THE VOICE OF PATIENTS AND FAMILIES

How Using the Term “Non-Compliant” Keeps Providers From Partnering With Patients

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The aim of this article is to offer an alternate perspective for nurses to consider when assigning the label “non-compliant” to a patient. This discussion contains three examples of experiences of people who were designated non-compliant patients, and how they were then thought of as problems, and a fourth example in which the patient’s autonomy was respected. The unintended negative consequences of labeling people as *non-compliant* are examined through the lens of three ethical principles: (a) respect for autonomy, (b) beneficence, and (c) non-maleficence.

Keywords: non-compliance; patient autonomy; beneficence; non-maleficence; care plans; partnership

Health-care professionals who use the term *non-compliant* to refer to patients and families who appear to be disregarding a recommended plan of care have an ethical obligation to examine the consequences of their use of this word. The term non-compliant indicates a wanton disregard for a suggested path to well-being but fails to acknowledge the mistrust, disruption, inaccessibility, and even the marginalization that sometimes perpetuates a person’s need to deviate from a health professional’s care plan. As a person of color, I find this label to be analogous to another familiar term—disobedient—which is disparaging, offensive, and infantilizing, as well as socially, economically, and politically disenfranchising. This article contains three examples of people who were designated non-compliant patients, and how they came to be thought of as problem patients, as well as a fourth example in which the patient’s autonomy was respected. Their names have been changed to ensure their privacy.

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MAMA CLARA

Before she died, my neighbor, Mama Clara, an elderly African American woman, shared with me her concerns about her health-care provider reporting to her family that she was non-compliant with her medical regimen; she was deeply disturbed that they would think of her as disobedient. Mama Clara was a dedicated and lov-

ing woman who always tended to the needs of her children, grandchildren, and loved ones, sometimes at the price of her own physical health. She experienced her bliss and what she saw as “God’s intention” through caring for her family. So, when she missed one of many medical appointments because she was attending to her grandchildren and great-grandchildren when their parents couldn’t pick them up from school, or was assisting an emotional neighbor facing eviction, she maintained a resolve in her heart that her service to her family and community would provide her healing. She was not opposed to the care plan her health-care provider prescribed—not disobeying or refusing to comply. She simply moved toward what fulfilled her—what made her feel better—rather than following a plan that would have kept her from what mattered most to her.

When we consider what the provider’s staff reported as non-compliance, we must question whether Mama Clara’s provider had ever asked her about what effect the plan of care would have on her life or whether she thought the plan could work for her. When it was discovered that the plan was not working for Mama Clara, the discussion should not have been about her lack of compliance; it should have been about how Mama Clara and her provider could partner to devise a plan that would be effective medically while fitting as well as possible into the parameters of what mattered most to Mama Clara.

LARRY BROWN

Larry Brown took legal custody of his two toddler sons from their drug-addicted mom after she left them unattended while in search of a fix. Larry was illiterate, and often close to homeless, and he suffered from brittle diabetes requiring dialysis. As the boys grew, behavioral difficulties related to their cognitive and neurological delays from prenatal drug exposure became more evident, and he felt compelled to be present for any needs they had. Larry himself went without new clothes or haircuts so his children could have what they needed.

As his sons entered middle school with its many events and conferences, it became more difficult for Larry to get to his dialysis appointments on time, if at all. During one medical appointment for which he was 10 minutes late because the bus he took had detoured, a nurse new to the clinic demanded that he leave due to his history of “non-compliance” and his disheveled appearance. Few of his caregivers even knew of his commitment to his children.

They didn’t know, because they didn’t ask. The label non-compliant put Larry into a category that facilitated an attitude, on the part of the nurse, of, “If you’re not going to do right by us, we’re not going to do right by you.” The label non-compliant, which was documented in his file, marked Larry as a disposable person, and the nurse disposed of him.

