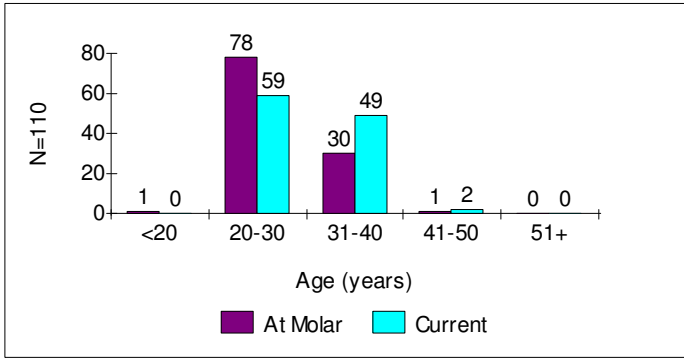# MyMolarPregnancy.com Molar Pregnancy Profile Survey Results
### Data Collection: October 10–25, 2004

Age of respondents at time of molar pregnancy diagnosis and at time of survey. Although the women were split nearly 50/50 between the 20–30 and 30–40 age groups at the time of the survey, it is clear that most of the molar pregnancies diagnosed among the respondents occurred during their 20s. In fact, most of the women were diagnosed in the latter half of that decade, with 58 women (53%) indicating diagnosis between 25 and 30 years of age. This is in sharp contrast to the generally accepted belief that molar pregnancies occur more frequently among women in their late 30s and 40s. The partners of these women were generally in the same age ranges, with most (50%) falling in the 20–30 range, closely followed by the 31–40 range (45%).
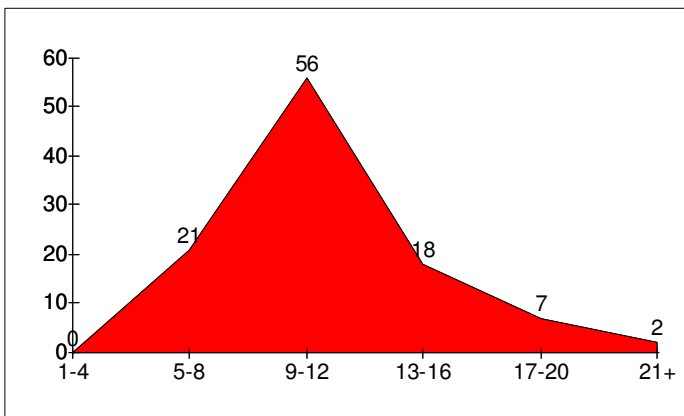

