Client Perception of Oral Contraceptive Side Effects: A Research Survey

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by
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Observations

"To treat illness, the healer must dare to meet the patient in the messy, confusing, always special context of lived experience." Arthur Kleinman, The Illness Narratives, p. 206.

"Well, just because he doesn't have any pain, doesn't mean it doesn't hurt!" Client, Multnomah County Health Department.

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Abstract

The purpose of this descriptive survey was to describe women's perceptions of oral contraceptive side effects. Utilizing a convenience sample (n= 372) of clientele from Planned Parenthood clinics in the greater Portland area, a one page survey composed of 12 questions was distributed and collected during August and September 1992. Results indicated that clients were more likely to perceive as "serious" those side effects which are medically classified as "minor". Further statistical analysis revealed that education consisting of a review of symptoms had no subsequent positive effect on the client's ability to correctly name serious side effects of birth control pill use. Length of time on oral contraception also had no relationship with identification of medically serious side effects in this population. Implications for practitioners include an acknowledgment of the importance women attach to so-called minor side effects, and the need for suggested management of these symptoms. Further research is also needed into how women can be taught to correctly identify serious side effects of oral contraceptives, perhaps utilizing changes in educational and instructional literature or birth control pill packaging.

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Chapter 1

Perception of side effects and their subsequent significance may differ from client to client. In addition, divergence may be noted between definition of the term "serious side effect" in educational literature versus the experiential definition of the birth control pill user. Compliance and satisfaction with the pill regimen has been inversely related to pill side effects, which may be perceived by women as "minor" or "serious" in nature. The role of the clinician in this process may be problematic. As noted by Hillard (1989) "women's independent judgments about their oral contraceptives played a more important role in oral contraceptive continuation or discontinuation than did explicit medical advice" (p.1413).

Package inserts and instruction sheets may not help clarify side effect information, particularly in the teenage population, as fewer than 10% of compliant teenagers reported reading their pill package inserts in one study (Emans, Grace, Woods, Smith, Klein, and Merola, 1987). In addition, inserts are often written at a reading level above that of their target audience. Zion and Aiman (1989) found in reviewing 74 pamphlets developed by the American College of Obstetricians and Gynecologists (ACOG) that 64 were written at a level higher than the mean U.S. literacy level, which is at or below the eighth grade.

Serious effects from birth control pills, while not common, are feared by many women, and their risk level may be erroneously perceived. One example is the fear that birth control pills cause breast cancer, a fear which has been reassuringly allayed in several studies (Center for Disease Control and National Institute of Health, 1986) (Peterson and Lee, 1990). Nevertheless, many women perceive birth control pills, even the newer lower dose pills, as dangerous. According to a 1985

Gallup poll, approximately 75% of women queried believed that birth control pills cause serious health problems (Mishell, 1989).

In addition, the line between "side effects" and "dissatisfaction" may be blurred for users. Although discontinuation rates for birth control pills may be as high as 50% within the first year for select populations (Hillard, 1989) side effects have been clearly differentiated from general dissatisfaction as a reason for discontinuing pill use by some researchers. Bracher and Santow (1992) found that women who discontinue pills may do so for a number of reasons ranging from desire for pregnancy, to the end of a relationship, to the inability to remember to take pills correctly.

Still, side effects such as bleeding irregularities, or perceptions that pills have serious health consequences can play a major role in pill discontinuation, especially with the adolescent population (Hillard, 1989). It is hoped that the clinician can play a more active and effective role in the client's perception of birth control pill efficacy and desirability, by educating the client to anticipate and differentiate between minor versus major side effects or problems with pill use. Information on client perception of side effects may be useful for the nurse who provides a majority of health care education in family planning clinics.

Review of Literature

Published literature on perception of birth control pill side effects has primarily focused on the adolescent population (Speroff, Jones & Davis, 1992; Balassone, 1989; Emans et al., 1987; Kaunitz, 1992), wherein perception of side effects is related to patient compliance with the pill regimen. Hillard (1989) reiterated the results of several studies which "suggest that bleeding irregularities are a primary

reason for discontinuation of oral contraceptives, especially among adolescents" (p.1412). Hammerslough (1984), in studying women age 15-44, found particularly high discontinuation rates at the end of one year's use for contraceptive users of any method except rhythm began by women age 21 or younger. Adolescents may be influenced to discontinue birth control pills on the basis of so-called "minor side effects". Speroff et al. (1992) noted that, while clinicians focus their education and follow-up on identification of major side effects such as cardiovascular complications, "it's really those 'minor' issues that affect compliance greatest: fear of weight gain, breakthrough bleeding, and amenorrhea" (p.105). Both Emans et al. (1987) and Kaunitz (1992) found that side effects have a primary influence on pill compliance.

