# Appendix 3:
# Factors Related to Pregnancy Disclosure

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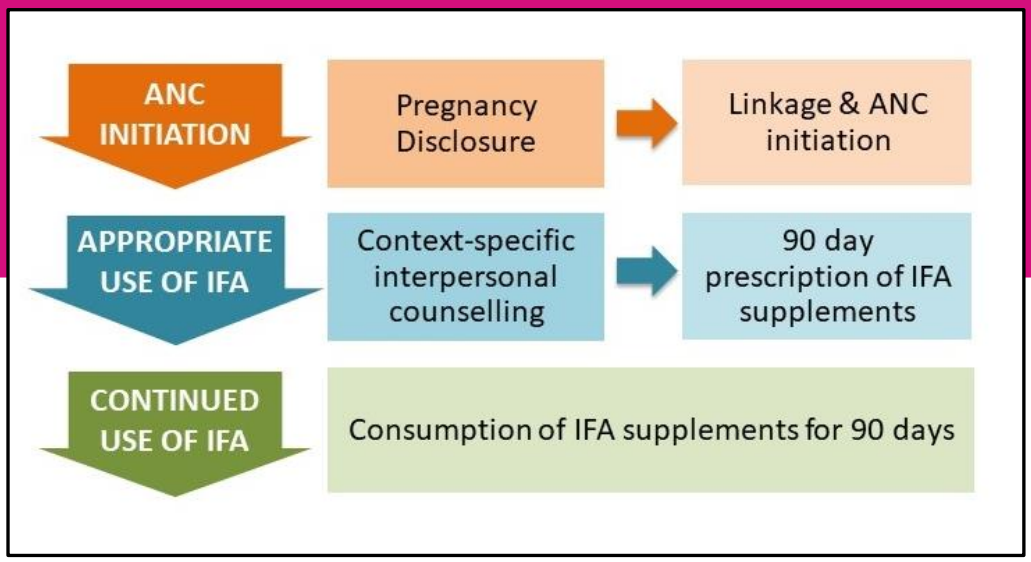


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## SUMMARY

The Kenya team discovered a paucity of research specifically focusing on factors affecting pregnancy disclosure. However, they did find a number of studies reporting on pregnancy disclosure as a minor or incidental finding in studies related to ANC more broadly. Highlights from this review include:

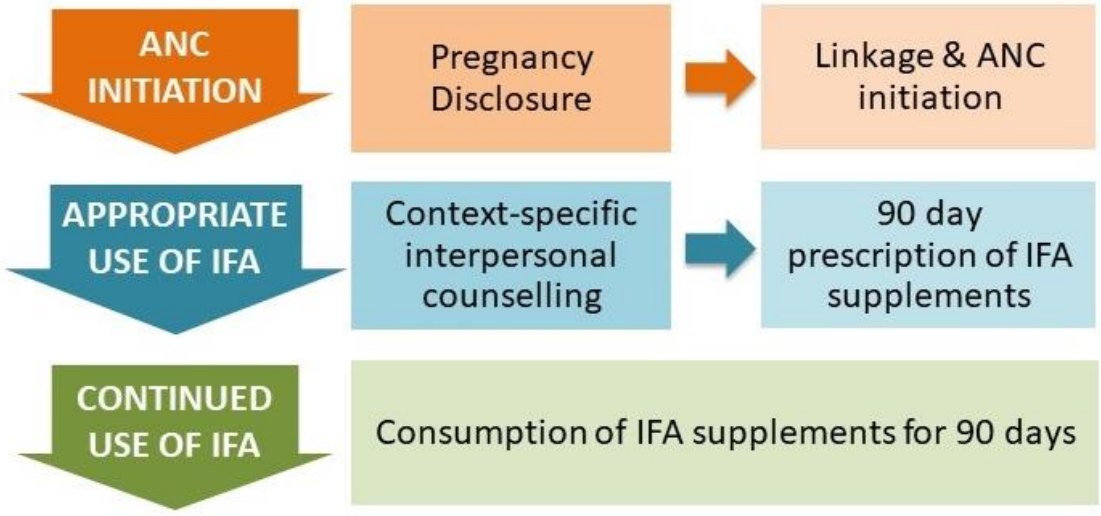
1. ***Young age and/or unmarried*:** adolescents and unmarried young women, especially those who are still in school are not likely to disclose their pregnancy. Adolescents and unmarried younger women hide their pregnancies to avoid the potential social implications of disclosure of pregnancy: exclusion from school, expulsion from their natal home, partner abandonment, stigmatization, and gossip. A related finding is that lack of familiarity with the signs of pregnancy for primipara young women can unintentionally lead to non-disclosure of the pregnancy.
2. ***Household income:*** Disclosure of pregnancy places a cost burden on the household, especially where the woman is expected to access ANC services frequently. Also, travel to ANC services often requires "pocket money" to spend during the visit.
3. ***Cultural beliefs:*** In some cultural settings, early disclosure of pregnancy is avoided or forbidden due to fear of "evil eye," witchcraft or other supernatural causes. In cultures with formal female initiations, conception and motherhood before this is rite of passage is completed is unacceptable because the pregnancy is ritually unclean and can "pollute" the social group.
4. ***Birth spacing/number of children under five years:*** Mothers with children under two years, including mothers who still are breastfeeding, are afraid to disclose pregnancies early due to social pressures within household and community. Some studies have reported that mothers were ashamed about lack of adequate birth spacing between siblings and the number of children under five was considered as a barrier to early disclosure due to mother's responsibilities of child upbringing, nature of work at household level and age of child.
5. ***Traditional birth attendants*:** Pregnant women in communities where traditional birth attendants (TBA) are the preferred service providers is associated with delayed pregnancy disclosure, in part because the TBA is a custodian of culture expectations for pregnant women. Moreover, TBAs may not encourage women to disclose until after the first trimester.
6. ***Health worker behavior:*** Shouting, scolding, and reprimanding of mothers by health workers has been reported as a barrier to ANC attendance in general and early pregnancy disclosure in particular. This is especially the case for adolescents or mothers with a short birth spacing interval. In communities with TBAs pregnant women prefer to disclose their status and seek advice from them, as opposed to health workers, and the TBA's service experience was considered superior to that of health workers.
7. **HIV testing:** The change from voluntary to provider-initiated testing for all mothers attending ANC services, which has occurred in many countries, has increased the coverage of prevention of mother-to-child transmission (PMTCT) programs; however, mandatory HIV testing can prevent early disclosure of pregnancy, especially where service providers insist on couple testing. This introduces a strong element of fear, including a fear by a woman that her partner may abandon her. Also, disclosure of pregnancy can be withheld for as long possible to avoid subsequent activities that may involve conducting HIV testing.

## PREGNANCY DISCLOSURE

ANC services include IFAS, skilled delivery, family planning and emergency obstetric care; those are key elements of the package aimed at improving maternal and newborn health[1]. In Kenya, there is a wide variation of ANC attendance: although 95% of pregnant women attend formal ANC only once, only 57% attend ANC at least four times [2]. Considering the paucity of research (and absence of comparative studies on the topic of pregnancy disclosure), we explored studies on initiation of ANC and qualitatively coded information by separating, sorting and synthesizing data to develop conceptual understanding of phenomena around disclosure.

In the context of IFA supplementation, the process of consumption of IFA supplements can be defined as the extent to which pregnant mothers adhere to consumption of IFA supplements during pregnancy in amounts that are in accordance with recommended protocols. Adherence to consumption of IFA supplements involves three basic elements: (1) ANC initiation (disclosure of pregnancy and initiation of ANC care) (2) appropriate use of IFA (pregnant mother receiving counselling on importance of IFA supplements, how to manage side effects and receiving prescription or purchasing IFA supplements for daily oral use) and (3) continued use of IFA (pregnant mother consuming IFA tablets for duration of the pregnancy and seeking prescription refill via subsequent ANC visits). The sequence of these activities is illustrated below as the Program Impact Pathway (PIP) depicting the sequence of pregnant mother behavior based on recommendations and policy guidance.

