A Qualitative Study of the Perceptions of Dissatisfied Norplant Users

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Background. The purpose of this study was to examine specific factors that motivated the request for early removal of Norplant among a group of young, low-income women who were dissatisfied with this contraceptive method.

Methods. Focus groups were conducted to obtain qualitative in-depth attitude and opinion data about Norplant from women who had used this method of contraception for a period ranging from 2 months to 25 months and had requested its removal because of side effects.

Results. Patient motivation for requesting Norplant removal was based on side effects. No other reason for early removal requests emerged from the focus group discussions. However, the comments of many participants raised questions about the psychosocial context in which patients obtain information about Norplant and request early removal. Many participants mentioned having felt pressured to accept Norplant and not being fully informed about possible side effects. All but two said they were encouraged to "wait out" side effects and that physicians were reluctant to remove the Norplant capsules. Many participants recalled that they had to request removal several times before their physicians complied with their wishes.

Conclusions. The results of this study suggest that there is a need to review the process of educating patients about Norplant, the situational context of Norplant counseling, and physician practices related to patients' requests for early removal.

Key words. Norplant; contraception; contraceptive devices, female; patient acceptance of health care; patient satisfaction. (*J Fam Pract 1995; 40:465-470*)

Despite widespread contraception use in the United States, few studies have assessed women's satisfaction with specific methods, particularly in the primary care setting. Specifically, little is known about American women's satisfaction with Norplant, a system of subdermal contraceptive implants introduced in the United States in early 1991 after years of testing and use in other countries.[1] Studies have demonstrated that the majority (76% to 90%) of Norplant users continue using this method after the first year but that 10% discontinue it because of menstrual irregularities and other side effects.[2,3] Because Norplant has been available in the United States for a limited period, most surveys that have examined American women's perceptions of this method have focused solely on the period shortly after insertion.[4-6]

Studies of Norplant acceptance typically show that the majority of women who request early removal for reasons other than a desire to become pregnant report intolerable side effects, such as menstrual disturbances, headaches, weight gain, and depression.[5,7,8]

It has been hypothesized that preinsertion counseling plays a key role in women's acceptance of Norplant. In the Population Council's International Committee for Contraception Research study,[9] the continuation rates were 81% after the first year and 42% at the end of 5 years. The low 5-year continuation rate was attributed to lack of patient and clinic staff counseling about possible side effects.[9] Another recent report on Norplant suggests that acceptance and continued use of this contraceptive

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method depends, in part, on the extent of counseling about risks, benefits, and potential side effects.[10,11]

The impetus for the present study arose from observations by family physicians in our research group, the South Carolina Family Practice Research Consortium. The high number of requests for early Norplant removal observed by these physicians in recent years suggests widespread dissatisfaction with Norplant among this patient population. This trend prompted us to question why many Norplant users were requesting early removal and the extent to which counseling adequately prepares women for possible side effects. Our objective was to explore, from the young, low-income user's point of view, the full range of influences on Norplant satisfaction and the early-removal decision.

Methods

Qualitative research strategies are useful to obtain a full understanding of patients' perspectives.[12] The focus group method offered several specific benefits in exploring women's perceptions of Norplant and their motives for early removal. First, we considered the possibility that there are secondary influences on the early removal decision that are not likely to emerge from a survey. Second, the focus group format allowed women to speak openly and honestly about their removal decision without the pressure of reimbursement considerations, the presence of a physician or nurse, or other potentially biasing variables. Focus groups also permitted us to explore in depth the extent to which women had been educated about possible side effects before having Norplant inserted. We expected that Norplant user perceptions and concerns that have not been previously identified by quantitative research methods would emerge from the focus group discussions.

Participants were drawn from the patient populations of health clinics servicing low-income areas and from medical centers serviced by family medicine teaching programs in three South Carolina cities. All the sites accepted South Carolina Medicaid. The participants at each site received care from 15 different physicians. With one exception, participants requested and obtained Norplant removal after at least 2 months of use during the year preceding the focus group discussions. Women who had requested removal because of their desire to become pregnant were not included in the study.

The moderator started the focus group meeting with a brief explanation of its purpose: "to learn more about women's experiences with the Norplant method." It was emphasized that the research was confidential. The moderator then asked for permission to audiotape the session, explaining that only she, her assistant, and a colleague would listen to the tapes, and that individual participants would not be identified by name.

The focus group discussion was guided by the topic outline, which consisted of a sequence of broadly stated questions: (1) What to you are the best things and the worst things about this method of birth control? (2) What made you decide to request removal of Norplant? (3) What type of information did you receive about the Norplant method before deciding to use it? and (4) Do you think that you would consider using the Norplant method again?

