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What matters to women: a systematic scoping review to identify the processes and outcomes of antenatal care provision that are important to healthy pregnant women

Downe, Soo, Finlayson, K., Tunçalp, Ö and Metin Gülmezoglu, A
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Downe, Soo, Finlayson, K., Tunçalp, Ö and Metin Gülmezoglu, A (2016) What matters to women: a systematic scoping review to identify the processes and outcomes of antenatal care provision that are important to healthy pregnant women. BJOG: An International Journal of Obstetrics & Gynaecology . ISSN 14700328

It is advisable to refer to the publisher's version if you intend to cite from the work.
<http://dx.doi.org/10.1111/1471-0528.13819>

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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*
8

9 **Soo Downe**, Professor of Midwifery: Research in Childbirth and Health (ReaCH) group, University of
10 Central Lancashire, Preston PR1 2HE UK,
11

12 **Kenneth Finlayson**, Senior Research Assistant: Research in Childbirth and Health (ReaCH) group,
13 University of Central Lancashire, Preston PR1 2HE UK,
14

15 **Özge Tunçalp**, Scientist, Department of Reproductive Health and Research including
16 UNDP/UNFPA/UNICEF/WHO/World Bank Special Programme of Research, Development and
17 Research Training in Human Reproduction (HRP), World Health Organization, 20 Avenue Appia, 1211,
18 Geneva, Switzerland
19

20 **A. Metin Gülmezoglu**, Coordinator, Department of Reproductive Health and Research including
21 UNDP/UNFPA/UNICEF/WHO/World Bank Special Programme of Research, Development and
22 Research Training in Human Reproduction (HRP), World Health Organization, 20 Avenue Appia, 1211,
23 Geneva, Switzerland
24
25

26 Corresponding Author: Prof Soo Downe

27 Tel: +44 (0) 1772 893815

28 E-mail: SDowne@uclan.ac.uk
29

30 **Abstract**

31

32 **Background**

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

36

37 **Objectives**

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

39

40 **Search strategy**

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

43

44 **Data collection and analysis**

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

48

49 **Main results**

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

58

59 **Conclusions**

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

63

64 **Keywords**

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

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

69

70

71 **Introduction**

72 Universal access to antenatal care (ANC) is one of the key indicators in the 2015 Millennium Goal 5¹. The
73 2002 WHO recommendations for ANC provision are based on the findings of a rigorous systematic
74 review². They promote a package of at least four visits with evidence-based interventions through goal-
75 oriented clinic visits. This is known as focused antenatal care (FANC)³. Since 2002, many low and middle-
76 income countries have adopted FANC into national policies, guidelines and institutional protocols.
77 However, in 2012, only 52% of pregnant women had four or more ANC visits during pregnancy, an
78 absolute increase of only 15% in 22 years⁴. Lack of agreement about the optimal content, frequency, and
79 style of delivery of ANC may be a barrier to uptake if local ANC provision does not meet the needs and
80 expectations of women and families. Indeed, marked coverage gaps occurred for recommended ANC
81 procedures in most of the 41 countries reviewed in 2014⁵. Arguably, health care programmes can increase
82 the likelihood of uptake and, therefore, of health improvement if they are designed on the basis of
83 outcomes that matter to all relevant individuals, and if they provide care components that have the best
84 chance of delivering those outcomes, in a way that is acceptable, accessible, and appropriate for the
85 intended service users⁶.

86
87 The primary outcomes examined in the current Cochrane Review of trials of alternative versus standard
88 packages of antenatal care for low-risk pregnancy encompass death and serious morbidity only⁷. This
89 suggests that what researchers and service providers think ANC is for, even for healthy women and
90 babies, is the identification and prevention of pathology. Some researchers have measured 'satisfaction'
91 and levels of attendance in relation to specific ANC programmes^{8,9}. However, studies of why women
92 don't use ANC suggest that other, more complex, outcomes might also be important to them^{10,11}. The
93 2015 WHO ANC guideline development steering committee recognized the need to maximize uptake of
94 ANC, by designing programmes and interventions that are acceptable and relevant to all pregnant women.
95 To inform the guideline development process, the objective of this evidence synthesis of the qualitative
96 literature was to describe what women in high, medium and low income countries want and expect from
97 antenatal care, based on their own accounts of their beliefs, views, expectations and experiences of
98 pregnancy.

100 **Methods**

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

104 **Reflexive note**

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

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

114 **Search strategy**

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

121 **Inclusion/exclusion criteria**

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

134 **Data sources**

135 Eight databases were searched. The first search was undertaken in May and June 2014 in six of the eight
136 databases (Medline, PubMed Cinahl, EMBASE, LILACS, AJOL). PsycInfo and AMED were searched in August
137 2014. Reference lists of included papers were scrutinized (backchained). Zetoc alerts were set up for over
138 50 relevant journals, and these have continued to date. Papers generated by the secondary searches
139 (PsycInfo and AMED) as well as the papers from the back-chaining and Zetoc alert processes were used as
140 confirmatory data against the emerging themes from the main review.