Number of weeks pregnant at diagnosis (N=104). By far, most respondents learned of their molar pregnancy diagnosis in their first trimester, with 21 women (20.2%) diagnosed between 5 and 8 weeks and 56 (53.8%) between 9 and 12 weeks. However, in a significant number of cases (18, 17.3%) the diagnosis was made in the first weeks of the second trimester, with an additional 7 women (6.7%) diagnosed as late as 17–20 weeks and at least 2 women (1.9%) diagnosed at 21 weeks or longer. *When* a molar diagnosis is made may be related to the practice of individual doctors, because many diagnoses are made using ultrasound, which is often not employed until the mother is in her second trimester. Earlier diagnoses may occur either as a result of natural spontaneous miscarriage that is later diagnosed by pathology or because the mother has had an early ultrasound or a beta hcg reading that indicated a problem.
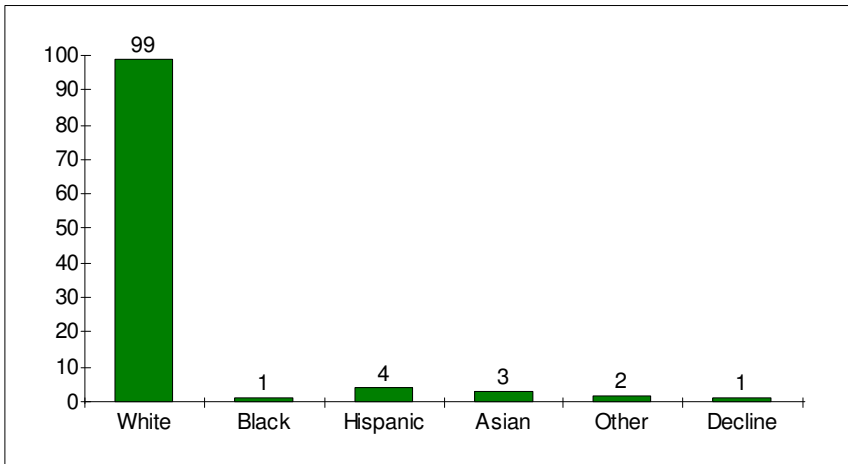
Racial composition of sample (N=110). Although it is generally believed that Asian women are more likely to experience a molar pregnancy, the sample for this survey was predominantly white, with only a handful of respondents from other racial and ethnic backgrounds. The lack of control in sample selection may make these results somewhat less definitive but still worthy of note.
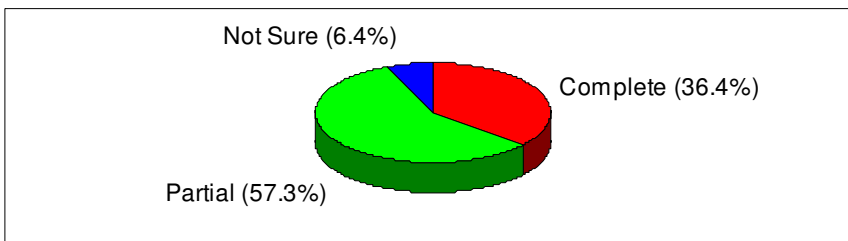
Type of molar pregnancy reported by sample (N=110). Partial moles were reported by most respondents. Diagnosis was either unknown or still pending for seven subjects ("Not Sure").
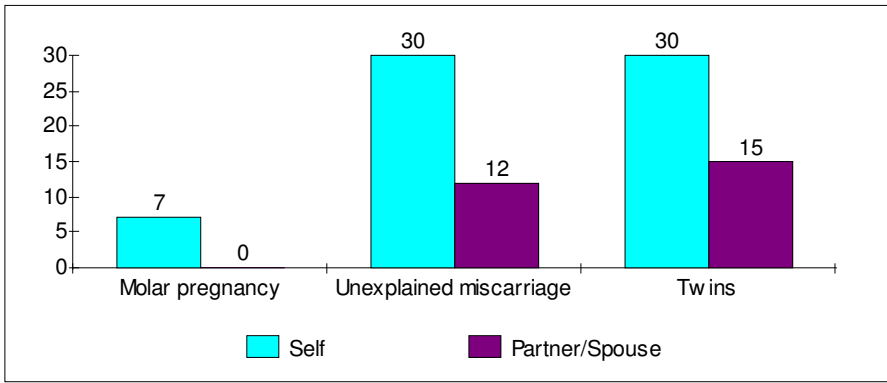
Family history. Seven of the 110 women (6.4%) had a family history of molar pregnancy, whereas none of their partners or spouses did. However, a large percentage of women (27.3%) and their partners (10.9%) had a family history of unexplained miscarriages as well as successful twin births (27.3% and 13.6%, respectively). This leads me to wonder whether some of the unexplained miscarriages experienced by family members may actually have been undiagnosed molar pregnancies, although obviously this is a question that can never be answered.

Of the 110 women who responded to the survey, 91% (100) had no preexisting condition that might have contributed to the molar pregnancy. Six women (5.5%) had some prior condition, including polycystic ovary syndrome (PCOS) in three cases. Other conditions included a recent precancer biopsy test and thyroid problems. Four women declined to answer. Prescription, over the counter, or illicit drug use by self or partner were reported by only 8 (8.3%) of the 96 who responded to this question; the drugs listed included Viagra, Paxil, Adderall, Trileptal, Wellbutrin, Elavil, and Celexa, but none of these with any significant frequency.

