medical ethicists as aiding them in their decision-making. While the new realities of collaboration may reduce individual autonomy of the neonatologist, it may also increase collective autonomy of the physicians as a whole. Even more, the reduction in autonomy may come with an overall reduced pressure that the neonatologists themselves face when making difficult choices about end-of-life care. Or, in other words, a shared responsibility for difficult decision-making.

“So, we call other, you know, parties, too, so just to make sure that, ultimately...you know, or ultimately, we as a physician or parents, caregiver, main caregiver, they don't feel like they could have done something different.” [2016, Interview 4]

Technology as Complicating Autonomy: 2016-17

In this final wave of interviews, perhaps the main source of variation from the first two waves is that the types of technology are notably different. Technology is no longer exclusively used to treat conditions after birth. People need not be born to be susceptible to medical care. Genetic technology is used to pre-screen for hereditary conditions and thus change the course of treatment and neonatology practice. Routine use of ultrasound leads to the use of surgical technology to operate on fetuses, which are then returned to the uterus. Birth no longer defined the limits of the physicians' craft.

“Big thing now is people are pushing, even in the world of ethics at these national meetings “Oh, trisomy 13 and 18, it's the next Down's Syndrome and we should be resuscitating all of those babies and letting families have the option of having everything done.” [2016, Interview 5]

Neonatologists in the final wave also changed from concerns about the efficacy of technology to ethical concerns about the power of genetic and genomic technology. They

described efforts to consistently improve genomic technologies, and the ongoing debates about pushing viability to younger and younger ages. The majority of the neonatologists interviewed were uncertain regarding these debates, alluding to the potential harm or reduced quality of life of the infants.

“I don’t think it’s possible to tell you every detail about every ethical dimension of it, but yea...The questions of ethics, there are some bigger questions like should we or should we not resuscitate and how much medical interventions are appropriate for a baby, but then there are also some that are minor, but I think also important as to how much monitoring and surveillance should we be doing for babies that are in the NICU for five months?” [2016, Interview 7]

The most recent interviews revealed a deep concern for the wellbeing of newborns who are discharged from hospitals to live lives dominated by complex chronic conditions. The neonatologists also questioned whether parents had the ability to provide care or pay for such intensive care for infants and later children with serious hereditary conditions or chronic diseases. The time in NICU, as challenging as it can be for parents, is only the beginning of a very long journey for many of these families.

“My hunch is that more kids who used to die are making it home on a ventilator. I think that’s one, because we’re getting better at this. But two, because we’re getting less paternalistic. I think we used to decide more this baby should just die and the field has moved towards, ‘if your parents think your life is worth living our job is to support that goal.’” [2016, Interview 2]

Better survival rates have also led to more kids with severe disability needing a lifetime of care at home. This means that providers are not just working toward survival and discharge, but more often considering whether survival and discharge is the best goal. Detection of and treatment for genetic disorders make it possible to intervene on more newborns than ever before. In addition, better medical equipment makes it possible for parents to care for severely disabled children at home more often than before. Yet there is a tension in the area of genetic disorders between what technology makes it possible to treat and what ethics agrees it is proper to treat. In the face of the reservations neonatologists may have, the providers interviewed described routinely deferring decision-making to other providers or parents regarding the use of the technology.

“In general, we will try to avoid disagreements with family because our goal is to help the family meet the goals that are reasonable to them for their child even if it doesn't really meet the opinion that we have exactly. If I feel that this baby with a bad genetic diagnosis should probably not have a big heart surgery, but the family wants to, then we will still recommend what we in our opinion feel should be the way to go, but the ultimate decision is the family's.” [2016, Interview 7]

“It's challenging. Take care of parents, and they [newborns] die. Okay? How can I help you? They die more here than any place else in the medical center. Every week, someone dies. It's yours to come to terms with that, but then that's - you say, ‘Not me. Not the medicine. Not the technology. It's what happens’ ...Now I'm here on my horse again...” [2016, Interview 1]

Here, we again see provider autonomy diminishing in the case of medical decision-making, due to the interaction between neonatologists, other specialists, and parents in complex cases. Neonatologists do not see themselves as the final authority on the question of whether the patient shall live. This tension may or may not make complex decision-making easier. The neonatologists did not discuss their feelings regarding the costs/benefits of deferred decision-making directly, although they certainly reflect on the inherent challenge of coming to terms with decreased authority, which reduces the individual pressure they face to make the best choice. Yet simultaneously, some express reservations about not being able to wield more authority over cases they find ethically problematic, or risky for the infants.