Gaps in the literature on this topic involve the limitation of applying existing data on adolescent populations to a larger adult population with different patterns of contraceptive use, parity, sexual behavior, education and other variables. A large retrospective study (n=2,547) undertaken in Australia using women age 20-59 years who participated in personal interviews for the 1986 Australian Family Project (Bracher and Santow, 1992) found lower first year discontinuation rates for non-adolescent pill users (10%) with side effects still noted as a reason for premature discontinuation. However, discontinuation was also common in this age group for reasons not conceptually linked to dissatisfaction, such as desire for pregnancy, menopause, or sterilization of self or partner. This underscores the fact that caution must be used with this group when attempting to correlate side effects with discontinuation.

"Compliance" was less of a conceptual focus for research on adult users. Many studies on adolescents focused on compliance, with the underlying assumption that pills are difficult for adolescents to take correctly (Kaunitz, 1992; Speroff et al., 1992; Brown, Cromer, & Fischer, 1992; and Emans et al., 1987). Bracher and Santow (1992), however, note the limitations of their adult focused study to ascertain how conscientiously methods are used based on self-reporting methods, and refer frequently to "accidental pregnancy" rather than "user failure". They state that "presumably any woman can forget to take her daily pill, or can run out without having a backup supply and then fail to take alternative precautions" (p.64). Studies are also limited in their time scope, as very little longitudinal research has been done on pill users who may experience perceptual shifts towards their method and it's side effects as time passes. Bracher and Santow (1992) note that dissatisfaction with pills, and perhaps subsequent lower tolerance of minor side effects tends to rise during years 1-4 of use, and state that long term users, while more "compliant" in the sense that they have avoided pregnancy and presumably use their pills more correctly "appear to become increasingly disenchanted with the pill or apprehensive of it" (p.61).

Conceptual Framework

In order to provide a working definition of "serious side effects" that is congruent with the education protocols of Planned Parenthood and thus likely to be used with the target population for client education, use of the ACHES acronym was utilized for conceptual analysis. The ACHES acronym is used as a teaching tool per protocol for each client at their 3 month birth control check visit. While taking the client's blood pressure, clinic support staff review the ACHES warning signs and

document their presence or absence in the pill user. This visit must be completed before an initial client receives their 4th cycle of birth control pills. This initial client may be either: a) a new birth control pill user or b) new to the Planned Parenthood system. ACHES represents the early pill danger signs of abdominal pain, chest pain, headache, eye problems, and severe leg pain. The most recent edition of Contraceptive Technology (1990-92) also adds the recommendation to "see your clinician if you have any of these problems, or if you develop depression, yellow jaundice, or a breast lump" (Hatcher, Stewart, Trussell, Kowal, Guest, Stewart, and Cates, 1990, p.293). Planned Parenthood client information handouts (Appendix A) include arm pain and weakness or numbness on one side of the body as serious pill problems which can signify a blood clot. Clients are also told to contact the clinic for advice if they experience heavy bleeding, a change in moles, or shortness of breath. A total of 14 serious symptoms were identified according to this criteria.

Minor side effects were defined as those effects which, while common with birth control pill use, are excluded from the listed criteria for major pill problems. Specifically listed in the patient information sheet given to birth control pill users at Planned Parenthood are: breakthrough bleeding, bloating, water retention, breast tenderness, nausea or appetite change, and missed periods. Breakthrough bleeding is defined as that which occurs at any time when menses is not due, whether spotting or heavy flow. Clients are not advised to contact their provider unless bleeding is to the extent of soaking one or more pad or tampon per hour.

Weight gain is also a common minor side effect as listed in the literature (Speroff et al., 1992) which may be of particular concern to young women. Acne may be improved or exacerbated by pill use (Kaunitz, 1992) and its exacerbation would be

considered a minor side effect. A total of 7 listed minor side effects were identified through utilization of the patient handout: breakthrough bleeding, amenorrhea, nausea, bloating, breast tenderness, and blood pressure changes or "other". Blood pressure changes, which would be noted at an annual or 3 month symptom review, are not explicitly listed but are noted as a potential side effect in light of the requirement that the patient have their blood pressure checked after the first 3 months of birth control pill use.

Errant responses, including health concerns which have not been linked to pill use in current statistical data such as breast cancer or infertility are assumed to indicate an inability to identify serious side effects, as well as an inability to discriminate between serious and minor side effects in the proposed survey participants. For the purposes of this survey, 28 "non-listed" responses were identified, consisting of side effects which may or may not be linked to pill use (i.e. weight gain) but are not listed as serious or non-serious in the symptom education literature provided to patients. These categories were based on data collected from coding of the actual client responses gained in the survey process, and were used to identify a pattern of client generated symptom concerns.

Research Questions

The primary research question of focus in this study asked: What do participants perceive as serious side effects of birth control use? A second question explored whether participants could correctly name and discriminate between "serious" and "minor" side effects.