One lifestyle factor that did have a significant response was whether the women ate red meat during or near the time of their molar pregnancy. Eleven women, making up 10% of the total responses, indicated that they were eating a vegetarian or vegan diet or a diet with limited red meat consumption at the time of their diagnosis. Although nothing definitive has been stated regarding the relationship of diet to molar pregnancy, one common theory is that a lack of animal protein, specifically from red meat, in the mother's diet is one contributing factor.

Another significant finding in the survey was the irregularity (16 women, 14.5%) or absence (2 women, 1.8%) of menstrual periods among the respondents in the time before they became pregnant with their molar pregnancies. In addition, 10% of women in the survey (n=11) had had fertility treatment at some point prior to their molar diagnosis; 45% (n=5) of these women had had fertility treatment to conceive the pregnancy that ultimately became molar.
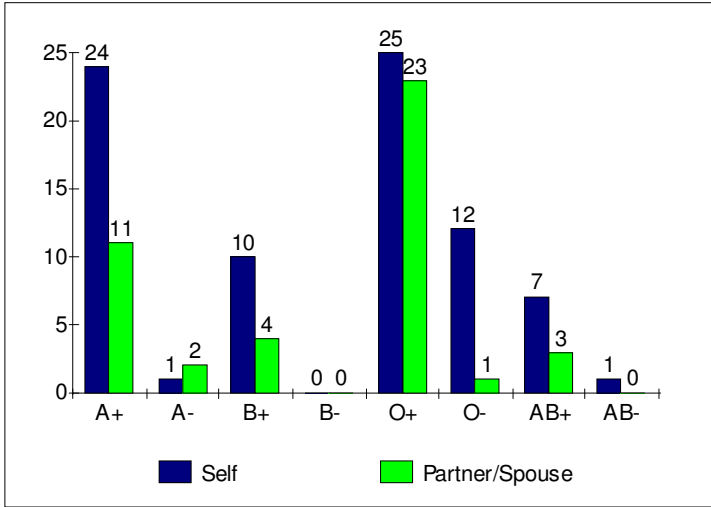

Blood types of women with molar pregnancy and their partners/spouses. Only a portion of the total survey group (N=110) was able to provide blood types for themselves (n=80) and/or their partners (n=44). However, the results show a distinct trend toward two common blood types, A+ and O+, in both women and men. The negative blood types seem to be far less common among those with molar pregnancy, with the exception of O-, which followed well behind A+ and O+ in frequency, and then only among the women. Across the board positive blood types, including B+ and AB+, were more predominantly represented. The structure of this survey (and my own limited scientific knowledge) make it impossible to determine whether any female/male combination of these blood types may have any bearing on molar pregnancy; I am do not know enough about blood types to know if a specific blood type is more common than another. Regardless of my own limitations, however, I think these results are interesting and worthy of further consideration.
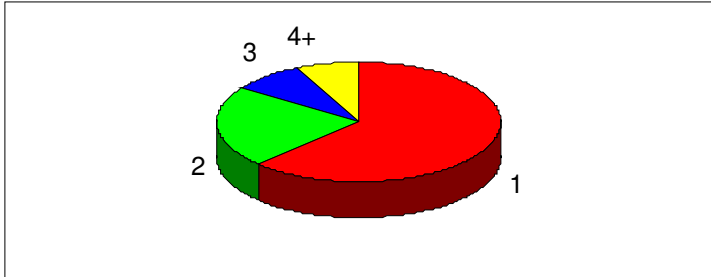