Parents Bearing Burdens of Autonomy: 2016-2017

The second notable source of variation in the final wave of interviews from the first two waves is a substantial increase in parental involvement in care planning and medical decision-making. Where parents were hardly mentioned in the first two waves, neonatologists in the final wave consistently referred to their interactions with parents, and how that interaction affected their practice and treatment decisions.

“I mean, it [communication challenge] may be the parents. If we did everything the parents wanted us to do, then... They have a very different perspective.” [2016, Interview 3]

Changing norms and practices of parenting as well as developments in obstetrics and prenatal care might have helped to change parents' expectations and the demographics of parents interacting with neonatologists. In addition, several neonatologists directly described the new role of the Internet and social media.

"I wouldn't say it's very often but there, there are some parents who would, like, say, okay, I read, ... especially, I had couple of parents who were Trisomy 18 and 13, "Oh, but the other kid is living for, like, that many years, and doing fine." So sometimes those or sometimes they have this "We found this treatment on the Internet, and it works." So, once in a while it is fine, but sometimes it just, it's false information... Definitely, it has become more frequent. It wasn't there, like, maybe ten years ago it was less. Now, parents are very, like, especially the educated parents, they want to know what's happening." [2016, Interview 4]

Studies from the time period of earlier waves align with the shift in our findings, where parents were involved, but with less assertiveness than during the third wave (Duff and Campbell, 1973, Guillemin and Holmstrom, 1986). Educated parents had been inquiring and advocating long before the internet and social media, but social media and the internet undoubtedly reduce the costs of research and make it possible to look up topics, in seconds and anywhere, for better or for worse.

Regardless of the reasons, the neonatologists emphasized that parents are continually involved in medical decision-making, seeing this constant involvement as a source of pressure for them, and a challenge in providing care and determining the best courses of treatment for their patients. The neonatologists described parental involvement as a challenge for two main reasons. First, parents sometimes disagree with neonatologists' recommendations to withhold treatment. The parents want to proceed. This is a shift from the earlier waves with conflicts often arising when families were more hesitant about aggressive treatment.

"You know, back in time, I think that people talked more about the parents wanting to not do things and medicine wanted to do things, and I think it's almost like those things have flip flopped now ... Occasionally, you know, there's always one of the discussions in the world of neonatal ethics is always the limits of viability and should we be resuscitating a 22, 23, 24 weeker. It's funny because people always bring up the case, "Well, you know, what is a family of a 25 weeker says they don't want you to resuscitate" and I always say, "I've never run into

that." The problem tends to be more the family who is 22 weeks that wants us to, and we're telling the chance is like this, and then how are we going to limit that." [2016, Interview 5]

Secondly, the neonatologists discussed parents as being a challenge regarding care after discharge, even if parents agree with neonatologists' recommendations. As outlined above, babies with serious disorders can now live longer, though many require labor-intensive and costly care. Challenges arise from concerns about whether or not parents may actually be able to care for their newborn outside of the hospital.