Chapter 2

Methods

This chapter describes the methods used to answer the primary and secondary research questions under consideration: 1) What do women perceive as serious side effects of birth control pill use and 2) Are study participants able to correctly discriminate between "serious" and "minor" side effects in accordance with instructional literature provided by their clinic? An overview is given of study design, setting, variables, participants, measurement tool, and procedures. A description of statistical methods utilized for data analysis will conclude this chapter.

Design

The study used a descriptive survey format to explore correlational variables which may affect women's ability to identify serious side effects of birth control pill use. A qualitative component of the design was used in asking women to name 3 serious side effects of birth control pill use which they would consider serious and would report right away (Appendix B). It was hoped to discover which side effects women defined as serious, and, through quantitative analysis, how independent and intervening variables might influence the accuracy of responses given.

Setting

Surveys were distributed and filled out in four Planned Parenthood clinics located in Southeast and Northeast Portland, Beaverton and Gresham, Oregon. Preliminary pilot testing of the instrument was completed at the Vancouver, Washington clinic, and this data was excluded from final analysis. All clinics accept

Medicaid and offer sliding scale services to some degree, though only the Southeast clinic received Title X funding to offer free services and contraceptives.

An uncontrolled variable in this study included the loss of federal funding for the Southeast Portland clinic as of July 1, 1992, which may have decreased the number of low-income birth control pill clients.

Participants

A convenience sample was obtained from the Gresham, Beaverton, Northeast, and Southeast Portland Planned Parenthood clinics with a sample size totaling 372 participants over the period of August-September 1992. Entry criteria excluded clients under the age of 18 from participation. Clients were offered the option of refusing to participate without jeopardizing their access to birth control pills or health services at Planned Parenthood. The primary entry requirement was that participants must currently be using birth control pills obtained from one of the four clinics under study. Participants were also required to read and write English. Necessity of informed consent was waived per exemption category 2 (45 CFR 46.101(b)) of OHSU's research statute. The design tended to target women who pick up birth control pills more frequently as it was fairly limited in time scope. In addition, the use of non-randomized sampling methods limit generalizibility of study results to the population under consideration.

Data Collection Instrument

A survey questionnaire was developed for the study (Appendix B) in order to measure what women consider serious side effects of oral contraceptives, and how accurately they are able to identify them according to Planned Parenthood educational handouts. These handouts are given to every new pill user and reviewed

Procedure

Participants were asked to complete a one page descriptive survey consisting of 12 questions which use both multiple choice and short answer format (Appendix B). Surveys were marked with a study ID# which identified the clinic of origin only. No identifiers were used which could link survey to participant. All data collected was anonymous , and confidentiality was maintained.

Surveys were distributed and completed at each site by clients as they obtained their supply of birth control pills. Estimated completion time was from 5-10 minutes, based on input provided through pilot testing of 25 women at the Vancouver clinic. Vancouver clients were asked to pilot the survey in order to decrease threats to validity which may be caused by subsequent alteration of the measurement tool. Administration of the tool was done by clinic support staff, who were trained and oriented to the tool prior to beginning the study. Completed surveys were collected weekly by the investigator at the Portland Planned Parenthood office. Clinic managers were responsible for data at each clinic, which was stored in a secured envelope and transported to Portland in the course of routine administrative visits.

Potential uncontrolled variables included the fact that the clinic was in the process of changing birth control pill information sheets effective August 1, 1992, though non-serious side effects were the same in both old and new handouts. Danger signs have been changed to delete "a breast lump or fluid discharge from the breast" and "a new mole, or mole that grows or changes." During the course of this study, clinics

were asked to refrain from using or handing out the new birth control information sheets.

Data Analysis

The CRUNCH 4 statistical package was used for data analysis. The characteristics of participants were compiled using descriptive statistics to analyze the responses to questions 1-11. Descriptive analysis included computation of mean, SD, and frequency distributions The research question was then answered by coding responses to question 12, which asked women to name three serious side effects. Responses were categorized based on constant comparative analysis of patient generated side effects listed. A total of 45 categories resulted (Appendix C) which were coded to identify 14 serious, 7 non-serious, and 24 non-listed side effects of birth control pill usage. Finally, correlations and t-tests were used to further analyze the impact of independent and intervening variables on the correct identification of serious side effects in the population studied.

Chapter 3

Results

Participants

A total of 374 responses were returned, of which 372 were usable. The mean age of respondents was 23 (SD=4.2) with a range of 18-41 years.. The mean income of respondents was $900 per month. Education level was high in this sample, with a mean level of 13.6 years of education (SD=1.7). The majority of participants identified their race as White (91%), followed by 3.23% Hispanic, 2.7% African-American, 2.16% Asian and less than 1% American-Indian, Alaskan Native, or "other". The average client had been on birth control pills for 3 years (SD=1.97) with 39% stating they were long-time pill users of 5 years or more.