Number of miscarriages up to time of survey, including molar pregnancy. For most of the 109 women who answered this question, the molar pregnancy was their first miscarriage. However, a large group of respondents had had at least one (22%) miscarriage prior to their moles, and 15.6% had had at least two, with one woman reporting as many as six miscarriages.
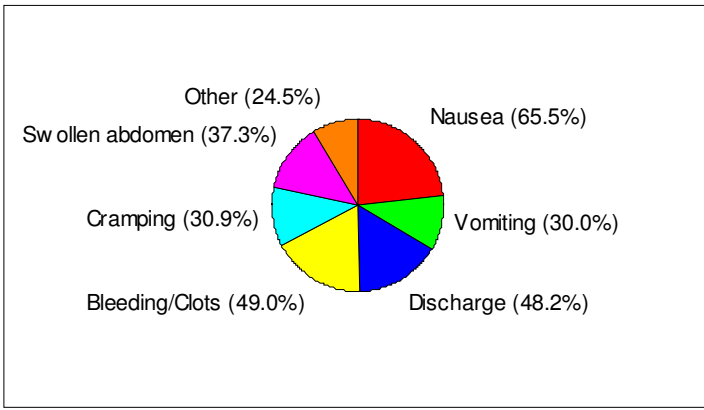
Symptoms of pregnancy or miscarriage noted prior to molar diagnosis. The most common symptoms listed by women in the survey were moderate to severe nausea, bleeding or passage of clots or other discharge, and prematurely swollen abdomen. Cramping and vomiting were also common. Other symptoms listed less frequently were fatigue and weight gain. Although several of these symptoms are common of any pregnancy, such as nausea, vomiting, or fatigue, others are more indicative of a problem. Whether any of these signs are specific to molar pregnancy is hard to say, however, except perhaps for the premature abdominal swelling, which seems to be a response to the unnaturally high hcg levels present in women with molar pregnancies.
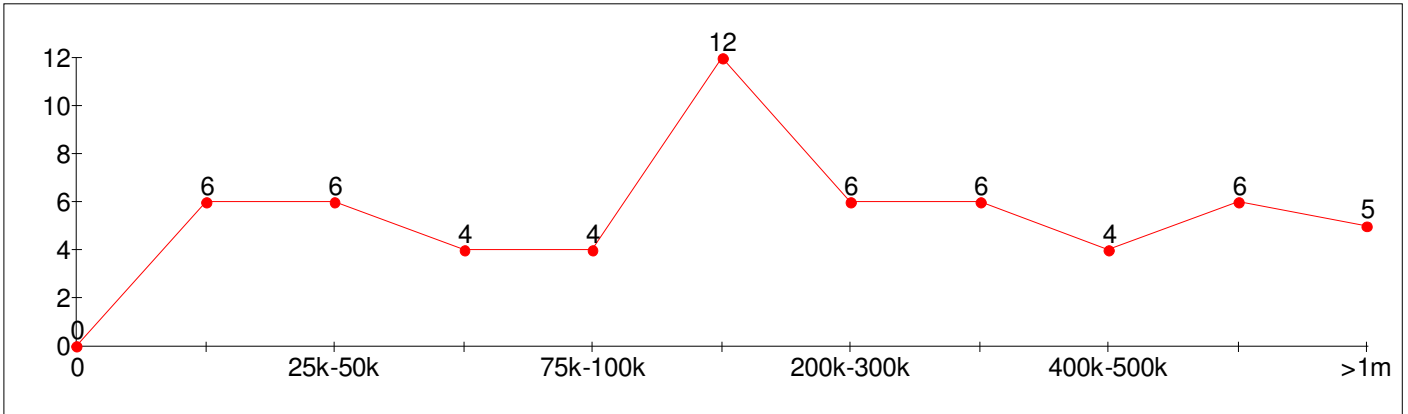
Beta hcg levels at time of miscarriage or dilation and curettage (D&C). Abnormally high hcg levels in early pregnancy are a standard indication of a molar pregnancy and were common among the women in the survey. Of the 110 women who responded, only 59 (54%) knew their exact hcg level at the time; of these 59 women, 39 (66%) had an hcg level higher than 100,000 at the time the pregnancy was ended, and 5 (8.5%) had a level above 1 million.
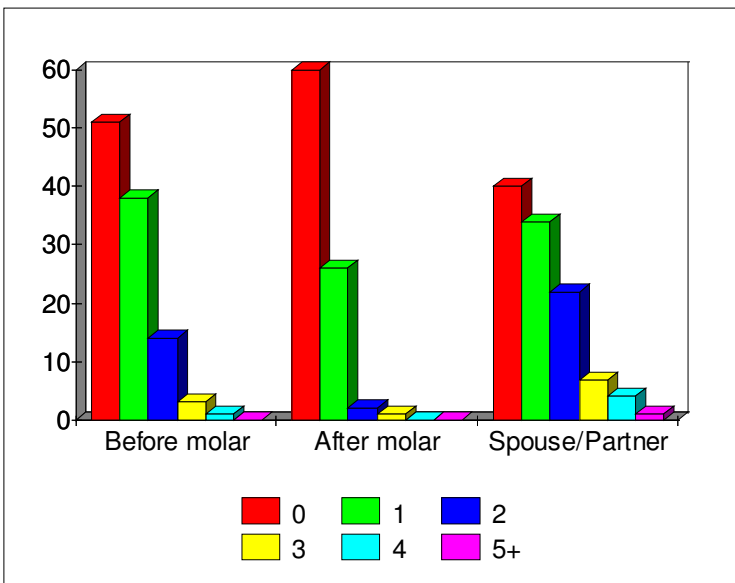