The first and the last questions were asked in a "'round the room" format that gave every participant an opportunity to speak. The second and third questions were directed toward the group. Moderators added appropriate "probes" to explore specific issues and themes in the discussion. For example, we asked participants who had received counseling about Norplant while in the hospital for childbirth how they felt about this. Probes varied from group to group.

Each respondent was paid $35 for participating in the study. The moderators emphasized that payment was for participants' time and willingness to share opinions, not for any particular type of opinion.

Audiorecordings of the focus group discussions were transcribed. The transcripts were reviewed by the authors for common themes. The authors discussed the transcipts to identify the major findings of the study. Because participants' perceptions were consistent across groups and among individuals in each group, it was not difficult to reach consensus. The process of immersion and crystallization,[13] in which the authors "immerse" themselves in the data and jointly discuss its meaning, sufficed as a means of analysis because of the small number of groups and the high degree of participant agreement.

Results

Recruitment

The participants were asked to enroll in the study based on their request for early removal of Norplant. They were asked by telephone, using a standardized script, to volunteer for small-group discussions about birth control methods. Standardized follow-up letters were sent as a reminder. The participants were not aware at the time of recruitment that they were invited because of their request for Norplant removal. On the day of the focus group meeting, each participant signed a consent form.

At site 1, nine patients had successfully requested Norplant removal during the 1.5-year period preceding

the focus groups. Six patients agreed to come to the focus group and three actually participated at this site. One participant at site 1 had requested early removal but had not yet undergone the procedure. At site 2, five patients had requested and obtained Norplant removal within the 6 months before the focus group meeting. All five patients agreed to come to the focus group and three actually participated at this site. At site 3, approximately 30 patients had had the Norplant System removed at their request within the 3 months preceding the focus group meeting. The 11 patients who agreed to come to the focus group were selected based on the availability of telephone access and limited by the desire for a total group size of fewer than 12. Nine patients participated at this site.

In all three groups, discussion was highly animated and distributed evenly among participants. Most of the women shared with other members of the group their experience with Norplant, including the circumstances under which they had first heard about it, the side effects they experienced, and the removal process. Much of this information was expressed in response to the first question about the advantages and disadvantages of Norplant.

Participant Characteristics

Focus group participants ranged in age from 18 to 26 years, with a mean age of 20.4 years. One third were married. All participants had used Norplant for at least 2 months, with a mean of 13.8 months.

Sixty percent of focus group participants were black and 40% were white. All but one participant reported having had at least one child before having Norplant inserted.

Reported Advantages of Norplant

Focus group participants generally agreed that the advantages offered by Norplant included convenience, as opposed to the pill or a barrier method; overall reliability in preventing pregnancy; long-term (5-year) duration; and low cost, compared with other methods. Without exception, focus group participants were adamant that they wanted to avoid pregnancy and that the Norplant System, as described to them, seemed to be an ideal method. For example, one participant said:

I thought it was a good thing that you didn't have to take a pill every day. . . . Another good thing was in the long run, the cost was cheaper than having to go out and buy pills every month. . . . Also a good thing was knowing that it was one of the most effective contraceptives on the market; this was quite relieving.

Side Effects

Questions about the "worst things" about the Norplant method produced discussion about the severity and persistence of a range of side effects. To participants, prolonged bleeding, headaches, and mood swings were the most troubling side effects. Weight gain, hair loss, and localized pain were also mentioned by several participants:

I had headaches two or three times a week. I stayed nauseated. My hair would fall out when I took a shower.

I had it in for 2 years and I stayed dizzy, had headaches. I gained 46 pounds in those two years.

[My period] was like 2 weeks out of the month and I did not feel good. Migraine headaches, lack of energy, and just general depression.

The prolonged bleeding was particularly distressing for some participants:

The bleeding became so bad that I got to the point I didn't want to deal with it anymore.

Mood changes were typically described in the following manner:

One day you might feel good and the next day, you are so depressed . . . you snap at everything around you. The people I work with have told me I have a split personality.

It was like sometimes when you have your period and you tend to get emotional. . . . You are like that all the time when you are on the Norplant. I mean, it was bad.

When they became aware that not all Norplant users experience side effects, some participants expressed disappointment that they were among those who did. For example, one mentioned:

I think it was upsetting because the side effects happen to some people and some people are not affected. I guess I was upset that I was one of those people that has the side effects because you know it would have really been wonderful if it had worked.