The sample population was representative of Planned Parenthood clientele when compared with 1991 socio-demographic statistics compiled by their organization, with the exception of slightly higher income levels in the survey sample. No statistics on educational level were available for comparison, but the fact that the majority of this population had completed almost 2 years of college is quite high when considering the mean educational level of the United States is 12.6 years of education (Zion and Aiman, 1989). Many clients had been a part of the Planned Parenthood system for a long time, with the mean time receiving pills from this organization of 2 years. Most patients (30%) were taking Triphasil pills or Ortho-Novum 1/35 (29.2%) followed by Ortho-Novum 777 (17.3%). Four percent of clients were not sure which birth control pill they are taking at present.

Most clients (94%) stated that they had read the package insert which came with their pills listing various side effects and warning signs of contraceptive pill problems. In addition to this information, Planned Parenthood provides a handout stating serious and non-serious side effects to each initial birth control pill user in their system, which is again reviewed when the client picks up their fourth pack of birth control pills. As only 11% of this sample were in the 0-3 month range of pill use (before the symptoms review visit and blood pressure check), the assumption was made that most of the study population had both read their package insert and been educated by staff members as to the identification of serious side effects of birth control pill use. Few clients felt they had actually experienced a problem with birth control pill use (27%), and of those who had, 54.6% did not stop their birth control pills. Many clients wrote in the margin that they changed their pill, which may have been interpreted when answering the question as "stopping".

Research Question One

The first research question asked what women consider serious side effects of birth control pill use. In naming serious side effects of birth control pill use, it was of interest to note that 15% of this sample did not list any side effects in the space provided. However, a majority of the sample (68.2%) did list at least 3 side effects as requested. If more than 3 side effects were listed, the first 3 listed were entered for tabulation and analysis. Frequencies were then tabulated for the ten most often named side effects (Table 1)

The second part of research question one was to determine which side effects were least often named by participants in this study (Table 2). Answers were also broken down to determine if listing format indicated perceived severity by birth

control pill clients. Side effects were referred to as "SIDE 1" "SIDE 2" and "SIDE 3" for the purpose of analysis, with the understanding that clients were not asked to rank these effects by importance or severity. When the top five frequencies were listed for side effects, it was of note that "severe pain in extremities" appeared only in SIDE 1 on the survey, while "cramps" appeared only in the SIDE 3 location. Other listed side effects, however, were distributed approximately evenly (Table 3), indicating that clients did not tend to rank effects as they moved down the list of symptoms.

Table 1

10 Most Frequently Named Side Effects (Rank Order)

Side Effect	N
*Severe headache	n=127
Breakthrough Bleeding	n=117
Nausea/Vomiting	n=57
Dizziness/Fainting	n=52
Cramps	n=46
*Severe Pain in Extremities	n=40
*Chest Pain	n=46
*Vision Change	n=39
*Numbness or Tingling	n=29
*Heavy Bleeding	n=29
*Blood Clots	n=28
*Abdominal Pain	n=24

Note. * Denotes a defined serious side effect

Table 2

10 Least Frequently Named Side Effects

Side Effect	N
Weight Loss	n=1
*Jaundice	n=1
*Mole	n=1
Back Pain	n=1
Nervousness	n=1
Hair Loss	n=1
Anemia	n=1
Libido Change	n=1
Diarrhea	n=1
Drowsiness	n=1

Note. * Denotes a defined serious side effect

Table 3

Frequencies of Side Effects By Placement

SIDE 1	Percentage
Breakthrough Bleeding	17%
Headache*	15.8%
Chest Pain*	5.7%
Severe Pain in Extrem.*	5.38%
Dizziness/Fainting	5.38%

SIDE 2	Percentage
Headache*	15%
Breakthrough Bleeding	10.6%
Nausea/Vomiting	5.98%
Dizziness/Fainting	6.64%
Chest Pain*	4.65%

SIDE 3	Percentage
Breakthrough Bleeding	12.2%
Headache*	11.4%
Nausea/Vomiting	9.45%
Cramps	6.3%
Dizziness/Fainting	5.9%

Note. * Denotes a serious side effect

Research Question Two

Of the total number (n=372) participating in this survey, 254 subjects were able to name 3 side effects as requested. Of the women naming 3 side effects, only 13.4% were able to correctly name defined serious side effects in all 3 provided spaces. More significantly, 16.1% of clients naming 3 side effects which they considered serious were in reality unable to correctly name a single serious side effect of birth control pill use.

The statistical program Crunch 4 was used to calculate cross tabulations using Chi-square to determine if clients who correctly named a defined serious side effect in SIDE 1 were able to also name a serious side effect in SIDE 2. Also examined was whether those who named a serious side effect as SIDE 2 could then name one for SIDE 3 as well. It was hoped that this would illustrate obvious patterns of ranking or guessing which might be involved in the naming of side effects.

