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3 **What matters to women: A systematic scoping review to identify the processes and**
4 **outcomes of antenatal care provision that are important to healthy pregnant women**
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7 *Women's views of what matters for care during pregnancy*
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Abstract

Background

Global uptake of antenatal care (ANC) varies widely and is influenced by the value women place on the service they receive. Identifying outcomes that matter to pregnant women could inform service design and improve uptake and effectiveness.

Objectives

To undertake a systematic scoping review of what women want, need and value in pregnancy

Search strategy

Eight databases were searched (1994-2015) with no language restriction. Relevant journal contents were tracked via Zetoc.

Data collection and analysis

An initial analytic framework was constructed with findings from 21 papers, using data-mining techniques, and then developed using meta-ethnographic approaches. The final framework was tested with 17 more papers.

Main results

All continents except Australia were represented. 1264 women were included. The final meta-theme was: *Women want and need a positive pregnancy experience*, including four subthemes: *maintaining physical and socio-cultural normality*; *maintaining a healthy pregnancy for mother and baby* (including preventing and treating risks, illness and death); *effective transition to positive labour and birth*; and *achieving positive motherhood* (including maternal self-esteem, competence, autonomy). Findings informed a framework for future ANC provision, comprising three equally important domains: clinical practices (interventions and tests); relevant and timely information; and psychosocial and emotional support; each provided by practitioners with good clinical and interpersonal skills within a high quality health system.

Conclusions

A positive pregnancy experience matters across all cultural and socio-demographic contexts. ANC guidelines and services should be designed to deliver it, and those providing ANC services should be aware of it at each encounter with pregnant women.

Keywords

Antenatal care; guidelines, World Health Organization, women's views, social support, pregnancy, wordclouds

67 **Tweetable abstract:** Women around the world want antenatal care staff and services to help them
68 achieve a positive pregnancy experience
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Introduction

Universal access to antenatal care (ANC) is one of the key indicators in the 2015 Millennium Goal 5¹. The 2002 WHO recommendations for ANC provision are based on the findings of a rigorous systematic review². They promote a package of at least four visits with evidence-based interventions through goal-oriented clinic visits. This is known as focused antenatal care (FANC)³. Since 2002, many low and middle-income countries have adopted FANC into national policies, guidelines and institutional protocols. However, in 2012, only 52% of pregnant women had four or more ANC visits during pregnancy, an absolute increase of only 15% in 22 years⁴. Lack of agreement about the optimal content, frequency, and style of delivery of ANC may be a barrier to uptake if local ANC provision does not meet the needs and expectations of women and families. Indeed, marked coverage gaps occurred for recommended ANC procedures in most of the 41 countries reviewed in 2014⁵. Arguably, health care programmes can increase the likelihood of uptake and, therefore, of health improvement if they are designed on the basis of outcomes that matter to all relevant individuals, and if they provide care components that have the best chance of delivering those outcomes, in a way that is acceptable, accessible, and appropriate for the intended service users⁶.

The primary outcomes examined in the current Cochrane Review of trials of alternative versus standard packages of antenatal care for low-risk pregnancy encompass death and serious morbidity only⁷. This suggests that what researchers and service providers think ANC is for, even for healthy women and babies, is the identification and prevention of pathology. Some researchers have measured 'satisfaction' and levels of attendance in relation to specific ANC programmes^{8, 9}. However, studies of why women don't use ANC suggest that other, more complex, outcomes might also be important to them^{10, 11}. The 2015 WHO ANC guideline development steering committee recognized the need to maximize uptake of ANC, by designing programmes and interventions that are acceptable and relevant to all pregnant women. To inform the guideline development process, the objective of this evidence synthesis of the qualitative literature was to describe what women in high, medium and low income countries want and expect from antenatal care, based on their own accounts of their beliefs, views, expectations and experiences of pregnancy.

Methods

The study was a systematic scoping review, followed by an evidence synthesis of qualitative data using a Framework approach¹², based on meta-ethnographic principles.¹³

Reflexive note

In keeping with quality standards for rigor in qualitative research, the authors considered their views and opinions on antenatal care as possible influences on the decisions made in the design and conduct of the study, and, in turn, on how the emerging results of the study influenced those views and opinions. All the authors believed at the outset that contact with formal and informal care givers throughout pregnancy

was valuable, but that formal ANC provision is generally over-focused on clinical procedures and the assessment of risk/ill-health, with too little focus on the psychosocial aspects of pregnancy. Refutational analytic techniques were therefore used to minimize the risk that these pre-suppositions would skew the analysis and the interpretation of the findings.

