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Ensuring our research reflects our values: The role of family planning research in advancing reproductive autonomy

Christine Dehlendorf, MD, MAS^{a,b,c,*}, Reiley Reed, MPH^a, Edith Fox, MPH^a, Dominika Seidman, MD, MAS^c, Cara Hall, MD^d, and Jody Steinauer, MD, MAS^c

^aUCSF Departments of Family & Community Medicine, San Francisco, CA

^bUCSF Departments of Epidemiology & Biostatistics, San Francisco, CA

^cUCSF Department of Obstetrics, Gynecology, & Reproductive Sciences, San Francisco, CA

^dDuke University Department of Family & Community Medicine, Durham, NC

Debates about women’s reproductive health and reproductive health care often reflect fundamental disagreements about women’s autonomy and agency over their bodies. As reflected in Dr. George Tiller’s guiding philosophy, whether or not politicians, policy makers, and advocates “trust women” is a central division in discussions around abortion restrictions and contraceptive provision. For those committed to advancing women’s empowerment, the belief in women’s reproductive autonomy – defined as their ability and fundamental right to make and act on decisions about their bodies, including whether to have sex, whether to use contraception to prevent pregnancy, and whether to continue a pregnancy [1] – is a fundamental ethical foundation.

While the role of research in advancing the field of family planning from a scientific perspective is readily apparent, the degree to which family planning research contributes to, or can detract from, a commitment to reproductive autonomy is less frequently considered. What questions researchers ask, how the research is framed, and what outcome variables are used have implications for the lens through which women’s reproductive health is seen, not only by those working in family planning research and health care, but also in society at large.

On one side, researchers’ choices can reflect and contribute to narratives that frame women’s reproductive health around population-based or ideological perspectives that devalue individual women and their lived experiences. Alternatively, the choices family planning researchers make in these areas can contribute to efforts to prioritize women’s autonomy and empowerment by explicitly focusing on women and their needs. This research also can help address reproductive health inequities and injustices by foregrounding the experiences and

*Corresponding Author: Christine Dehlendorf, 1001 Potrero Avenue, Building 20, Room 2205, San Francisco, CA, 94110, USA. (415) 206-8712, Christine.Dehlendorf@ucsf.edu.

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preferences of those individuals and communities – including poor women and women of color – whose reproductive desires have been historically devalued [2–4]. In doing so, family planning research can become better aligned with Reproductive Justice, a framework developed by women of color as a response to the experience of oppression and injustice across the full range of reproductive experiences, which explicitly prioritizes understanding and addressing the intersectional experiences of marginalized communities [5].

In the current political landscape, in which reproductive health and science are facing unprecedented attacks, we as the family planning community must commit ourselves to doing research that reflects our core ethical values. Below we review specific considerations related to the choice and framing of research questions, as well as the selection of outcome variables that affect the relationship of family planning research to advancing women’s reproductive autonomy.

What is it we want to know? The impact of the questions we ask

Through the choice and framing of research questions, researchers have the power to define what questions are considered scientifically legitimate and which topics have scientific evidence to inform policy and practice. An obvious example of how the selection of a research question can both reflect and contribute to the fundamental differences in perspectives about reproductive autonomy is the current active discussion regarding the role in adolescent reproductive health research of abstinence-only education [6]. Researchers who ask questions designed specifically to determine the effectiveness of abstinence-only approaches are adopting and feeding into a fundamentally proscriptive narrative about teen sexuality. In contrast, research that tests the effects of comprehensive sexual education, including efforts to promote healthy teen relationships, contributes to a perspective that acknowledges the universality and legitimacy of human sexuality. The choice of research questions regarding abortion similarly reflects these distinct perspectives. For example, research on abortion restrictions can either focus on their impact on abortion rates, or can instead investigate the impact of these restrictions on the experience of women receiving and those providing abortions. The difference between these two types of research questions reflects whether prevention of abortion is the goal, or instead whether the goal is the optimization of women’s reproductive experiences.