In order to analyze if placement of a side effect in space 1, 2 or 3 had an effect on the ability to correctly name a serious side effect, with some clients perhaps naming the "most" serious side effect first, while others might "remember" it correctly by the end of the side effects list, cross-tabulations were done using Chi-square. The purpose of Chi-square was to demonstrate if correctly naming a serious side effect in SIDE 1 could predict the ability to also name one in SIDE 2. The relationship between correctly naming an effect in SIDE 2 and subsequently identifying one in SIDE 3 was also explored. Results demonstrated the effect of correctly naming a serious side effect in SIDE 1 was not significantly related to naming one in SIDE 2 ($p=0.28$, $DF=4$), nor was there a predictive relationship between naming a serious

side effect in SIDE 2 and subsequent identification of a serious effect in SIDE 3 ($p=0.38$, $DF=4$).

T-tests were used to compare Group 1 (receiving pills less than 4 months from Planned Parenthood) and Group 2 (4 months-4 years of pill use through Planned Parenthood) to determine differences in the ability of pill users to both name a side effect of birth control pill use and to correctly identify serious side effects. Those obtaining birth control pills less than four months in the Planned Parenthood system had not yet been given a review of serious symptoms, nor were they perhaps as familiar with these symptoms as long time pill users. Clients using pills for 5 years or longer through Planned Parenthood ($n=83$) were excluded from consideration. It was hypothesized that clients would be better able to correctly name serious side effects after their review. In fact, T-testing demonstrated no significant relationship between those who had received Planned Parenthood's 3 month birth control pill review of symptoms and ability to name any side effect ($p<0.30$, $DF=49.4$), nor the likelihood of correctly naming a serious side effect in SIDE 1 ($p<0.49$, $DF=43.1$), SIDE 2 ($p<0.55$, $DF=35.7$), or SIDE 3 ($p<0.74$, $DF=29.9$).

A Spearman correlation was used to determine if total length of time on birth control pills, could positively affect a client's ability to correctly name serious side effects of birth control pill use. Again, this was found to have no significant effect on the clients ability (in spite of increased exposure to pill use) to correctly identify a serious side effect in SIDE 1 ($p=0.36$), SIDE 2 ($p=0.52$) or SIDE 3 ($p=0.07$).

Discussion

Side effects of birth control pill use and their perception by adult women who use them is an area infrequently studied by researchers. Participants in this study, while rarely (27%) experiencing problems related to oral contraceptive use, are still concerned about side effects which may be considered "minor" to their health provider. In asking women to name three birth control pill side effects which they consider "serious" and would report right away to a health provider, it was hoped to gain a sense of what women considered both serious and urgent signs of birth control pill side effects.

Of the five most frequently named serious and urgent side effects for birth control pill users in this study (severe headache, breakthrough bleeding, nausea/vomiting, dizziness/fainting, and cramps) only severe headache is considered an actual "serious" side effect of birth control pill use. Conversely, of the five least frequently named serious side effects (weight loss, jaundice, mole, back pain, and nervousness) two are considered potentially serious effects of birth control pill use (mole and jaundice) which require notifying a health provider "immediately" according to Planned Parenthood's birth control pill information handout (Appendix A).

The obvious discrepancy between what educators and women identify as serious side effects of birth control pill use in concerning. The inability of women to recognize medically serious side effects may be attributed to several factors which affect how a patient may perceive her illness or side effect. Women may only list side effects which they themselves have experienced, which not only emphasizes the

experiential perception of side effects identified, but may also explain the fact that 15% of women studied were not able to or did not identify a single sign of birth control pill complications which would compel them to contact their provider right away.

Women in turn may also only identify as "serious" any side effects which they worry about (in which case "weight gain" might have been ranked more highly) or those which they feel are most likely to occur. The likelihood of "jaundice" (n=1) may correctly be perceived as very low compared to the chances of experiencing "breakthrough bleeding" (n=117) in the average oral contraceptive user. Many women seemed to list symptoms of pelvic inflammatory disease, with fever (n=16), vaginal discharge (n=8) and cramps (n=46) as symptoms of note which are not traditionally associated with birth control pill use. The high ranking of "severe headache" (n=127) may be attributed to the commonality of headache as a sign of generalized illness which is culturally recognized. Kleinman (1988) notes that, especially when vulnerable to stressors of everyday life:

> Tension headaches may express a number of states: from exhaustion, chronic inflammation of the cervical spine, or the distress of an acute upper respiratory infection or of worsening diabetes, to the misery that results from job loss, an oppressive work situation, or a systematically demoralizing marital relationship. (Illness Narratives, p. 13)

Thus headaches are both a common and wide-ranging symptom which can indicate "something serious" to the general population. Severe headaches can also be a symptom of pregnancy induced hypertension, as can nausea and vomiting (n=57),

dizziness (n=52) and blood pressure changes (n=22). Women who may have had a previous full-term pregnancy, then, may recognize and remember these symptoms of "something serious" from their frequent prenatal visits. The belief that cancer is a feared side effect of birth control pill use (Hillard, 1989) was not born out in this study, with only two subjects mentioning cancer signs or symptoms.