Successful pregnancies among women with molar pregnancy both before and after their moles as well as successful pregnancies fathered by their partners or spouses at any time. For many women in the survey, their molar pregnancy was either their first pregnancy or one among a number of miscarriages. However, a substantial percentage of women had had at least one successful birth (38, or 35.5% [*N*=107]) prior to their mole, and 29 women (30.8% [*N*=94]) had gone on to have at least one and in some cases two or three successful births after recovering from their molar pregnancy. At the time of the survey 60 women (63.8% [*N*=94]) had not yet had a successful birth since their moles, but this might be ac-counted for by the fact that most of these women were still in the post-mole waiting period and had not been cleared to conceive again. The number of pregnancies fathered by the women's partners or spouses did not seem to have any direct bearing on the results, because more than half of the men (63% [*N*=108]) had fathered at least one successful birth either before or after the molar pregnancy.
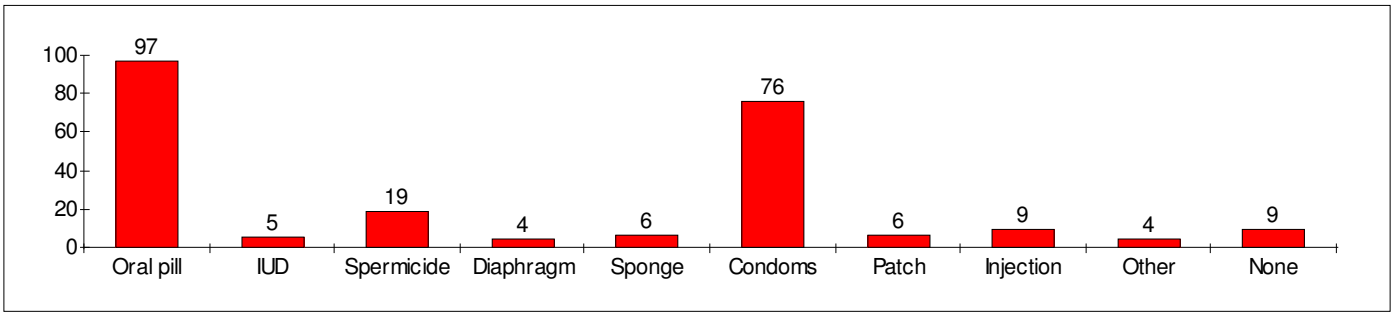
Contraceptive use prior to molar pregnancy. Respondents were asked to indicate what forms of birth control, If any, they had used at any time before their molar pregnancy diagnosis. Oral birth control pills were by far the most common, with 88.2% of women reporting some previous pill use. Many women had used multiple forms of contraception in the past, making it difficult to say with any degree of certainty (at least in this sample) whether use of a particular contraceptive measure may have had any bearing on the development of molar pregnancy. As for duration of use, there were no clear trends to indicate that length of use of a particular method was a factor. The method(s) of choice were in use for 2 years or less in some cases (34 women, representing about 31% of the sample) and as much as 10 years (10 women, 9.1%) or more (19 women, 17.3%) in others.