Search strategy

The search terms covered the criteria of Context (antenatal or antenatal or antepartum [Ti or Ab]); Intervention (care or clinic or outpatient\$ or education\$ or session\$ [Ti or Ab]); Topic (want or like or desire or expect\$ or anticipate\$ or view\$ or experience\$ or encounter\$ or belief [Ti or Ab]) and Study Type (qualitative or review or interview\$ or group or ethnograph\$ or phenomenol\$ or grounded + theory [Ti or Ab]).

Inclusion/exclusion criteria

No language restrictions were imposed. Studies published before 1994 were excluded, to ensure that the findings reflect the current generation of women who may encounter antenatal care. Studies were included if they reported women's views directly (and not through staff opinion, or observational data), and if these were the views of the general population of healthy women. To ensure that the data reflected the views and experiences of the general population of healthy women in any specific study setting, and that they were not focused on services that were actually available to them (which may or may not be what they actually wanted and/or needed), studies were excluded if they reported on views and experiences of specific antenatal care provision, or of specialist services that were not provided to the population of pregnant women, and/or on specific subgroups of women with particular health problems. KF screened the initial hits against the inclusion criteria. Abstracts and full text papers were included based on consensus between at least two team members.

Data sources

Eight databases were searched. The first search was undertaken in May and June 2014 in six of the eight databases (Medline, PubMed Cinahl, EMBASE, LILACS, AJOL). PsycInfo and AMED were searched in August 2014. Reference lists of included papers were scrutinized (backchained). Zetoc alerts were set up for over 50 relevant journals, and these have continued to date. Papers generated by the secondary searches (PsycInfo and AMED) as well as the papers from the back-chaining and Zetoc alert processes were used as confirmatory data against the emerging themes from the main review.

Quality assessment

The included studies were subject to quality appraisal using the instrument developed by Walsh and Downe¹⁴ and modified by Downe et al¹⁵. This is a simple appraisal system that rates studies against 11 criteria, and then allocates a score from A-D (see box one). Studies scoring D were excluded on quality grounds.

Scoring criteria for quality appraisal

A: No, or few flaws. The study credibility, transferability, dependability and confirmability are high;

B: Some flaws, unlikely to affect the credibility, transferability, dependability and/or confirmability of the study;

C: Some flaws that may affect the credibility, transferability, dependability and/or confirmability of the study.

D: Significant flaws that are very likely to affect the credibility, transferability, dependability and/or confirmability of the study.

Analytic strategy

The analytic process was undertaken in three steps. A modified Framework Analytic approach was used to structure the data synthesis¹².

In step one, the summarised findings from the studies included after the searches undertaken in May and June 2014 were entered into Google Wordle OpenSource software, first with the complete set of text, and then minus words that related to the inclusion criteria for the studies, or their geographical location, and not the findings ('prenatal', 'pregnancy', 'women', 'health care', 'themes', American, African). Text mining software is increasingly sophisticated¹⁶ and the resulting visual word-clouds allowed for the rapid development of an inductively derived thematic framework that was then tested deductively with further sets of data from the total dataset in steps two and three.

In step two, the initial framework was tested and further developed by mapping detailed findings of all the studies contributing to the data-mining outputs one by one against the framework elements. Meta-ethnographic analytic techniques¹³ of reciprocal and refutational translation were used to assess fit and relevance. The explanatory power of the framework was established using the CERQual approach based on methodological limitations, adequacy of data, coherence and relevance¹⁷. This included an examination of the number of studies contributing to each element of the framework, and the quality and geographical spread of those studies.

In step three, studies emerging from the second set of searches (in PsychInfo and Amed) and papers from the back-chaining exercise and Zetoc alerts were used as the basis for confirmatory testing of the framework developed in steps one and two.

The findings were then translated into principles for future antenatal care provision, and were the basis of an associated new, woman-centred framework for audit and research in this area.

Results

Included studies

The initial search strategy generated 8205 hits including 5781 from a single database (Pub Med). To make the screening stage more manageable the results from PubMed were sorted by relevance and the first 1500 were screened by title. All of the hits from the remaining databases were included in the screening stage meaning that 4554 results were reviewed by title. 4185 studies were excluded at this stage primarily because they were deemed to be unrelated to the topic of interest. The remaining 369 studies were taken forward for abstract review and a further 167 were excluded at this stage. The reasons for exclusion were: representing the views of other stakeholders rather than women (n= 49); explicitly quantitative (n= 72); not deemed to be research studies (n= 9); not directly related to the topic (n= 23); duplicates (n = 10) and dissertations (n= 4). 202 studies were therefore taken forward for full text review and, of these, a further 178 were excluded because they either represented the views of specific sub-populations, e.g. women with HIV, women with a BMI >30, etc.; (n= 114) or they were concerned with a specific component of antenatal care e.g. fetal anomaly screening, HIV counselling, etc.; (n=64). After quality appraisal another 3 papers were removed. One was a systematic review evaluating women's experiences of antenatal care rather than their expectations¹⁸, one was predominantly quantitative¹⁹, and one was about the factors affecting antenatal care utilization rather than what women want from services²⁰ (see figure 1 for flowchart of included studies).