Women may also not recognize potential serious side effects of birth control pill use as a failure of the clinical education process. The fact that most of the sample studied were well-educated (mean years of education=13.6), had read their package insert (94%), and had been receiving birth control pills for an extended period of time (mean=2 years) through Planned Parenthood did not affect their ability to correctly identify serious side effects. The effectiveness of using the ACHES acronym and birth control pill information sheet at the three month refill appointment was also not statistically associated with an increase in the targeted assimilation of knowledge of serious side effects. However, the answer may not necessarily lie in increasing the education of clients, nor in adjusting the reading level of materials (Zion and Aiman, 1989), as this highly educated and presumably literate sample population indicates. While teens may misunderstand symptoms due to their failure to read package inserts (Emans, Grace, Woods, Smith, Klein, and Merola, 1987) this adult population did read their package inserts with high frequency. As clinicians, we must be prepared to evaluate the perception and meaning of side effect symptoms in the oral contraceptive population. As noted by Kleinman (1988):

> ...the practitioner cannot avoid responding to the patient's perspective on risk and vulnerability and to his expectations regarding treatment. But many physicians respond according to an outmoded health education approach that simply configures the problem as lack of effective knowledge. The actual dimensions of the problem are much greater: laymen possess alternative forms of knowledge, not merely insufficient scientific knowledge...(p.242)

The meaning of symptoms is, as previously stated, highly individualized and subjective. Given the high severity value of breakthrough bleeding demonstrated in this study, the clinician may wish to consider this a potential barrier to compliance for adult women using birth control methods, such as the Norplant implant, which cause irregular bleeding. In one five year study; Shoupe, Mishell, Bopp, and Fielding (1991) found that 66.3% of Norplant users experience irregular bleeding cycles during the first year, a rate which is only decreased after one full year of use. These irregular cycles, while medically "minor", may be perceived as serious indeed by the contraceptive user.

Summary

Client perception of the severity of birth control side effects differs in context from medically defined serious side effects. In the sample studied, women were more likely to perceive as "serious" those side effects which the medical community classifies as "minor". In examining correlational factors, a commonly used side effects educational handout along with the four month review of symptoms did not

statistically increase women's ability to correctly name serious side effects of oral contraception. Length of time on oral contraception, which may increase familiarity with pills and their side effects through increased exposure to the health care system, was actually found to have no relationship with correct identification of serious side effects in this population.

Limitations

The number of women in this study, while large (n=372) and comparatively representative of the Planned Parenthood clientele in the greater Portland, Oregon area during 1992, is not random nor thus applicable to women birth control pill users as a whole. This sample excludes adolescents who, by virtue of their lack of experience with medications and illness as a whole, may be even more likely to interpret so-called "minor" side effects as serious. The sample studied was fairly well-educated and had a mean income of $900 per month, though it was not asked how many people their income supported. Women in this study were mostly White (91%) and had been on birth control pills for two years or longer.

In interpreting results, it was noted that 15% of clients named no side effect which would concern them. The validity of this response is doubtable, and may indicate a flaw in the assessment tool (Appendix B). It is surmised that some clients may have interpreted question 12 to refer only to side effects which they themselves had experienced. Others appeared to stop filling out the survey after question #10 "Have you ever experienced a problem from birth control pills?" was answered "no". This further supports the supposition that clients felt question #12, in asking about serious side effects, pertained only to those who had experienced a problem with their pills. The naming of only symptoms which had been personally

experienced might also lead to an over-reporting of "minor" side effects, as these would be most commonly noted by the general population.

A final limitation of this study would be the inability to control for symptom information from sources other than Planned Parenthood's educational handouts and review. The majority of subjects reported reading the package inserts which came with their various types of birth control pills. Others may have gained different interpretations of serious side effects of pill use from friends or family, books, school, or other sources. Not all sources may provide clients with current or correct information on side effects of oral contraceptive use.

Suggestions for Further Research

With consideration of factors previously discussed, one might conduct further analysis as to how clients acquire their knowledge of symptoms which they attribute to birth control pill use. A meta-analysis of package inserts, health education curriculum, lay literature, and private physician office literature as well as that of public clinics could be conducted to compare symptom information for consistency and veracity. As some clients seemed to list symptoms recognized as common to pelvic infections and pregnancy induced hypertension, previous parity and relevant medical history may add salient information to further studies on this topic. Clinicians might also find useful a similar survey which asks clients instead to name benefits of birth control pill use, in order to help highlight these benefits to a target population.