While these two examples clearly reflect ideological divides, there are more subtle ways in which research questions and how they are framed reflect whether or not women’s reproductive autonomy is being prioritized. For example, in research on contraceptive use, aligning a research agenda with making abortion “safe, legal, and rare” is an inherently stigmatizing perspective that is in contrast with research framed from the perspective of enabling women to make informed reproductive decisions with full access to contraceptive methods. While the actual research question or intervention may appear to be the same, the second perspective makes it explicit that women and their needs are being placed front and center, while the first implicitly accepts the framing of women’s reproduction as something to be controlled and stigmatized.

The framing of research in specific populations also can reflect and contribute to these different perspectives. For example, research on women with substance use disorders or who are incarcerated can either be considered from the framework of “high-risk” populations, whose reproduction should either explicitly or implicitly be prevented, or from the perspective of meeting the needs of those whose reproductive health, and reproductive autonomy, is commonly neglected. While the first framing feeds into a narrative of reproduction as something that can be judged and restricted, the second highlights the need to elevate women’s reproductive autonomy, especially among those who are most marginalized.

How do we measure success? The need for patient-centered outcomes

In addition to the choice of research questions and their framing, the selection of outcome variables represents a critical point at which family planning researchers can reflect values related to empowerment and autonomy, as opposed to normative goals about reproduction (such as those related to timing and number of children and the circumstances in which parenthood should occur). The importance of strategically and conscientiously selecting outcome variables is in agreement with the movement in health research across a range of clinical areas towards patient-centered outcomes, as opposed to focusing only on clinical or population-level outcomes, as a means of ensuring that research answers questions of highest relevance to patients. Examples of this shift include research in diabetes, with assessment of quantitative measurements like hemoglobin A1c and fasting glucose now being supplemented with more patient-centered measures such as quality of life and patient satisfaction [7, 8], and cardiology, with increasing efforts to include patient goals such as improvements in daily function and well-being in addition to disease-centered outcomes [9]. Given the context of reproductive autonomy, as well as the historical and social context of eugenics and stratified reproduction [1–3], family planning research is a critical area in which to apply this growing understanding of the importance of patient-centered outcomes.

To elucidate the ways in which the choice of outcomes can reflect or not reflect prioritization of reproductive autonomy, below we review commonly used outcome measures in family planning research and the extent to which they are grounded in respect for the needs and values of individual women.

Unintended pregnancy

Preventing unintended pregnancy is generally considered the gold standard outcome for public health and clinical interventions in family planning [10]. Use of this measure is based on the underlying assumption that an unintended pregnancy is a universally negative outcome [11]. Increasingly, however, research investigating women’s own views on pregnancy indicates that concepts of “intention” and “planning” do not fully capture the reality of pregnancy in women’s lives. Rather, intention may be better understood as a spectrum. Further, whether or not a pregnancy is “unintended” can be unrelated to whether a woman would have positive or negative feelings about a pregnancy [12, 13]. As a result, for some women, having an unintended pregnancy may not be an adverse outcome. Therefore,

using a metric of whether a pregnancy was intended to judge whether a pregnancy should be judged as “bad” or “good” has significant limitations from a patient-centered perspective.

In addition, implicit in the use of unintended pregnancy as the preferred outcome is the assessment that abortion is a negative outcome. This assumption neglects the range of women’s feelings about abortion as a potential part of their reproductive life course. For example, a woman may use condoms for contraception, with the understanding that she will choose to have an abortion if her primary method fails. If she uses abortion, regardless of how many times, to achieve her reproductive goals and is satisfied with the experience, then by any patient-oriented measure, the outcome is a success. Together, these considerations raise the question of the appropriateness of relying on measures of pregnancy intention in patient-centered family planning research.