"With something that you thought was kind of ethically optional to begin with, now when the parents can't do it, they're faced with the choice of that child goes to foster care to get this care. In some situations, they eventually get the kid back, actually. Like the kid's needs deescalate and they can get the kid back. But the kid goes to foster care, or "Would you like to reconsider your decision to do this at all?" "Knowing that you can't take this baby home should we talk again about whether comfort care is what you want?" That is the most unresolved issue that I face. It comes up more often than I thought it would." [2016, Interview 2]

What holds across the final wave, is that with neonatologists overwhelmingly described deferring to the wishes of the parents. Few providers mentioned legal issues, or practice norms resulting from external legal debates in the field. Yet despite practitioners' limited reflection on case law, the historical findings regarding norms of patient care support this increased deference to parents. This deference illustrates another reduction in provider autonomy, wherein, delegation to parents reduces the burden associated with being the single decision-maker.

Discussion

Autonomy emerged as the prevailing theme of the interviews, but it was not always obvious whether physicians wanted more autonomy or less. Building professional autonomy was essential early on for neonatologists to establish authority over their new space of work, but several factors made such a high level of autonomy difficult to bear. For example, the need to deliver care before practitioner pipelines were fully developed meant that the burden of care and the knowledge of the specialty were borne by very few individuals. As the number of neonatologists has increased over time, so have the number of other professionals, such as nurse

practitioners and advanced practice registered nurses. The same strategic reduction in autonomy can be said about including parents in more of the care and decision-making of NICU patients. There is no doubt that including parents adds a layer of complexity into decisions. It is a layer that is sometimes a tremendous challenge for neonatologist to negotiate, but on the whole, it seems that giving more authority to parents has achieved a balance in responsibility for life and death that neonatologists find more bearable, particularly in marginal cases that may be ethically questionable related to the reaches of technology. It is a reduction in professional autonomy, but it is one that the profession has largely welcomed.

The profession has not welcomed all reductions to their professional autonomy, however. Perhaps the most prominent example was the way federal law was used in 1984 in response to the case of Baby Doe. The law's requirements for care and the telephone hotlines for reporting abuse created an environment where professional autonomy was dramatically curtailed, signifying to neonatologists that the public did not trust them to self-regulate as a profession. The U.S. Supreme Court struck down the law in 1986, but for reasons of states' rights and not for violations of professional or parental autonomy. In the past several decades, neonatology has also experienced a reduction in autonomy from the sometimes-unwelcomed incursion of other specialists into the care of their patients. To be sure, increasingly complex in-utero surgeries and post-delivery procedures often require collaboration with specialists outside of neonatology. When the skills of other specialties are needed to properly care for patients, the collaboration is largely embraced.

At the same time, the interviewees noted several situations where collaboration did not result in better outcomes. For example, some feel that fetal surgeons are often more aggressive in their recommendations for care than the neonatologists feel is appropriate and some surgeons do not fully appreciate the challenges that then await the neonatologists, the parents, and the newborns. In addition, greater frequency of consulting across specialties creates more situations where neonatologists feel that those unfamiliar with the physiology of their (very small) patients are making decisions that they ought not be making. For example, one interviewee in the third wave complained that nephrologists, accustomed to adults, systematically over-diagnosed chronic kidney disease in neonates. What makes these reductions in professional autonomy different than those professional collaborations that neonatologists more readily welcome? It seems to be whether or not authority and responsibility are aligned. The frustration is clearest in

situations where neonatologists have the responsibility to care for the newborn, but other physicians have the authority to make decisions that affect care.

One of the very practical reasons why medical professions benefit from finding the right balance of autonomy is because burnout and compassion fatigue may arise when the burden of care rests too heavily on individuals. The rise in physician burnout is well established, with some estimating that 50% of practicing physicians exhibit the risk factors for this phenomenon (Rothenberger, 2017). Moreover, moral distress, or the state that arises when one is tasked with acting in a way that is different than one believes is ethically correct, is one of the risk factors that contribute to burnout (Fumis et al., 2017). Interestingly, even though burnout is more discussed today than in the past, physicians were more likely to reference burnout, distress, and fatigue in the earlier waves of interviews. Even though the issues are no less complex today than they were in past decades, this is likely because the earlier generation of neonatologists did yet have the supportive infrastructure to bear some of the weight of the decisions they were forced to make.

