A Study on Women's Experiences with Depo-Provera (Major findings of the study)

Women's groups in India have been aware of the controversy surrounding injectables like Net En and Depo in the US and the UK, where women's organisations and health activists have been raising questions about the health risks associated with long acting hormonal contraceptives and the potential for abuse. However, in India, due to the extreme secrecy surrounding the clinical trials and the decision to introduce these methods, women's groups have always struggled to gather information and data. Although injectables are not included in the Family Welfare Programme, doctors, even in public hospitals, can prescribe them if they are legally available in the market. We have come across many private doctors and public hospitals in Delhi that have been prescribing Depo Provera regularly. However, there is lack of data on the conditions under which these are prescribed, as also on the follow-up and counseling services they provide. Along with examining this, there is a need for a long-term interaction with women who have used Depo Provera, document and analyse their experiences with the injectable.

Sama initiated the study in September 2001. Even though the sample size (52) was small, we still felt it was important to go ahead with the study as it was important to get a first-hand account of the women's experience with Depo, and to know directly from them how they were provided with information, how they perceived the side-effects, and what kind of follow-up services were available to cope with these. We also felt that the findings from even a small sample would be able to provide at least an indication to what could be the larger picture.

Specific objectives of the study were:

- To study and observe the screening, follow-up and counseling procedures followed by the public health professionals and institutions while providing Depo Provera
- To assess the medical establishment's response to the health problems following the use of the injectable
- To assess the impact of the use of this contraceptive on the health of the women.
- To understand the gender dynamics and the decision making process within a family regarding adoption of injectables.

Such a study, we hoped, would also enable us to understand how the concept of informed choice operates within the public health set-up and about the procedures regarding the procurement of injectables.

Findings:

I. Recommended literature states certain minimal mandatory facilities in terms of the setting, as well as prescribes specific conditions and procedures to meet the ethical standards under which the injectable should be administered. The study findings indicate that NONE OF THESE NORMS has been strictly adhered to.

There are serious violations in terms of

1. Providing the women with **Informed choice**: most of the women were given no information about other methods that are available that they could choose from (31 out of 50) or any possible side effects (42 out of 50).

- 2. The procedures and conditions of administration of the injectable: as many as 28 women out of 50 did not undergo ANY of the required screening criteria, i.e. they were not made to undergo even the most basic mandated physical or medical examination. Even more shocking was that 31 of them had history of medical conditions that the provider should have inquired about and prescribed tests for, before even considering giving them Depo Provera. All of these are conditions that require strict follow-up to observe even the slightest hint of a problem.
- 3. Follow up of problems and side effects experienced: women experienced multiple and severe side-effects enough for almost half of them to discontinue, and yet their complaints elicit very casual and extremely insensitive responses from the doctors. There was almost no monitoring, follow-up and counseling.

"motopa acheha hota hai. This is not weight gain but normal growth". Response of the doctor to woman who suddenly put on 10 kg after she was administered Depo. She also experienced several other problems, leading her to take the decision to discontinue. "I have suffered enough".

II. The study looked at the short-term risks of the use of Depo¹. It was understood from the study that 43 women out of 50 were in the reproductive age group. 48 of the women reported problems after using the injectable and each woman had multiple problems. 26 of the women reported five or more problems, with one experiencing up to 13 problems. The risk of administering this drug to women during this prime period needs to be weighed against the potential hazards. The most common problems reported by women were amenorrhoea (25), weakness (20), excessive bleeding (16), headache/ migraine (13), hot flushes (10), weight gain (10), hair loss (9), dizziness (9), lack of sexual desire (8).

The research findings prove and effectively demonstrate that the health delivery system studied was grossly inadequate in meeting the minimal necessary infra structural requirements of introducing an injectable such as Depo Proverb. It can be concluded that in the absence of sophisticated medical equipment, diagnostic facilities, skilled medical personnel, it is very unlikely that a woman will be adequately screened or monitored for subsequent problems as is required. The debate on choice cannot be carried forward without taking into account these realities. To ignore these would be to display complete disregard and apathy to the risks that women are subjected to.

About Sama:

Sama is a Resource group for Women and Health working closely with women, men and adloescent girls from tribal, dalit and minority communities. We work primarily on health, reproductive rights, violence and socio economic well being of women and the underprivileged.