**Figure 1: Program Impact Pathway for consumption of IFA supplements by pregnant women**




### *Definition of pregnancy disclosure*

The clash between cultural and biomedical perceptions of pregnancy disclosure is among the many reasons the understanding of this topic has not been widely studied. Also, considering the social nature of pregnancy and the central role that reproduction often plays in the women's lives and the stigma that surrounds infertility, including the implications that childlessness have for a woman's relations with male partner and in-laws, confirming pregnancy is particularly important [3]. Based on this perception, we considered the definition of pregnancy disclosure to be associated with confirmation of a pregnancy. We define pregnancy disclosure based on three themes namely: acceptance, comfort, and willingness.

Based on review of published literature, the *acceptance* of woman's state of pregnancy is based on the importance associated with confirmation of pregnancy and disclosure to male partner or her close social support network (e.g. mother, friend, or close relative [3]. There are some community barriers that influence behavior of pregnant women towards disclosure, for example in some communities women did not disclose their pregnancies early in order to protect unborn child from sorcery, witchcraft and attacks of jealous neighbors [4]. *Comfort* is based on perceptions of happiness, security and lack of anxiety as a result of support in the social environment. The acceptance of pregnancy confers an alleviation of distress or unnecessary anxiety about the pregnancy. Happiness about current pregnancy provides confidence to address any challenges during the nine months and the state of comfort empowers the mother to seek and learn more about her state of pregnancy. Acceptance of the 'personal' pregnancy considers the contribution of mindset in the recognition and acceptance of pregnancy, influenced by knowledge of pregnancy symptoms, pregnancy planning and desire. *Acceptance* of the 'public' pregnancy considers women's assessment of the social consequences of pregnancy, and the relevance and priority of antenatal care [5].

Social acceptance leads to comfort which results in positive actions by the pregnant mother to seek ANC and protect the unborn child. The desire to know whether baby is progressing well drives the willingness to enroll early for ANC [6].

## *Enablers of pregnancy disclosure*

The enablers of pregnancy disclosure can be categorized based on their affinity to the three themes on acceptance, comfort, and willingness.

***Mother's knowledge on pregnancy***

The exposure to various channels of information regarding pregnancy can influence behavior of pregnant mothers. The mother's knowledge on pregnancy is a key enabler for early disclosure since the lack of knowledge on pregnancy and misconceptions of pregnancy can contribute to late disclosure. For example, mothers who have knowledge on pregnancy and had accepted their current state are more likely to have correct information on pregnancy. However, in cases where there's little knowledge about pregnancy, mothers may perceive pregnancy as a condition that does not require medical attention and only when some unusual signs and symptom are experienced that treatment is required [6]. The poor community awareness on the importance of early disclosure and initiation of ANC is exacerbated by social economic status and mothers' level of education.

***Community awareness / exposure***

Several studies report that late entry to ANC visit can be associated with socio-demographic variables, parity, media exposure, lack of social support, and cultural factors [7]. Therefore, communities that have high exposure to messaging on pregnancy and ANC can provide social support system to pregnant mothers based on resources available in communities (e.g. community health volunteers, skilled health personnel, community groups promoted behavior that support early disclosure and timely initiation of ANC services). The availability of resources in the community that support pregnant mothers can be considered an enabler for early disclosure of pregnancy.

***Family support***

Family support goes beyond the provision of financial resources and relates more to the social support system. The social nature of families is considered a key enabler to early disclosure for example, support

for pregnancy in form of encouragement from a parent or close relative, provision of help to reduce burden of household chores and in cases or primipara or first-time pregnancies for young women, the support through encouragement received from mothers or mothers in-law [8].