NICU physicians report a lower rate of burnout than non-physicians working in the NICU. Moreover, lower rates of burnout are associated with lower rates of infection among patients, suggesting that protecting professionals is not only good for the professionals themselves, but is also good for the patients they serve (Tawfik et al., 2017). The first result raises the question as to why physicians in the NICU experience burnout at a lower rate than their non-physician counterparts. Of the many possible explanations, one is that physicians have more strategies to insulate themselves from the pressures that would otherwise lead to burnout (Weintraub et al., 2016). These insulation strategies come in many forms, including the use of professional ethicists for challenging situations, shared decision-making with parents, and justification for adequate staffing due to neonatology's consistent contribution to a hospital's bottom line. Providers across specialties experience moral distress, compassion fatigue, and burnout, which compromise both the well-being of the provider as well as the quality of care the patient receives (Prentice et al., 2018). Seeking the right degree of professional autonomy may be one way to minimize the negative effects of stressful workplaces such as intensive care units.

Another area where professional autonomy is likely a mixed blessing for neonatologists is when they must make decisions where there is a good deal of uncertainty and where the outcomes have lasting effects on the life, disability, or death of their patients. Neonatologists and

parents may differ significantly in the ways that they assess the appropriateness of treatment. Health care professionals provide lower utility scores than parents and adolescents to hypothetical health states, especially those with severe disability (Lam et al., 2009) and parents of term infants provide lower utility scores than parents of preterm infants (Lam et al., 2009). Health care professionals responding to vignettes choose to resuscitate premature babies less often if they are just given gestational age than if they are given prognosis, even when the prognosis is the typical outcome for a given gestational age (Janvier et al., 2008). This all points to the reality that shared decision-making in the NICU truly requires individuals to step back from their own value system and appreciate how others experience the situation. Interviews with parents of preterm infants suggest that optimism, hope, and realism about death are the more salient themes for their experience (Arnolds et al., 2018, Wraight et al., 2015), rather than concerns about futility or future quality of life, which were consistent themes in our interviews with neonatologists.

There are several limitations to this study. First, the interviews occurred with neonatologists in one Midwestern metropolitan area, with supplemental interviews with neonatologists in a different place who were familiar with the site. We therefore do not make any claim that the experience of these individuals is generalizable across all neonatologists. At the same time, we do not have any reason to believe that the environment we studied is so distinctive that the experiences do not reflect the general experience of physicians practicing in this specialty. Second, different interviewers conducted the interviews, occurring over the course of many decades, and their scripts varied. Therefore, we cannot say whether or not some of the variation we found may be related to research strategies rather than true changes over time. However, the researcher who conducted the first two waves of interviews is one of the authors of this article. We are therefore fairly confident that differences due to research strategy were minimized insofar as possible.

Conclusion

The physicians' lived experiences, as related to us, join the social, legal, and technical environments that shaped their new specialty. One of the major movements in the field of medicine over this same period of time was the shift away from medical paternalism toward shared decision-making (Kon, 2010). Yet this shift is not without its own dangers. Among them

is physicians abandoning too much responsibility for, and thus becoming indifferent toward, treatment decisions. Even as others are brought into the decision-making process, maintaining an appropriately strong sense of professional autonomy is one way that this risk might be avoided. The approach to achieving such autonomy changes over time, but the issue remained ever-present in this study's interviews.

How did these practitioners in this specialty negotiate the complex pressures of a dynamically evolving field to reach decisions acceptable to themselves and their environment? The results show that neonatologists in each time frame struggled with the big questions that have loomed over their specialty (who should live, what kind of life is worth living, who should make these decisions?). The history of neonatology makes clear that there can be strategic limitations to professional autonomy that ultimately serve the profession as well as those affected by the profession's work. Allow too many limitations and one no longer has a profession; but without limitations, the profession suffers in different ways.

Data Availability: The data that support the findings of this study are available on request from the last author. The data are not publicly available due to privacy or ethical restrictions.

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