However, when asked how long they had stopped using contraception before conceiving their molar pregnancies, 31 of the 106 women who responded (29.2%) had only been off their method for 3 months or less. A total of 50 women had been off contraception for 6 months or less, representing nearly half of the sample (47.1%), and in all 65 women (61.3%) had been off for a year or less. The survey structure does not allow me to compare which specific method(s) of contraception was used by the women whose molars occurred so soon after the method was stopped, so it is impossible to point to any particular method—or the abrupt disuse of a method—as a causative factor. However, this may be an issue for further consideration: Could the use and abrupt stoppage of any particular contraception, followed by active attempts to conceive, lead to a potential for molar growth? Oral contraceptives were by far the most frequently used contraceptive, reported by 97 of the 110 women in the sample; is it then logical to infer that oral contraceptive use and cessation may have an influence in molar pregnancy? This is only conjecture, and to my knowledge is not scientifically proven—or perhaps even studied—but it does raise an interesting question.
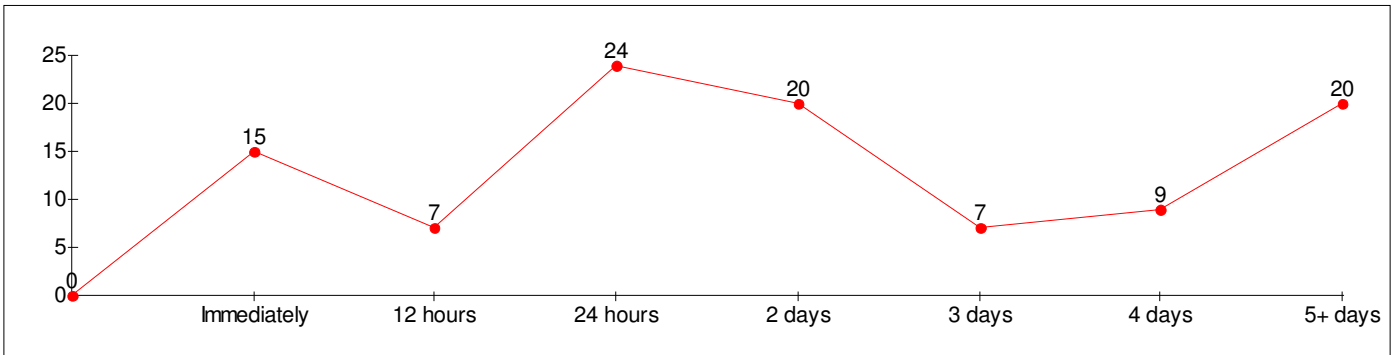
Length of time from molar diagnosis to D&C. The 102 women who had a D&C to remove their molar pregnancy had varied lengths of time between when they received their diagnoses and when they underwent the D&C procedure, ranging from immediate emergency surgery to delays of 5 days or more. Another eight women miscarried their pregnancies naturally. Most of the group, however, had their D&Cs within 48 hours after diagnosis (n=66, 64.7%), including those who had immediate treatment.
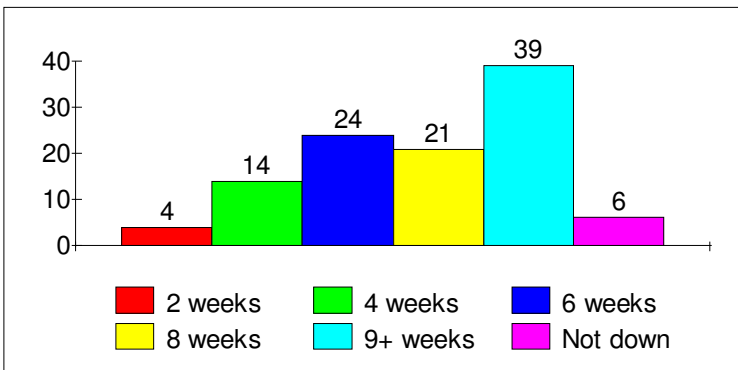
Time until hcg levels reached normal. Following pregnancy termination, hcg levels in most women (58.3%) returned to normal levels (defined as levels less than 5) within 8 weeks, although 39 women (36.1% [N=108]) had elevated levels for 9 weeks or longer, and hcg levels in 6 women (5.5%) had not yet returned to normal at the time of the survey. Normal menstruation returned for most women (90 women, or 85.7% [N=105]) by 8 weeks as well, with most periods returning between 6 and 8 weeks; however, 11 women (10.4%) waited 9 weeks or longer for their periods to return, and 4 (3.8%) had not yet had a period at the time of the survey.