***Parity***

The parity of pregnant women can be an enabler or barrier to early disclosure of pregnancy. Women with one parity are more likely to disclose that they are pregnant and initiate ANC within first 12 weeks. For example, in cases where a woman with more than one parity and with child under five years, disclosure of pregnancy was delayed due to fear associated with chastisement from peers, health workers etc. – based on family planning messages on birth spacing [9]. Further, age and parity concurrently can be considered as barriers to disclosure. For example, older women with more than four children are more likely not to disclose early, as well as an older multipara woman with children, due to stigma associated with conceiving children at an older age.

***Male partners support***

Male support relates to the dimension of social acceptance of the pregnancy and decision made by partner to help nurture their unborn child. The involvement or participation of male partner confers the social status and respect to pregnant women. In some cases, the support of male partner related to their role as decision makers, source of economic empowerment, and influential nature in society [4]. The support of male partner allowed disclosure of pregnancy early based on their influential nature within family and societal expectations as provider. Male partners in formal or non-formal unions usually were notified first about the pregnancy, this was especially for first time pregnant mothers.

***Social norms / etiquette***

Social norms can be considered based on socio economic status of pregnant women and if societal expectations relate to how economically empowered the woman is; this may create barriers to early disclosure due to burdens associated with these social norms. Pregnancy has a social dimension and for a pregnant woman, there's perception of decorum in respective communities for women to abide by during pregnancy. For example, preference for proper dressing during pregnancy; occupation status of mother and place [4] or residence are factors that influence the nature of norms and etiquette for pregnant women. These social norms may unnecessarily put pressure on pregnant women and may affect disclosure. Also, pregnant mothers engaged in economic activities may be more likely to disclose early given the nature of work and associated norms. Likewise, women in urban areas are more likely to disclose early as compared to counterparts in rural areas based on social norms or etiquette associated with these social environments [10].

***Pregnancy complications***

Pregnancy complications are considered an enabler to early disclosure and relate to problems experienced during various trimesters of pregnancy. For example, in cases of women who experienced difficulties during previous pregnancies, disclosure was done very early, and confirmation of pregnancy done based on last menstrual period (LMP) [4]. Also, the mother's knowledge or exposure to the danger signs during pregnancy contributed to early disclosure of pregnancy based on recognition and acceptance of pregnancy, influenced by knowledge of pregnancy symptoms, pregnancy planning and desire for safe delivery.

***Family planning***

The use of family planning methods is an indication of preference for planned pregnancies and hence it can be considered an enabler to early disclosure. The exposure to various methods of family planning

enables women to be in control and when they conceive, disclosure is done early because the pregnancy is planned and timed appropriately. However, some women who reported extended use of contraceptives did not disclose their pregnancy until it was physically visible because they were not able to tell if they were pregnant or not [4].

## *Barriers to pregnancy disclosure*

The barriers to pregnancy disclosure can be considered based on how they influence the three themes of acceptance, comfort, and willingness.

### *Age at first pregnancy*

The social pressures and public humiliation of the unplanned pregnancy coupled with the young age affect disclosure of the pregnancy. For example, adolescents and unmarried young women, especially those still in school and with an unplanned pregnancy are likely not to disclose their pregnancy [11]. Also, the lack of familiarity with the signs of pregnancy for primipara young women can unintentionally lead to non-disclosure of the pregnancy, this is mostly due to uncertainty of pregnancy.

Adolescents and unmarried younger women hide their pregnancies to avoid the potential social implications of disclosure of pregnancy: exclusion from school, expulsion from their natal home, partner abandonment, stigmatization, and gossip. In contrast, older women do not make active efforts to hide their pregnancies. However, they would only directly disclose their pregnancy to close relatives and their husband. In cases of students, the young women almost never disclose the pregnancies due to the fear of expulsion from school or reprimand by the school administration [12]. However, in rare cases, school administrators who found out that some students were pregnant provided support during the pregnancy. The age at first pregnancy and experience for first time mothers is key determinant for how they behave during the subsequent pregnancies.