Implications for Practice

Clients surveyed in this population seem satisfied overall with oral contraceptives, as evidenced by length of time on pills and lack of reported problems. In targeting clients with potential serious effects related to pill use, however, it would seem that the gap between client and provider defined serious symptoms is wide. Though clients might recognize a symptom such as "chest pain" as being serious, and would undoubtedly seek medical attention, it is of more significance to note that "headaches", "breakthrough bleeding", and "nausea/vomiting" may be of greater concern to this population which in turn may affect their satisfaction and compliance.

Clinicians, in planning and implementing oral contraceptive education, should tailor their focus not only towards the ACHES and "serious symptoms" of oral contraceptive use, but also to the recognition of and subsequent management tactics for more common and equally distressing "minor" symptoms. Breakthrough bleeding, as an example, may be explained not just as "expected in the first few months of pill use" or "annoying" but also as a symptom which may be lessened by adhering to a regular and timely schedule of pill taking.

Periodic symptoms review of both "minor" and "serious" complaints may help detect management issues such as taking pills in an irregular or sporadic fashion. The three month review of symptoms as Planned Parenthood is one tactic of managing pill problems, although not statistically related in this study with client's differentiation of "serious" versus "minor" oral contraceptive complaints. Perhaps more frequent reviews or greater access to nurse advice lines could help alleviate and address client concerns with oral contraceptive side effects, especially those which may not warrant a practitioner visit.

Education materials, especially birth control pill inserts, might be designed to contain a simple list of expected side effects ("minor") and how to manage them. As clients seemed also unable to identify serious side effects of oral contraceptive use, manufacturers and clinics may wish to consider an easily accessible mnemonic, such as the ACHES, which could be placed on a small label attached to the inside of each pill container. Above all, the clinician needs to accept and recognize the experiential value of symptoms in the patient's lifestyle context, in order to offer individualized care in the very personal sphere of contraceptive choice and usage.

References

Balassone, M. (1989). Risk of contraceptive discontinuation among adolescents. Journal of Adolescent Health Care, 10:6, 527-33.

Bracher, M. and Santow, G. (1992). Premature discontinuation of contraception in Australia. Family Planning Perspectives, 24:2, 58-65.

Brown, R., Cromer, B., and Fischer, R. (1992). Adolescent sexuality and issues in contraception. Obstetric and Gynecology Clinics of North America, 19:1, 177-91.

Center for Disease Control and the National Institute of Child Health and Human Development Cancer and Steroid Hormone Study. (1986). Oral contraceptives and the risk of breast cancer. New England Journal of Medicine, 315:7, 405-411.

Emans, SJ., Grace, E., Woods, ER., Smith, DE., Klein, K., and Merola, J. (1987). Adolescent's compliance with the use of oral contraceptives. JAMA, 257:14, 3377-81.

Hammerslough, C. (1984). Characteristics of women who stop using contraceptives. Family Planning Perspectives, 16:1, 14-18.

Hatcher, R., Stewart, F., Trussell, J., Kowal, D., Guest, F., Stewart, G., and Cates, W. (1990). Contraceptive Technology (15th ed.). New York: Irvington Publishers.

Hillard, P. (1989). The patient's reaction to side effects of oral contraceptives. American Journal of Obstetrics and Gynecology, 161:5, 1412-5.

Kaunitz, A. (1992). Guiding adolescents in proper contraceptive use. Contemporary Ob/Gyn, 37:5, 15-33.

Kleinman, A. (1988). The illness narratives: Suffering, healing, and the human condition. New York: Basic Books.

Mishell, D. Jr. (1989). Optimizing contraceptive decisions: Clinical implications of the triphasic randomized clinical trial. American Journal of Obstetrics and Gynecology, 161:5, 1385-9.

Peterson, H. and Lee, N. (1990). Long-term health risks and benefits of oral contraceptive use. Obstetrics and Gynecology Clinics of North America, 17:4, 775-87.

Shoupe, D., Mishell, D., Bopp, B., and Fielding, M. (1991). The significance of bleeding patterns in Norplant implant users. Obstetrics and Gynecology, 77:2, 256-59.

Speroff, L., Jones, K., and Davis, A. (1992). Compliance problems with OC's and HRT. Contemporary Ob/Gyn, 37:4, 88-110.

Zion, A. and Aiman, J. (1989). Level of reading difficulty in the American College of Obstetricians and Gynecologists patient education pamphlets. Obstetrics and Gynecology, 74:6, 955-59.