The second search generated 708 hits, of which, 578 were excluded by title, 46 at the abstract stage and 68 following full text review. 16 were therefore taken forward for quality assessment and 3 of these were excluded at this stage because they were predominantly quantitative²¹⁻²³. (Full details of this search are shown in figure 1). There were no additional studies from the Zetoc alerts and 4 studies were obtained from the back-chaining exercise. These four studies were assessed for quality and included in the confirmatory analysis. A total of 38 papers were therefore included in the analysis²⁴⁻⁶¹. These are coded 1-38 in the following tables, and these codes are given in square brackets at the end of each relevant reference in the reference list.

--- INSERT FIGURE 1 ---

Characteristics and quality of included studies

Characteristics of the included studies were tabulated (see supplementary file Table S1). The date range was 1994-2013. All regions of the world were represented except Australasia. By continent, the largest number of studies were based in North (13) or South (8) America. Four were from Africa, four each from Europe and Asia, two from the Middle East, and one study included four countries (Cuba, Thailand, Argentina, Saudi Arabia).

The majority of the included studies used qualitative techniques, and most data were collected by individual interviews and/or focus or discussion groups. Sample size ranged from 5-164. The studies

included women from a wide range of socio-demographic groups, and the overall age range was 13-49. The quality of most studies was fair to high (B or above).

The results of the data mining process for all the findings text for the 21 papers located in the first search (studies 1-21 in supplementary file Table S1) are given in supplementary file Figure S1. The results for the reduced set of text, are given in figure 2:-

--- INSERT FIGURE 2

The framework for analysis derived from the data mining exercise, and amended following the comprehensive mapping of all the 21 papers in step two, is given in tables one and two, and in the supplementary file (Table S2) ~~table three~~ (text in black in each table).

Step three: Testing the analytic framework

The findings from the included studies at step three (studies 22-38) were then mapped to the amended framework to check that all the themes continue to have explanatory power, and to make sure no themes were missing (text in red in tables one and two, and in the supplementary file (Table S2) represent the studies identified in step three) . As in the planned analytic strategy, this comprised both a reciprocal process (when the data could be mapped to the framework) and a refutational one (to check if any of the data could not be mapped)¹³. The data from all the studies could be mapped to this final framework. The subthemes developed in step two were all supported by data from at least one of the studies in step three, except for availability of services.

-INSERT TABLES 1 and 2

What matters to women

A positive pregnancy experience emerged as a composite outcome from our results (Table 1). This was informed by four sub-themes or components (Table 1) that mattered to women in pregnancy, across countries, cultural groups, and varying socio-demographics, namely: *maintaining physical and socio-cultural normality*; *maintaining a healthy pregnancy for mother and baby* (including preventing and treating risks, illness, and death); *effective transition to positive labour and birth*; and *achieving positive motherhood* (including maternal self-esteem, competence, autonomy).

The findings also informed a proposed design for a revised, women-centred ANC service, comprising three domains: clinical care/therapeutic practices (biomedical interventions and tests, integrated with spiritual and religious practices, where appropriate); relevant and timely information (physiological, biomedical, as well as behavioural and socio-cultural); and support (social, cultural, emotional, and psychological) (Table 2). The final data set arising from the analysis concerned the attributes of formal and informal care

providers, including both positive interpersonal behaviours and skills and competencies; and health system requirements, including the quality and accessibility of the health system within which ANC was provided

Discussion

Main findings

The findings of this review confirm that women from a wide range of cultural and socio-economic contexts expect positive wellbeing for themselves and their newborns to be the main outcome of pregnancy.

Beyond this apparently common-sense conclusion, the analysis reveals that positive pregnancy experience has four distinct components, that could be operationalized in research, guidelines, and ANC provision.

The findings challenge the tendency for antenatal care to be focused on the identification and treatment of potential or actual pathology, without paying attention to the maintenance and promotion of positive health and wellbeing. This study therefore contributes to the on-going CROWN maternity care outcomes initiative⁶², in proposing a new composite measure to capture wellbeing.

The data suggests that routine service provision might provide only a small proportion of what matters to women (and, by extension, to their partners and families). This is especially so if routine provision cannot flex around the expectations, beliefs, needs, and resources of intended service users, and where it is largely or entirely focused on clinical detection and treatment of potential or actual pathology. In addition to the tailored (rather than routine) use of biomedical tests and interventions, the findings imply that ANC would be better able to deliver a positive pregnancy experience if it incorporated three key domains: local practices and knowledge where these are effective, as well as appropriate biomedical tests and treatments; social, cultural, emotional, and psychological support throughout; and the provision of relevant, appropriate and timely information. These latter two domains have been present in previous antenatal guidelines, but as underpinning principles, rather than as interventions to be given equal weight with clinical treatments and processes³.