The question "Why did you request removal?" seemed to have been addressed by the consistent and intense manner in which participants described side effects. Therefore, when the moderators asked this question, they probed to discover other possible motives for

removal among participants and "other young women like you." Specific questions were asked about reasons for removal that are not related to side effects, such as the desire to become pregnant or a male partner's negative reaction to Norplant. In all three focus groups, the responses to these probes further impressed the moderators that intolerable side effects were the sole reason for early removal.

The moderator also asked participants how convinced they were that the physical and emotional discomfort they experienced was related to Norplant. All were sure that this was the case, pointing out that the side effects dissipated once the Norplant System was removed.

[After removal] it felt like something was lifted up off your body or something. . . .

Counseling

All participants indicated on a data collection form the type of education they had received about the Norplant System before insertion. Nine of the 15 participants said they had been exposed to a combination of educational methods: written information, discussion with a health care provider, or an instructive video (Norplant System Levonorgestrel Implants, Counseling Guidelines, Wyeth-Ayerst Laboratories, Philadelphia, Pa, 1990). Four of the participants had viewed the video, and two had been given written information regarding Norplant. The majority of participants recalled that the information they had been given emphasized the positive aspects and minimized the possibility of adverse side effects. Most participants had the impression that side effects were uncommon and not as severe as they later experienced. For example, one participant recalled:

I watched a film about it. They talked about the good things and the side effects. Well, I thought the side effects happen today rarely . . . but I believe I had every one of them.

Several participants commented on the unanticipated severity of the side effects they experienced. One said:

One fact they say is that periods are going to be irregular, and you can deal with that thing but not to the extreme that you bleed.

Another said:

They say you might have some mood changes but not severe.

Some participants had been counseled about Norplant in the hospital after giving birth. These participants believed that they had been rushed and, to some extent, "pressured" to agree to Norplant insertion while still in the hospital. One of these participants said:

I really did not want it but after I had my baby, they came in my room and asked me to look at the [educational] movie. . . . They put mine in the day I had my little girl and they just kept hassling me.

Another participant who received Norplant insertion in the hospital after having a baby said:

They were telling me, "What you gonna do for birth control? Are you gonna get a Norplant? It's good. . . . Medicaid will pay for that to go in," you know. I had a week to figure out what I was gonna do . . . so I just jumped on that.

Some participants believed that they did not receive adequate counseling about Norplant and possible side effects before insertion. One said:

I think they should educate you more. I mean, we're young but we're not stupid.

Another participant felt she should have educated herself about Norplant:

You know, it was my responsibility to read and study up on it before I had it done anyway. I don't blame anybody but it was a bad experience . . . because a lot of us say, that's really great and kinda went in feet first and didn't really stop and think about . . . are the side effects that severe? It was never stated as being that severe so you really need to know.

The Early Removal Experience

The majority of participants recalled that the medical staff reacted with some degree of reluctance to their request for early removal. This perceived resistance to removal was described by participants in a variety of forms. Several mentioned a reaction of skepticism on the part of the physician or nurse when describing their side effects. For example, one said:

I had it for a year and 2 months. Then when I called them to talk to the doctors to take it out, they did not want to take it out at all. They gave me some kind of stuff about, you keep it in there, this happens to everybody. . . . It made me feel like I was trying to lie about how I was feeling.

Another mentioned:

They look at you like you are stupid and they make you feel that way, too. You keep on calling [to request removal] and they can't tell how you feel but they can make you think they know how you feel. . . . They don't know what it's like to have that thing in there and they don't care what harm it does.

Many participants recalled having been encouraged by the doctor to "wait out" side effects. One said:

I was still having heavy bleeding . . . and they said, well, it takes a little while, so I went for a year. . . . It didn't get no better. I mean, who wants to go 19 days' worth of bleeding? They don't jump to take it out but they sure do want to put it in.

Some participants perceived a generally negative attitude on the part of the physician who removed their Norplant. For example, one said:

When he took mine out, he criticized the reason why I wanted to get it taken out. [He said] "Well, most [of them], when they get them taken out, will be back in here in 3 months pregnant."

Because the prevailing perception was that physicians were unwilling to remove Norplant, the moderator asked participants what they thought accounted for this reluctance. One theme in responses centered on participant status of being young, already having one child, and for some, being unmarried. For example, one mentioned:

I think that's why they push it a lot is because we are young and, you know, you need this because you just had a child or whatever.

Another mentioned cost factors associated with pregnancy in the low-income group:

I think that's why they push the Norplant, because if you already have one child while you are in the hospital, they put it in so you won't be coming back. If they can spend $200 over the long run of 5 years to have it put in now, that will save them over the long run.