Appendix A

COMMON, NON-SERIOUS SIDE EFFECTS

1. BREAKTHROUGH BLEEDING, spotting or any flow at a time in your cycle when you are not due for a period. Unless the bleeding is heavier than your normal menstrual period flow, continue to take your pills as directed. If the bleeding is very heavy, call the clinic for advice. Breakthrough bleeding often follows a day when you have missed taking a pill. It can be annoying, but it is not serious.

2. MISSING A PERIOD. Your periods may become very light and short, or you may not have any bleeding at all when you take birth control pills. If you miss one period, continue taking your pills. If you have no menstrual period twice in a row, call the clinic for advice. We may have you come in for a pregnancy test and a change to another kind of pill.

3. NAUSEA OR APPETITE CHANGE. Especially during the first month or two of pill use, be sure to take your pill when you have recently had something to eat. Your body will adjust more easily to the pill if you find an easy time of day to take your pill and then stay on schedule as closely as possible.

4. BLOATING, WATER RETENTION AND BREAST TENDERNESS. These symptoms usually disappear as you adjust to taking your pill. Avoid salty foods in your diet to help prevent these changes.

YOU MAY CALL US AT THE CLINIC AT ANY TIME TO DISCUSS ANY BODY CHANGES WHICH CONCERN YOU!

THESE ARE PROBLEMS WHICH COULD BE WORSEND BY YOUR USE OF BIRTH CONTROL PILLS. CALL US FOR ADVICE IMMEDIATELY IF YOU NOTICE:

1. SEVERE ABDOMINAL PAIN
2. YELLOWING OF THE SKIN (jaundice)
3. SERIOUS DEPRESSION
4. A BREAST LUMP OR A FLUID DISCHARGE FROM THE BREAST
5. A NEW MOLE, OR A MOLE THAT GROWS OR CHANGES

DANGER SIGNS

Although not common, these problems have been associated with use of birth control pills. Call us at the clinic or report to a hospital emergency room if you have one of these problems:

1. SEVERE HEADACHE with vomiting, loss or change of eyesight, flashes or sparkles in your vision.
2. SUDDEN CHEST PAIN with shortness of breath and coughing when you are not currently having symptoms of a cold or flu.
3. SEVERE PAIN IN ONE ARM OR LEG with numbness or tingling. If you cannot remember an injury to explain this problem, it may be a symptom of a clot in a blood vessel.
4. WEAKNESS AND/OR NUMBNESS in one side of your body.

Appendix B

Date_____
THIS IS A CONFIDENTIAL SURVEY. WE DO NOT NEED YOUR NAME. WE'D LIKE TO LEARN MORE ABOUT USE OF BIRTH CONTROL PILLS AND ANY PROBLEMS YOU MAY HAVE WITH THEM. THANKS!

1. What is your age?____

2. Your actual monthly income before deductions? _____

3. Your highest level of school completed (or GED)?_____

4. Your race? (Circle) African-American (Black) Alaskan Native

American Indian Asian Hispanic White Other_____

5. How long has it been since you began taking birth control pills?(Circle)

O-3 months 4-11 months 1year 2 years 3 years

4 years 5 or more years

6. Please state the longest amount of time you have been on birth control pills without a break_____

7. How long have you received pills from Planned Parenthood?(Circle)

O-3 months 4-11 months 1 year 2 years 3 years 4 years 5 or more years

8. Which pill are you currently taking?(Circle)

Ortho Novum 1/35 Ortho Novum 777 Triphasil LoEstrin Demulen Other

Not Sure

9. Have you ever read the package insert that comes with your pills?(Circle)
Yes No

10. Have you ever experienced a problem from birth control pills?(Circle)
Yes No

If yes, describe below:

11. Did you stop taking your pills because of this?(Circle)
Yes No

12. Name three birth control pill side effects which you would consider serious and would report right away to your health care provider:
1.

2.

3.

THANK YOU FOR YOUR TIME. THIS SURVEY WILL HELP US BETTER SERVE YOU AND YOUR HEALTH CARE NEEDS.

Appendix C

Side Effect Data Codes

1) abdominal pain*	2) jaundice*
3) depression*	4) breast lump*
5) mole*	6) severe headaches*
7) chest pain*	8) severe pain in extremities*
9) shortness of breath*	10) numbness or tingling*
11) weak or numb one side*	12) vision change*
13) blood clots*	14) breakthrough bleeding
15) amenorrhea	16) nausea
17) bloating	18) breast tenderness
19) heavy bleeding	20) blood pressure change
21) other non-serious	22) vaginal/cervical pain
23) back pain	24) cramps
25) dizziness	26) weight gain
27) weight loss	28) swelling
29) irregular heartbeat	30) skin rash
31) varicose veins	32) vaginal discharge
33) cancer	34) nervousness
35) irritability/anger	36) hair loss
37) anemia	38) libido change
39) fever	40) diarrhea
41) drowsiness	42) chills
43) general ill health	44) other non-listed
45) general pain	

*indicates serious side effect