The data also indicate that the characteristics, attitudes and behaviors of formal and informal care providers are important to pregnant women. This includes positive interpersonal behaviours, and clinical, cultural, and social skills and competence. Finally, women required that the health system they were accessing should enable ANC to be available, safely accessible, affordable, good quality, and that it should enable enough time for each woman to ensure her particular needs were met, in private spaces that permitted social exchange between women and staff, and between pregnant women and their peers.

Strengths and limitations

The study used secondary data, collected for a range of reasons. The conclusions are therefore based on what the original authors chose to report, and not on the whole dataset generated for each study. Some

studies included small numbers of women. Australia was not represented, but two Australian papers published after the review was completed reinforce the findings^{63 64}, as does an earlier empirical study looking at relevant outcomes in one specific model and country setting (midwifery led antenatal care in one Irish clinic),⁶⁵ providing external evidence that the findings are comprehensive and transferable. Each of the domains emerging from the analysis mapped to a large number of studies, from a range of cultural, linguistic and income level settings, and so the final results can be accepted for most contexts with high confidence. Methodologically, the use of word clouds to explore large amounts of qualitative data is relatively new and our approach demonstrates how these may be used to integrate findings from qualitative research into evidence based practice.

Interpretation

As part of the core dataset of maternity care outcomes and current WHO-led initiatives to improve quality of care for pregnant women and newborns⁶⁶ we propose that ‘positive pregnancy experience’ should be operationalized, either by mapping to existing tools and techniques that measure the four components identified, or by developing new instruments. These may include individually tailored Quality of Life tools such as the Mother Generated Index⁶⁷. These indicators should then be used for the evaluation of any future guidelines, interventions or programmes developed for antenatal care provision.

We suggest that the active provision of social support should occur both in formal care settings, and in communities. This could be done by including service design (incorporating the environment where care is delivered) and delivery approaches that provide psycho-social and emotional support for staff and service users, and that enhance physiological processes, hope, and positive feelings, to help women to understand and deal with normal changes in pregnancy, and to prepare actively for labour, birth, and mothering.

We also propose that provision of information in pregnancy should include physiological, behavioral, social, cultural, and biomedical components, and it should value embodied and cultural knowledge, as well as biomedical evidence. It should be tailored to the needs of the particular woman at the specific time in her pregnancy when that particular information is needed, and it should be given in a manner and through a medium that is comprehensible and accessible for her.

Our interpretation of what might work to deliver a positive pregnancy experience is compatible with the new WHO quality of care framework for maternal and newborn health⁶⁶, which incorporates evidence-based practice for routine care and management of complications, effective communication, emotional support, respect, and dignity, provided within a functional health system that allows access to care, with the aim of increasing desirable people-centred outcomes. These elements also underpin the Lancet Quality Maternal and Newborn Care framework⁶⁸, suggesting that they might apply across the maternity episode, and not just in the antenatal period.

There is some *a priori* evidence that the three proposed ANC domains identified in Table 2 (care practices, information and support) might be acceptable to pregnant women, on the basis of positive evaluations of group antenatal care, which is designed to maximize social support as well as clinical provision⁶⁹. Indeed, community women's groups that are set up in pregnancy and continue postpartum have delivered remarkable results in reducing neonatal and maternal morbidity in a range of low-income settings⁷⁰. Examination of the active mechanisms of these groups suggest that they include health education, confidence building, information dissemination, and increasing community capacity for action⁷¹. A shift towards an integrated ANC model that gives equal weight, resources, and time to tests and interventions, information and support, may, therefore, have positive effects on both physical and psychosocial wellbeing.

Conclusions

A positive pregnancy experience is important for women in a range of cultural and socio-demographic contexts. The four components of positive pregnancy experience identified in this review should be included in ANC research. ANC guidelines and programmes should include packages of care designed to encompass these components. Future research could test the capacity of ANC based on care practices, information, and support to deliver a positive pregnancy experience. All service providers (medical, midwifery and nursing professionals and lay health workers, in hospitals, health centres and local communities) should consider how they can work with women, families, local communities, and with each other, to provide care that results in this outcome, to ensure optimal uptake of ANC services, and to maximize well-being for mothers and newborns.

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Disclosure of Interest

None

Contribution to Authorship

OT had the idea for the review, under the overall leadership of MG. SD led the review, and did the detailed design and coordination. SD, KF and OT undertook the analysis, and interpretation of the data. All authors contributed to the development and finalization of the paper

Details of ethics approval

375 Not required

376

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