ETHICAL PRINCIPLES

These two stories of clinicians labeling people as *non-compliant*, when it was the clinicians who failed to adequately partner with their patients, show that the use of the term non-compliant raises ethical challenges (Browne, n.d.) that can be considered more thoroughly using four principles of biomedical ethics described by Beauchamp and Childress (2012): (a) respect for autonomy, (b) beneficence, (c) non-maleficence, and (d) justice. These principles serve as a foundation for consci-

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The phenomenon of patients not following plans of care can be viewed either as a problem in need of a solution (e.g., clinicians partnering with patients to ensure that care plans work within the patients' personal goals, motivations, and daily activities) or as a problem for which the solution is simply that patients need to comply with the care plans provided to them.

entious reasoning, and can help us establish a more clinically sound perspective with which to consider the ethics of using the term non-compliant. In this article, I will discuss only the first three principles; applying the principle of justice to the social and emotional injustices of the use of this term merits singular focus and is beyond the scope of this brief article.

The problem of patients not following—not complying with—an established plan of care (also referred to as non-adherence, a term I see as softer, but ultimately no more helpful than non-compliance), refers to a legitimate concern of health-care professionals. However, the phenomenon of patients not following their care plans can be viewed either as a problem in need of a solution (e.g., clinicians working together with patients to ensure that care plans work within the patients' personal goals, motivations, and daily activities) or as a problem for which the solution is simply that patients need to comply with the care plans provided to them.

Proponents of the term non-compliance maintain that non-compliant patients generally have less than optimal medical outcomes, and that billions of dollars in excess health-care costs are attributable to non-compliant patients (Iuga & McGuire, 2014). While there is little doubt that patients who choose not to follow their care plans often experience poorer outcomes, the question that will lead us to *better* outcomes isn't, "How can we get patients to comply with our plans?" The question is, "How can we partner with patients and families to create care plans they are willing, and perhaps even eager, to follow?"

Beneficence

The ethical principles of respect for autonomy and beneficence can serve as complementary concepts in studying the ramifications of classifying a patient as non-compliant. Beneficent actions purport to produce benefits, or good outcomes, for a patient. This principle recognizes that "we contribute to [patients'] welfare, including their health" and "assert the duty to help others further their important and legitimate interests" (Beauchamp & Childress, 2012, p. 148). When outcomes do not accord with providers' expectations based on their recommendations, non-compliance with the plan of care may be the first factor suspected. A response that better exemplifies beneficence, however, is one in which the provider moves into reassessment of the care plan rather than seeing the patient as the locus of the problem. While it is common in disciplines such as Occupational Therapy to look at anything they have recommended, but that a patient didn't act on, as an opportunity to find something that will fit better within the habits, routines, and rituals of the person's life (Roley et al., 2008), providers in other disciplines may not take this same perspective. The beneficent response is to partner with the patient for a more workable solution.

Respect for Autonomy

The principle of respect for autonomy addresses a clinician's ethical obligation to recognize a patient's right to self-determination. As Beauchamp and Childress explain: "The most general idea of personal autonomy is still that of self-governance, without constraints either by another's action or by psychological or physical limitations ... The autonomous person determines his or her course of action in accordance with a plan chosen by himself or herself... and is capable of acting on

the basis of such deliberations” (p. 59). The predominant indicator of autonomy is the patient’s ability to provide informed consent, not the outcome of the patient’s decisions. “The right to choose is not limited by the right to choose rightly” (Gorovitz, 1982, p. 46).

In any circumstance in which a patient has the capability for informed consent, it seems reasonable that the patient should have the same capability to navigate—and even co-design—their treatment course in a personally meaningful and satisfying way. Coy (1989), in an article on autonomy-based informed consent, states:

Although most patients consult a health care professional because they are seeking better health, patients have their own individual sets of values, beliefs, goals, and interests. Although a health care professional may be uniquely qualified to render advice concerning what options will optimize a patient’s health, optimizing health may or may not be the only goal, or even the primary goal, of any given patient. In today’s health care system, where health care providers generally do not have in-depth, long-term professional relationships with their patients, and given today’s pluralistic society in which individuals have extremely diverse value systems, it is unlikely that the health care professional has sufficient understanding of the patient as an individual to know, and appropriately weigh, all the factors involved in making such decisions. (Coy, 1989, p. 829)

It is the patient and family who have the best perspective from which to judge what is most right, advantageous, and desirable for them. It is the patient and family *in partnership with the provider* who can best work to find a care plan that features medical interventions that accommodate the habits, routines, and rituals of the patient. Just as a dietitian would never start a dietary recommendation with, “Well, first you’ll have to remodel your kitchen,” no clinician should ever impose a care plan with insurmountable hurdles in it. There are two ways to discover whether our care plans contain hurdles: (a) we can send people home with them and discover later that the plans were not followed, or (b) we can partner with patients and families at the outset to ensure that our care plans are hurdle-free.