Contraceptive Choice

Family planning interventions are also commonly evaluated by measuring their impact on contraceptive choice. For example, indicators such as the percentage of patients using a highly- or moderately-effective method, or the percentage of women choosing a long-acting reversible (LARC) method, are frequently reported [14–17]. The use of these outcomes is motivated by differential efficacy at preventing pregnancy across methods [18], and appears logical from a framework in which preventing unintended pregnancy is the gold standard. However, as described above, this framework does not acknowledge the nuances related to women’s reproductive decision making and experiences. In addition, this emphasis on the effectiveness of methods alone does not take into account that women have diverse preferences for the characteristics of their contraceptive methods, including adherence requirements, side effects, efficacy, and route of administration [19, 20]. While many prioritize effectiveness when choosing a method, others may consider aspects such as changes in menstruation, control over their method, weight gain or effects on acne, as equally or more important. In order for patients to choose a method that is the best for their values, lifestyle and circumstances, they may reflect on personal, social, and cultural factors [21], in addition to medical considerations such as whether or not there are contraindications to a specific method. By framing effectiveness at preventing an unintended pregnancy as the deciding factor for whether a method choice is a positive outcome, contraceptive interventions neglect the multitude of intersecting factors affecting women’s reproductive decisions [22], in the interest of prioritizing the prevention of unintended pregnancy. Method choice or LARC uptake therefore may not, in and of itself, be a patient-centered outcome, but rather a prescriptive projection of public health priorities onto an individual woman’s decision. Nevertheless, as will be discussed below, this does not obviate its potential use in certain contexts, particularly in combination with other measures.

Method continuation

Examining continuous use of a chosen method is another way of evaluating family planning interventions based on the potential for preventing pregnancy, as discontinuing methods can lead to gaps in use and therefore increase risk of unintended pregnancy [23]. While continuation could be considered a patient-centered outcome, inasmuch as it may reflect satisfaction with a chosen method, research and clinical practice in fact demonstrate that this

is not a consistent relationship. Patient preferences are dynamic, with many factors, including the availability of multiple options, influencing a patient's decision to continue or discontinue using a method [21]. As a result, method discontinuation may not reflect dissatisfaction, but rather a change in circumstance that influences how a method aligns (or no longer aligns) with a patient's lifestyle, values and preferences (such as relationship status or whether irregular bleeding is acceptable). In addition, features of specific methods, unrelated to method satisfaction, can influence method continuation. For example, patients are able to discontinue use of the pill, patch, ring, or condoms without seeing a provider, while LARC users must make appointments for both insertion and removal. Patients may also be unable or unwilling to reconnect with the health care system to obtain a different method, preventing them from discontinuing when they in fact wish to. Differential rates of continuation may not, therefore, necessarily indicate patient satisfaction, but reflect the relative challenge of method discontinuation. Further, recent research has documented providers placing barriers to desired LARC removals [24, 25]. In those cases, contraceptive continuation may be presumed to be a success, but this would clearly not reflect a positive patient experience or patient-centered outcome.

Given these complex factors influencing method continuation, a dichotomous measure of continuation/discontinuation that does not incorporate the context of this decision cannot capture whether continuation is a patient-centered outcome for that individual. Notably, studies assessing contraceptive continuation focus on continuation of more effective methods; there is a lack of research on continuation of less effective methods, such as condoms or withdrawal [26–28]. This neglect of continuation across the range of methods further limits the relevance of this outcome from a patient-centered perspective, because methods that may be effectively used with high patient satisfaction go unmeasured.

Recommendations to enhance family planning research's emphasis on reproductive autonomy

To advance the ethical foundation of family planning research, researchers can consider the following recommendations.

- 1. Choose research questions that reflect and support women's priorities and perspectives.** By deliberately and creatively formulating questions that reflect an emphasis on women's autonomy and lived experiences, researchers can proactively move the conversation about reproductive health. Examples of such innovative work in our field in recent years include the Turnaway Study [29, 30], research investigating abortion stigma and its impact on women's reproductive experiences [31, 32], women's lived experiences of abortion and abortion decision-making [33, 34], and women's experiences with contraceptive decision-making and counseling [21, 35]. Formative work that actively explores women's own views on their reproductive health, as well as including community and patient stakeholders in the development of research questions, can help to ensure that researchers are guided by the needs of groups they are working to benefit.

