Women's Health Issues 28-6 (2018) 477–479

WOMEN'S HEALTH ISSUES
www.whijournal.com

Commentary

Proposed Title X Regulatory Changes: Silencing Health Care Providers and Undermining Quality of Care

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Article history: Received 30 July 2018; Received in revised form 8 August 2018; Accepted 9 August 2018

Comprehensive information about treatment options and timely referrals to specialty services are essential to quality health care. In a striking new set of proposed changes to the federal Title X program, the Trump administration threatens the ability of health care providers to fulfill this key responsibility for low-income patients. Proposed regulatory changes would reverse a requirement that providers offer pregnant people served by the program "comprehensive, patient-centered counseling on their options" (i.e., prenatal, adoption, or abortion care as indicated) (U.S. Department of Health and Human Services, 2018) and would impose crippling restrictions on referral making.

Originally created under the Nixon administration, Title X has historically enjoyed bipartisan support. Grant funds are awarded based on merit through an open application and rigorous review process. Along with patient education and outreach, Title X funds cover the cost of clinical family planning services for low-income uninsured and underinsured individuals. The funds finance contraceptive services, testing and treatment for sexually transmitted infections including human immunodeficiency virus, cancer screenings, and other preventive family planning care to 4 million Americans annually, and have never been used to pay for abortion services. The proposed new regulations forbid use of program funds in any facility that also separately provides abortions and proponents of this policy are clear that their primary objective is to prevent Planned Parenthood clinics from receiving Title X grants. Among health care providers who remain eligible for Title X funding, the provision of full-spectrum pregnancy options counseling and abortion referrals would be prohibited. The proposed regulations outright forbid health care providers from initiating an open conversation about all three options for an unanticipated pregnancy: parenting, adoption, and abortion. This proposed change represents a complete about face—away from requiring high-quality, patient-centered information and counseling about options for continuing or terminating a pregnancy, toward requiring that providers withhold counseling and information. As noted by several leading physician and nursing organizations, such prohibitions on open communication between caregivers and patients could force Title X grant recipients to violate their conscience and breach professional ethics (American Academy of Family Physicians, et al., 2018; American Nurses Association, 2018), in addition to impeding providers' ability to meet their patients' needs.

The proposed prohibition of pregnancy options counseling and abortion referrals goes against a decades-long, sector-wide effort to make health care services increasingly responsive to patient preferences and better integrated at a systemic level. Care coordination, including appropriate referrals for specialty services, has been recognized by a variety of stakeholders as a hallmark of quality for decades. In 2008, the American Academy of Family Physicians published the Joint Principles of the Patient-Centered Medical Home Model, a codification of the key components of team-based, holistic, person-centered care developed beginning in the 1960s (American Academy of Family Physicians, 2007). Health maintenance organizations and, more recently, accountable care organizations similarly emphasize the role of a primary care team in coordinating specialty services for patients. The emergence of patient care navigator programs for conditions from cancer to opioid use disorder has increased in recent years.

These broad trends point to a central truth: our health care system is complex and accessing needed services can be overwhelming for patients. According to the National Assessment of Adult Literacy, 43% of individuals 16 years of age or older read at

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1049-3867/$ - see front matter
https://doi.org/10.1016/j.whi.2018.08.003

a basic or below basic level, potentially creating significant navigation challenges (National Center for Education Statistics, 2003). Navigation to care, regardless of the service needed, is more difficult for individuals in rural or medically underserved areas, or for those at heightened risk of discrimination in health care such as people of color or transgender individuals. A high-quality referral can be key to bridging the gap to any service, for any patient, anywhere—but may be most crucial for individuals who are not equipped to navigate our complex system or who must overcome additional barriers and discrimination based on who they are or where they live.

The need for appropriate referral making is intensified for abortion care compared with most other health care services given the lack of abortion providers in the majority of U.S. counties and policy restrictions that erode access. The number of abortion providers in the United States has recently decreased steeply as states enact new restrictions on abortion service delivery. According to the Guttmacher Institute, 16 states now have only three or fewer abortion clinics (Jones & Jerman, 2017). Laws prohibiting both private (in 26 states) and governmental (in 33 states) insurance coverage for abortion care pose additional barriers (Kaiser Family Foundation, 2017a, 2017b). Further, because abortion is highly socially stigmatized, pregnant people may have less social support for accessing abortion than they would for other services and are often confronted with misinformation about the legality and safety of abortion (Kumar, Hessini & Mitchell, 2009). Unsurprisingly, inappropriate referral is a documented primary reason for presentation for abortion care at a later stage of gestation (Drey et al., 2006).

Although the proposed regulations forbid full-spectrum pregnancy options counseling—that is, they prohibit a provider from proactively offering to discuss parenting, adoption, and abortion—they also describe how a provider must respond in the event a patient were to specifically ask about abortion care. As displayed in Table 1, the provider may offer a list of external referrals and this list could include an abortion provider so long as that provider also offers prenatal care services, but the list must also include other providers that only offer prenatal, and not abortion, care. Although the abortion provider can be included, they cannot be flagged as such on the list. However, the mere provision of a list of potential providers—much less a list that is intentionally confusing in its content and formatting—does not constitute a high-quality referral. One can imagine the response of a patient with lower literacy or limited English proficiency to receiving a referral list in which a clue to finding an abortion provider is intentionally buried. Furthermore, as described by Zurek, O'Donnell, Hart, and Rogow (2015), drawing on the literature from health care and social work, abortion referral making is a spectrum of behaviors that can include mere information provision (which must at a minimum be clear and accurate), but also the identification of support services and assistance with scheduling. Not all patients require or desire intensive support around referrals—but health care providers, trained to assess needs, are best equipped to tailor referrals to be patient centered in each case.