Non-Maleficence

There is a long history of injustice in medical study and treatment of African American people, combined with sustained historical trauma and the cultural relativism of those imposing afflictions upon African Americans, that has led to their distrust of Western medical practices (Corbie-Smith, Thomas, & St George, 2002; Nelson, 2016). This fact brings us to the third ethical principle: non-maleficence, the duty to do no harm. The Hippocratic Oath expresses the duty of non-maleficence together with the duty of beneficence: “I will use treatment to help the sick according to my ability and judgment, but I will never use it to injure or wrong them” (Beauchamp & Childress, p. 106). Yet there have been so many occurrences of morally and ethically questionable medical and scientific activities involving vulnerable children and adults, including the Tuskegee Study (Nix, 2017), the unacknowledged use of the HeLa cell strain (Skloot, 2010), the Guatemala Syphilis Study (Rodriguez & García, 2013), the Monster Study (Goel, 2013), and surgical experiments on concentration camp prisoners (United States Holocaust Memorial Museum, n.d.) and on slaves (Wall, 2006), that patients may feel compelled to rely on their autonomy

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There is no undoing the trauma caused by the medical malpractice of the past to people from marginalized communities. The ethical principle of non-maleficence requires us to do what we can to refrain from exacerbating that trauma. Offering a one-size-fits-all care plan is a form of casual diminishment (Koloroutis & Trout, 2017, p. 57) that inadvertently dehumanizes people. I submit that offering such plans to individuals carrying centuries of trauma related to the dehumanization of their ancestors, coupled with the continued marginalization of African Americans today, is an act of maleficence.

NURSES' ETHICAL RESPONSIBILITY TO SUPPORT AUTONOMY

The American Nurses Association's (ANA) *Code of Ethics for Nurses with Interpretive Statements* (Code; American Nurses Association [ANA], 2015) addresses the ethical imperative for nurses to regard patients' decisions about plans of care without labeling or stereotyping. Provision 1 of the Code is, "The nurse practices with compassion and respect for the inherent dignity, worth, and unique attributes of every person" (p. v). Interpretive Statement 2 of Provision 1 (IS 1.2) states:

Nurses establish relationships of trust and provide nursing services according to need, setting aside any bias or prejudice. Factors such as culture, value systems, religious or spiritual beliefs, lifestyle, social support system, sexual orientation or gender expression, and primary language are to be considered when planning individual, family, and population-centered care. Such considerations must promote health and wellness, address problems, and respect patients' or clients' decisions. Respect for patient decisions does not require that the nurse agree with or support all patient choices. When patient choices are risky or self-destructive, nurses have an obligation to address the behavior and to offer opportunities and resources to modify the behavior or to eradicate the risk. (ANA, 2015, p. 1).

The need for health care is universal, transcending all individual differences. The nurse provides care with respect for human needs and values, which should be considered in planning health care with and for each patient. Such consideration does not suggest that the nurse necessarily agrees with or condones certain individual choices, but that the nurse respects the patient as a person. Interpretive Statement 1.3 of the Code states, "Respect is extended to all who require and receive nursing care in the promotion of health, prevention of illness and injury, restoration of health, alleviation of pain and suffering, or provision of supportive care" (p. 2). Part of this respect is recognizing that departures from the plan of care are not necessarily risky or self-destructive. By what criteria do we label patients non-compliant? And why should we question their rights, since they are autonomous individuals, to depart from the recommendations of providers who have created care plans for them that did not take their values, beliefs, goals, interests, habits, routines, or rituals into consideration?