### *Culture*

Culture influences disclosure of pregnancy based on the anxiety and cultural norms of communities where the mothers reside. In some communities for example among the Kipsigis in Kenya, conception and motherhood before female initiation was unacceptable and condemned because it was considered ritually unclean and would “pollute” the tribe. Children from such pregnancies were considered “an abomination”. These cultural norms still exist today, and the fear of condemnation prevents disclosure of pregnancy among young women, as well as those who have had short interval pregnancies [6].

Cultural norms where pregnancies are considered normal events have conditioned behavior of pregnant mothers not to disclose their pregnancies especially where there is absence of any complications. However, communities steeped in cultural beliefs, early disclosure of pregnancy is forbidden due to the belief of “evil eyes” and witchcraft, in most cases the mothers fear loss of pregnancy through unexplained supernatural events [11].

### *Health worker behaviour*

Health workers behavior relates to the treatment of pregnant mothers at the health facility and is considered a barrier. For example, shouting, scolding, and reprimanding mothers create unnecessary anxiety about pregnancy, which can affect disclosure and subsequent access to ANC. In some cases, where social norms expect pregnant mother to seek ANC, some studies reported that pregnant mothers do not disclose their status for fear of reprimand from health workers, especially in cases of adolescent or mothers who are deemed not to be practicing good birth spacing [11]. In communities where traditional

birth attendants were easily accessible, pregnant mothers preferred to disclose their status and seek advice as opposed to health workers. In such cases, the service experience from traditional birth attendants (TBA) was considered superior to that of health workers [6].

***HIV Testing***

The transition from voluntary to provider-initiated testing for all mothers attending ANC has increased coverage of prevention of mother-to-child transmission of HIV/AIDS programs, however, the mandatory HIV testing in communities where stigma is high has made this a barrier to early disclosure of pregnancy. The anxiety associated with HIV testing can prevent early disclosure of pregnancy especially where service providers insist on couple testing. This introduces an element of fear in case results are positive and there is a risk that her partner may abandon the pregnant mother [4]. Disclosure of pregnancy can be withheld for as long as it is possible to avoid subsequent activities that may involve conducting HIV testing.

***Traditional birth attendants***

Pregnant women who reside in communities where TBA are preferred service providers can delay disclosing pregnancy because the TBA are custodians of culture and decorum for pregnant women. In such communities, TBA are trusted more than health workers, and their advice is sometimes considered infallible. For example, in some communities, TBA hold opinion that it is not necessary to disclose early but rather pregnant mothers wait until after the first trimester [6]. In these communities, TBA are trusted and considered to be more skilled than medical workers.

***Birth spacing / Number of children under five years***

Mothers who conceived whilst still breastfeeding existing children under two years are afraid to disclose pregnancies early due to social pressures within their household and community. Some studies have reported that mothers were ashamed of pregnancies due to lack of adequate birth spacing between siblings [7]. Likewise, the number of children under five was considered as a barrier to early disclosure due to the mother's responsibilities for child upbringing, nature of work at household level and age of child.

***Household income***

The social nature of pregnancy and norms and expectations regarding behavior of pregnant women can be considered as barriers to early disclosure in households that have low-income status. Disclosure of pregnancy would infer additional cost burden to the household especially where the mother is expected to access ANC services frequently. Social norms among communities for example where mothers attending ANC services are expected to carry some pocket money to spend during the visit may exert undue pressure to mothers from households with low income, who can opt not to disclose their pregnancies to avoid placing additional financial burden on the household.

## *Process of building capacity in country based on the literature reviews*

Based on this experience of literature review, the Kenya team undertook a follow-up process to further identify potential factors (barriers and enablers) that can affect consumption of IFA supplements. With the support of 10 research assistants, they conducted a systematic search for papers of interest based on the five topics informed by the bottlenecks previously identified namely (1) Barriers of access to IFA supplements, (2) Consumption of IFA supplements by pregnant mothers, (3) Counselling for pregnant women, (4) Community level IFA supplementation and, (5) Stock out of IFA supplements. This process helped to build the capacity of recently graduated nutritionists to carry out literature reviews while also lending to identify multiple factors relevant for programmatic purposes. The full report can be found here.

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