The American College of Obstetricians and Gynecologists and the American Academy of Pediatrics support comprehensive pregnancy options counseling and abortion referrals (American College of Obstetricians and Gynecologists & American Academy of Pediatrics, 2012; Hornberger, 2017) and the recommendations of the Centers for Disease Control and Prevention and of the Office of Population Affairs for high-quality family planning care include counseling in accordance with this standard (Gavin et al., 2014).

Table 1
Proposed Title X Abortion Referral Prohibition, Excerpted From Regulatory Changes Proposed by the Department of Health and Human Services on May 22, 2018

§ 59.14 Prohibition on referral for abortion.
(a) A Title X project may not perform, promote, refer for, or support, abortion as a method of family planning, nor take any other affirmative action to assist a patient to secure such an abortion. If asked, a medical doctor may provide a list of licensed, qualified, comprehensive health service providers (some, but not all, of which also provide abortion, in addition to comprehensive prenatal care), but only if a woman who is currently pregnant clearly states that she has already decided to have an abortion. This list is only to be provided to a woman who, of her own accord, makes such a request. The list shall not identify the providers who perform abortion as such. All other patients will be provided, upon request, a list of licensed, qualified, comprehensive health service providers (including providers of prenatal care) who do not provide abortion as a part of their services.
(e) Examples.
(3) After receiving comprehensive care at a Title X provider, a pregnant woman decides to have an abortion, is concerned about her safety during the procedure, and asks the Title X project to provide her with a referral to an abortion provider. The Title X project tells her that it does not refer for abortion but provides her a list of licensed, qualified health care professionals in the area (some of whom provide abortion as part of their primary health care services). The list includes, among other licensed, qualified, comprehensive health care providers, a local health care professional who provides abortions in addition to comprehensive prenatal care. Inclusion of this provider/clinic on the list is consistent with paragraph (a) of this section.
(4) A pregnant woman asks the Title X project to provide her with a list of abortion providers in the area. The project tells her that it does not refer for abortion and provides her a list that consists of hospitals and clinics and other providers that provide prenatal care and abortions. None of the entries on the list are providers that principally provide abortions. Although there are several appropriate licensed, qualified providers of prenatal care in the area that do not provide or refer for abortions, none of these providers are included on the list. Provision of the list is inconsistent with paragraphs (a) and (c) of this section.
(5) A pregnant woman requests information on abortion and asks the Title X project to refer her for an abortion. The project counselor tells her that the project does not consider abortion a method of family planning and therefore does not refer for abortion. The counselor further tells the client that the project can help her to obtain prenatal care and necessary social services, and provides her with a list of such providers from which the client may choose. Such actions are consistent with paragraph (a) of this section.

Research with physicians has demonstrated majority support for the inclusion of pregnancy options counseling and abortion referrals within clinical scope of practice. In a recent nationally representative survey of primary care physicians, more than two-thirds endorsed requiring pregnancy options counseling training during residency and reported believing clinicians are professionally obligated to provide abortion referrals, even when they have a personal religious or moral objection (Holt et al., 2017). Certified nurse midwives, nurse practitioners, and physician assistants also frequently receive didactic training in pregnancy options counseling during their graduate medical education, with approximately three-quarters of programs reporting this content in a national 2000 survey (Foster, Polis, Allee, Simmonds & Zurek, 2006). Full-spectrum pregnancy options counseling is a standard, routine clinical best practice for hundreds of thousands of physicians, nurses, and other health care providers across the United States. The proposed regulations would compel clinicians in Title X-funded programs to act against the norms, training, and ethics of their professions by withholding this service from patients in need.

Instead of restricting abortion referrals, federal policy, health care systems, and health care institutions should strive to improve care coordination for individuals in need of pregnancy

termination. All primary care, gynecological, pediatric, and social service professionals who care for reproductive age people should be prepared to offer pregnant clients basic information on where to access clinical services and social support related to prenatal care, adoption, or abortion. To achieve high-quality care, workers across disciplines must be trained in nonjudgmental pregnancy options counseling and supported with clear policies mandating timely referral making and with an up-to-date database of relevant resources. For more complex cases, such as individuals with certain medical conditions, seeking abortion at a later gestation, or facing extreme social and logistical barriers, a care navigator may be helpful. Inspired by the demonstrated efficacy of care navigation support in improving outcomes for gynecologic cancer, McKenney, Martinez, and Lee (2018) have identified the potential of care navigators to enhance access to care and promote self-efficacy for individuals seeking pregnancy termination. The Massachusetts Access Program, an abortion care navigation program for individuals with complex medical and social needs, has operated for more than a decade, providing information to up to 500 individuals and intensive case management to approximately 200 individuals seeking abortion annually (Ho & Janiak, 2018). A recent evaluation found the Access Program highly acceptable to abortion care providers, who report their patients benefit from the logistical assistance and patient education that the navigator provides (Ho & Janiak, 2018).

Patients who rely on Title X-funded services deserve the same standard of care as their wealthier neighbors with private insurance coverage. This care must include full-spectrum pregnancy options counseling and appropriate referrals to all needed services, including prenatal or abortion care. Anything less diminishes health care providers' ability to offer patient-centered care and contradicts the medical community's acknowledgement of abortion referrals as a component of health care. Scientific experts such as the American Medical Association and American Public Health Association, as well as public officials, have roundly denounced the proposed prohibition on abortion referrals, and states' attorneys general have begun to initiate lawsuits opposing the regulations, with more likely to follow (American Medical Association, 2018; American Public Health Association, 2018; Miller, 2018; Cha 2018). Whether the Trump administration's proposed Title X regulatory changes will withstand these objections and ultimately be implemented remains to be seen. That they would worsen rather than improve quality of care is already clear.

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