2. **Ensure the framing of research in scientific publications and media coverage reflect respect for and prioritization of reproductive autonomy.** When describing research, the language that researchers use will dictate whether the scientific and lay community hear messages that reinforce or detract from an ethical commitment to trusting women and their reproductive choices. Given the ideological divisions around reproductive autonomy, it is critical not to make assumptions about the lens through which research will be interpreted. For example, research designed to optimize the reproductive health of specific populations – such as women who use substances, or women who have had more than one abortion – has the potential to be seen as reflecting a lack of trust of these women and their decision-making capacity and to be used to support disempowering and/or stigmatizing policies and perspectives, even when that is not the researchers' intent. Similarly, research that focuses on access to highly-effective contraceptive methods can be interpreted as promotion of these methods for all women, even when the goal is to advance reproductive autonomy by removing barriers to use of these methods so that all women have the option to use them. Therefore, conscientiously and repeatedly framing research with respect to reproductive autonomy can ensure that research questions and results are not misinterpreted, and that the core value of women's reproductive autonomy is reinforced.
3. **Utilize patient-centered outcome measures:** Given the limitations in commonly used measures for family planning research, the following strategies can enhance the patient-centeredness of family planning outcomes.
 1. *Develop and use explicitly patient-centered measures assessing outcomes of relevance to patients.* Drawing on patient-centered outcomes literature in health care more generally, and on what is known about women's values and preferences around reproduction, family planning researchers can incorporate existing and novel measures to capture core aspects of women's experiences with family planning and family planning care. Examples of existing scales include the decisional conflict scale, which has been widely validated as a measure of quality decision making across a range of settings [36], and the Interpersonal Quality of Family Planning Care scale, developed specifically in the family planning context, as a measure of the patient-centeredness of contraceptive counseling [37]. Potential novel outcome measures that could be developed include reproductive quality of life measures and longitudinal measures of satisfaction with contraceptive methods. Additional formative work directly with women of reproductive age, especially those whose perspectives have been historically neglected, can help identify additional outcomes of interest to patients.
 2. *Incorporate nuance into the measurement and interpretation of unintended pregnancy.* There are ongoing efforts to improve understanding and measurement of the acceptability of pregnancy for an individual woman that will enhance our ability to document the

impact of family planning interventions from a patient-centered perspective. In the meantime, the use of this measure will likely continue to be necessary given both its long history in public health surveillance and its parsimony. In this context, however, the limitations of relying on intention alone when assessing the value of a pregnancy can and should be incorporated into how data about unintended pregnancies are interpreted and what conclusions are drawn from that data. Researchers should also avoid the tendency to describe any measure of pregnancy desirability as being a measure of intention, as this obscures the distinctions between different aspects of women's perceptions of pregnancy. An example of this false equivalence is when a measure of whether or not a pregnancy is viewed positively once it occurs is described as indicating whether or not a pregnancy was intended [11].

3. *Incorporate multiple measures, including contextual factors.* Difficulty in interpreting measures of method choice, method continuation, and unintended pregnancy often arise from a lack of adequate contextual information about the patient experience surrounding the specific outcome. As an example, interpretation of method continuation is difficult without information about access to care, the quality of interpersonal care, and the motivation behind or circumstances around method switching (including changes in reproductive goals, for example). Therefore, data showing improved method continuation with an intervention would be more compelling when combined with data about patient experience of interpersonal care and method satisfaction over time. Similarly, data showing increased LARC uptake could be seen as patient-centered if paired with information about experience of care and preference-concordant decision making, such as through the decisional conflict scale.

Through this critical reflection on the selection and framing of research questions and on the measurement of outcomes, family planning researchers can ask and answer questions that support women to reach the “highest standard of sexual and reproductive health” [38] as they themselves define it. Further, this unwavering commitment to the ethical foundation of women's empowerment can contribute to a broader societal narrative about the non-negotiable nature of women's reproductive autonomy.

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