A.

B.

3m   6m   9m
12m   12+m

C.
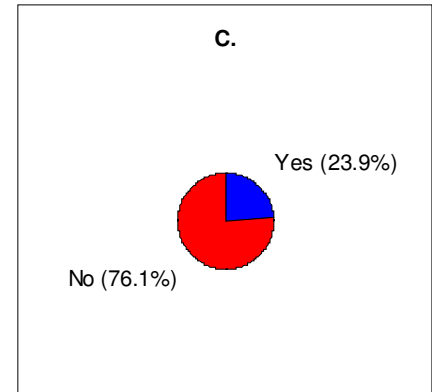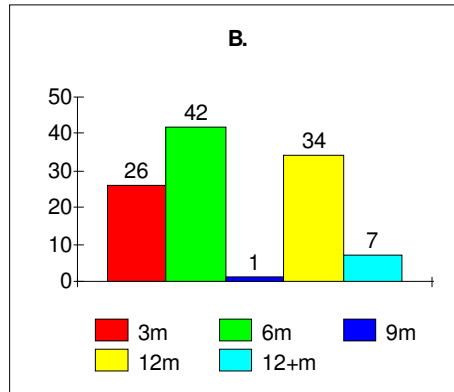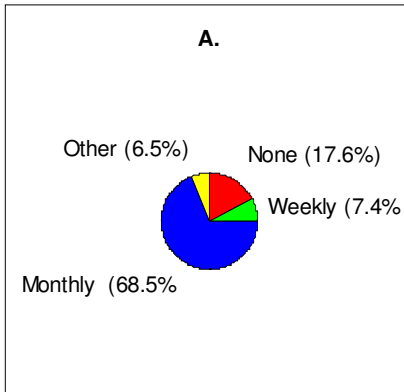
Prescribed methods and duration of hcg monitoring after molar pregnancy, and percentage of respondents reporting increases in hcg levels following pregnancy termination.

A, **Method of hcg monitoring (*N*=108).** Once their hcg levels returned to normal, most women had or were scheduled to have monthly blood draws (74, or 68.5% [*N*=108]) for up to a year or longer to monitor their levels; however, some women (8, 7.4%) continued to have weekly blood tests and others (19, 17.6%) had no monitoring at all. Seven women (6.5%) reported other methods of monitoring, such as urine rather than blood screenings.