BABY J

During my research for this article, an infant with complex medical conditions was admitted to the pediatric hospital in which I work. While assessing the baby, the

physician noticed that the parents were placing her in a prone position for sleep, which is contrary to American Academy of Pediatrics recommendations (National Institutes of Health, 2007). The physician instructed the nurse to strongly encourage the parents to place the baby on her back for sleep. The nurse responded that she already has instructed them to do so, but that the mother refused, stating that the baby sleeps better prone. The physician then enlisted me, the nursing supervisor, hoping that I could be more persuasive in enforcing this standard with these “non-compliant” parents (the physician used this term). The mother again resisted initially, then wearily gave in and said, “Fine, then all of you stay up with her tonight.” Feeling unsettled by this interaction, I went home and researched this infant’s comorbidities. Of her conditions, one of them, Pierre Robin Syndrome, contains a contraindication to placing the baby supine for sleep, because of the potential for respiratory complications (Children’s Hospital of Philadelphia, n.d.).

This mother had something to teach us, even if she didn’t have all the details worked out. She knew that the baby slept better prone. Our eagerness to educate her—to offer her a one-size-fits-all plan for how her baby should sleep—kept us from suspending our own agendas and getting curious instead (Koloroutis & Trout, 2012). The physician’s labeling of the mother as non-compliant slowed the team in finding the best course of action for this mother and baby. A nurse who had come to believe (though perhaps only unconsciously) that people who are labeled as non-compliant are less worthy of our full and continued attention, might have simply walked away from the interaction satisfied that the mother had complied, leaving the baby open to further, possibly fatal, complications. Instead we were able to come back to the mother and baby with a plan that worked best for their exact circumstances.

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MIKE L

Mike is a combat-wounded Vietnam veteran with major Agent Orange exposure. Among his many health issues are peripheral neuropathy severe enough to confine him to a wheelchair and limit his hand strength and function, and congestive heart failure with significant leg edema and some pulmonary edema. His cardiology nurse practitioner recommends daily furosemide to help control his edema, but taking this diuretic usually necessitates staying close to a bathroom for the next 6 to 8 hours and keeping a urinal close at hand. If he takes it too late in the day, he is up at night voiding. So, on days when Mike has activities planned, he skips the diuretic, departing from that particular aspect of the care plan, even if the edema is worse that day.

This isn’t another story of a patient being labeled non-compliant and having a poor outcome. This is a story in which the patient’s values, beliefs, goals, and interests are considered. His nurse practitioner is completely supportive of Mike’s decision to depart from her diuretic recommendation sometimes, because his quality of life is improved by that decision.

CONCLUSION

We can never guarantee that the plans of care we develop will turn out to be the right choice for any patient in any situation. However, care plans that actively support individuals’ rights to self-determination and self-efficacy are far more

likely to succeed. Our nursing practice may require a paradigm shift that goes beyond advocacy and encourages us to strive for “protection and enhancement of autonomy” (Coy, 1989, p. 829), eliminating any behavior that fails to respect the autonomy of the patient. The assumption of patients’ competence and therefore their capacity for autonomy and self-determination is morally, ethically, and legally established in the concept of informed consent (Coy, 1989).

When a patient who seeks advice from a provider chooses to depart from the resulting plan of care, the provider needs to gain insight into the reason(s) the patient has elected to act this way. Using the noun “compliance” to denote following a plan of care may be a practical, even positive use of this word. Identifying a departure from a plan of care is important for the patient’s well-being, but designating that departure with the noun “non-compliance” and the patient as “non-compliant” clearly implies that the patient is at fault. I propose an alternative way of thinking: When a patient departs from the plan of care, that departure can be our signal to offer additional support for a patient’s self-regulation and autonomous decision-making.

There is a reason that I have focused largely on the elimination of the term non-compliance without offering an easy alternative: It’s that an alternative label will not help us achieve our mission as health-care providers. We might refer to a situation in which we would formerly have labeled the patient as non-compliant by saying the patient is exercising patient prerogative or patient privilege, but that language doesn’t point us at a solution either; it just softens the blow as we keep the focus on how the patient has not done what we said to do.

It is likely that the paradigm won’t shift just because we’ve changed one term anyway, and it’s unlikely that the label non-compliant will go away any time soon. Perhaps the solution is for you and me, and all who read this article, to let the term non-compliant be our personal and professional call to action to get curious about what the patient needs that we have obviously failed, so far, to offer. Our professional code of ethics demands that we demonstrate, in every interaction, that not one of our patients is disposable, and that all of our patients are worthy of our complete attention, whether they do what we ask of them or not.

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