Along the same lines, another participant commented:

I believe that the reason they were so hard about taking it out is that they were thinking it was just some story to . . . get Medicaid to pay for [early removal].

Most participants were aware that they needed a "medical reason" for Medicaid to cover the cost of early removal. A few participants paid for early removal themselves, but most received Medicaid coverage. The majority said that the side effects were so severe, they were willing to pay for removal themselves. Typical of such comments was:

I was to the point where I didn't care what I had to pay.

One participant remembered having been told in the counseling session that Norplant would be removed if she didn't like it but that her doctor "didn't say that I would have to go through all these procedures before he decided I didn't like it."

A few participants reported positive removal experiences with sympathetic doctors. One of these said:

He took it out with no problem. He was the best doctor I ever had. He told me that he saw a lot of girls who came in to get it out and he had been taking them out left and right because they are not working.

We concluded the focus group session by asking participants what they had learned from their experience with Norplant. The majority of participants who felt they had encountered resistance to their request for removal expressed distrust of the medical system:

You can't believe everything that a doctor tells you. I've always had the impression of doctors [that] they are always right. But since I've had that experience, I would always do more research or . . . tell them to give me more information.

For some participants, this distrust expressed itself in the perception that they had been used as "guinea pigs" to test Norplant. These women believed that they had unknowingly served as subjects in a study to test Norplant side effects and that this was one reason doctors were reluctant to remove it.

The only participants who did not mention a lack of trust in the system as an outcome of their Norplant experience recalled having been treated sympathetically by their doctor when requesting early removal.

Discussion

The major findings of this study centered on patients' perceptions about the way they were counseled about Norplant and their experiences related to requesting removal. First, participants believed that the advantages of Norplant had been emphasized but that the potential side effects had been minimized. Many participants believed they had not been told the "whole story" about Norplant. A large segment of participants, particularly those who had received counseling about this method while in the hospital following childbirth, felt that they had been

pressured to agree to Norplant insertion. More disturbing were participants' descriptions about the difficulties they experienced in the removal request process: specifically, doctors appeared reluctant to remove Norplant; some participants were asked to "put up" with side effects they perceived as severe; and health care providers did not believe their description of side effects.

The results of this study must be interpreted cautiously in the context of its limitations. First, we recognize that participant perceptions were expressed in hindsight and, at best, represent reconstructed experiences. Patient beliefs about the physicians' motives do not necessarily take into account the full range of influences on physician behavior. For example, if participants expected difficulties with requesting early removal, they might have interpreted the physician's routine questions about their motives as reluctance to remove Norplant. Similarly, a physician's decision to delay removal to determine if the side effects are temporary might be interpreted by patients as reluctance to remove it. Second, the majority of participants were low-income patients who use clinics, and thus may lack continuity of care. This might have affected their perceptions of the medical staff's reactions (or staff's actual reactions) to the patients' requests for removal.

Considering the comments of our focus group participants, it is appropriate to question whether initial enthusiasm for Norplant among medical practitioners has become a "hard-sell" approach to promoting this method of contraception, especially to young and poor patients. It is possible that counselors inadvertently painted an overly favorable picture of Norplant based on the manufacturer's product literature available at the time our participants were counseled. This literature may have underestimated the severity and frequency of Norplant's side effects. For example, according to a patient education brochure on Norplant ("The Most Recent Innovation in Birth Control," Norplant System Levonorgestrel Implants, Wyeth-Ayerst Laboratories, Philadelphia, Pa, 1991), many women can expect menstrual irregularities to dissipate after 9 to 12 months. We also should determine if either the potential difficulty of Norplant removal or concerns expressed by medical staffs regarding Medicaid reimbursement policies on early removal have caused physicians to be reluctant to remove Norplant.

It is important to remember that the findings of this study are based on young, low-income women's experience with Norplant. It is possible that our participants found it less acceptable to wait out the side effects than would other groups of Norplant users. It is also possible that young, low-income women have less knowledge and fewer resources to cope with side effects than do older or more affluent Norplant users.

Our findings underscore how important it is that Norplant counseling address the educational and emotional needs of young, low-income women, who represent a key group of Norplant users. Counseling that better prepares women in this demographic group to expect and tolerate side effects might enhance acceptance of this method. A program of ongoing counseling for women who experience side effects may be one way to provide support and suggest coping strategies. For example, a clinic-based "Norplant hotline" could be established to meet users' needs for ongoing counseling. Considering that some US communities are now encouraging Norplant use among girls of high school age in inner cities, educational programs that support acceptance among young women should be developed.

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