B, **Wait time after reaching normal (*N*=110).** The lengths of time women were required to wait before conceiving again also varied, depending on the type of molar pregnancy as well as their doctors' individual preferences. Surprisingly, 26 women (23.6% [*N*=110]) were given permission to conceive within 3 months of reaching normal hcg levels, but most fell into the standard groupings of 6-month (42, 38.2%) or 1-year (34, 30.9%) wait times, with 1 woman reporting a 9-month wait and 7 others reporting waits of longer than a year.

C, **Development of choriocarcinoma or persistent gestational trophoblastic disease (*N*=109).** Regrowth of molar tissue and/or increase in hcg levels following pregnancy termination was reported by nearly a quarter of the respondents (26, or 23.8%). Treatment for these women included use of the EMACO (etoposide, methotrexate, actinomycin D, cyclosphosphamide and oncovin) chemotherapy regimen (4 women) and methotrexate (17 women) as well as dactinomycin and other unspecified treatments.
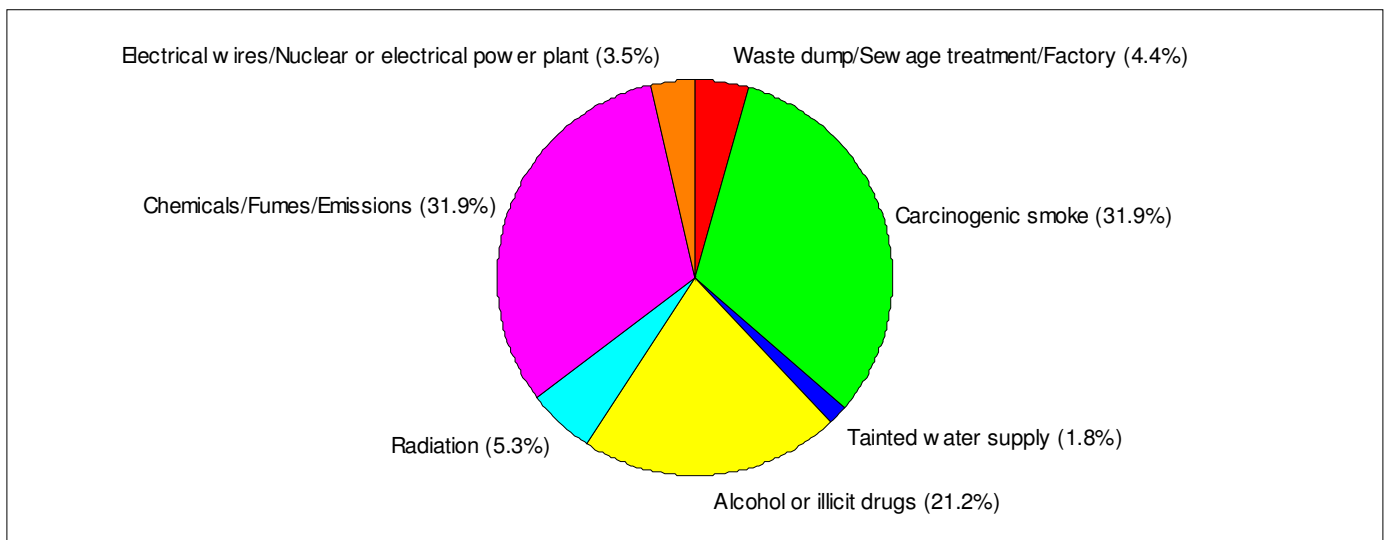
Exposure to potentially harmful environmental toxins before or during molar pregnancy. The environmental toxins to which women in the survey were most often exposed included chemicals and fumes, such as from hair color, perm solutions, or household cleaners; vehicle emissions, such as excessive exposure to car or bus fumes; carcinogenic smoke, such as from cigars, cigarettes, pipes, or other sources; and alcohol and/or illicit drug use. Radiation from x-rays; proximity to a waste dump, sewage treatment plant, factory electrical wires or power stations, or nuclear power plant; and exposure to a tainted water supply were also reported.