142 **Quality assessment**

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

147 **Scoring criteria for quality appraisal**

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

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

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

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

155
156 **Analytic strategy**

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

159
160 In step one, the summarised findings from the studies included after the searches undertaken in May and
161 June 2014 were entered into Google Wordle OpenSource software, first with the complete set of text, and
162 then minus words that related to the inclusion criteria for the studies, or their geographical location, and
163 not the findings ('prenatal', 'pregnancy', 'women', 'health care', 'themes', American, African). Text mining
164 software is increasingly sophisticated¹⁶ and the resulting visual word-clouds allowed for the rapid
165 development of an inductively derived thematic framework that was then tested deductively with further
166 sets of data from the total dataset in steps two and three.

167
168 In step two, the initial framework was tested and further developed by mapping detailed findings of all
169 the studies contributing to the data-mining outputs one by one against the framework elements. Meta-
170 ethnographic analytic techniques¹³ of reciprocal and refutational translation were used to assess fit and
171 relevance. The explanatory power of the framework was established using the CERQual approach based
172 on methodological limitations, adequacy of data, coherence and relevance¹⁷. This included an examination
173 of the number of studies contributing to each element of the framework, and the quality and geographical
174 spread of those studies.

175
176 In step three, studies emerging from the second set of searches (in PsychInfo and Amed) and papers from
177 the back-chaining exercise and Zetoc alerts were used as the basis for confirmatory testing of the
178 framework developed in steps one and two.

179
180 The findings were then translated into principles for future antenatal care provision, and were the basis of
181 an associated new, woman-centred framework for audit and research in this area.

182
183 **Results**
184

185 **Included studies**

186 The initial search strategy generated 8205 hits including 5781 from a single database (Pub Med). To make
187 the screening stage more manageable the results from PubMed were sorted by relevance and the first
188 1500 were screened by title. All of the hits from the remaining databases were included in the screening
189 stage meaning that 4554 results were reviewed by title. 4185 studies were excluded at this stage primarily
190 because they were deemed to be unrelated to the topic of interest. The remaining 369 studies were taken
191 forward for abstract review and a further 167 were excluded at this stage. The reasons for exclusion were:
192 representing the views of other stakeholders rather than women (n= 49); explicitly quantitative (n= 72);
193 not deemed to be research studies (n= 9); not directly related to the topic (n= 23); duplicates (n = 10) and
194 dissertations (n= 4). 202 studies were therefore taken forward for full text review and, of these, a further
195 178 were excluded because they either represented the views of specific sub-populations, e.g. women
196 with HIV, women with a BMI >30, etc.; (n= 114) or they were concerned with a specific component of
197 antenatal care e.g. fetal anomaly screening, HIV counselling, etc.; (n=64). After quality appraisal another 3
198 papers were removed. One was a systematic review evaluating women’s experiences of antenatal care
199 rather than their expectations¹⁸, one was predominantly quantitative¹⁹, and one was about the factors
200 affecting antenatal care utilization rather than what women want from services²⁰ (see figure 1 for
201 flowchart of included studies).

202
203 The second search generated 708 hits, of which, 578 were excluded by title, 46 at the abstract stage and
204 68 following full text review. 16 were therefore taken forward for quality assessment and 3 of these were
205 excluded at this stage because they were predominantly quantitative²¹⁻²³. (Full details of this search are
206 shown in figure 1). There were no additional studies from the Zetoc alerts and 4 studies were obtained
207 from the back-chaining exercise. These four studies were assessed for quality and included in the
208 confirmatory analysis. A total of 38 papers were therefore included in the analysis²⁴⁻⁶¹. These are coded 1-
209 38 in the following tables, and these codes are given in square brackets at the end of each relevant
210 reference in the reference list.

211
212 --- INSERT FIGURE 1 ---
213

214 **Characteristics and quality of included studies**

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

220
221 The majority of the included studies used qualitative techniques, and most data were collected by
222 individual interviews and/or focus or discussion groups. Sample size ranged from 5-164. The studies

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

225
226 The results of the data mining process for all the findings text for the 21 papers located in the first search
227 (studies 1-21 in supplementary file Table S1) are given in supplementary file Figure S1. The results for the
228 reduced set of text, are given in figure 2:-

229
230 --- INSERT FIGURE 2

231
232 The framework for analysis derived from the data mining exercise, and amended following the
233 comprehensive mapping of all the 21 papers in step two, is given in tables one and two, and in the
234 supplementary file (Table S2) ~~table three~~ (text in black in each table).

235 **Step three: Testing the analytic framework**

236
237 The findings from the included studies at step three (studies 22-38) were then mapped to the amended
238 framework to check that all the themes continue to have explanatory power, and to make sure no themes
239 were missing (text in red in tables one and two, and in the supplementary file (Table S2) represent the
240 studies identified in step three) . As in the planned analytic strategy, this comprised both a reciprocal
241 process (when the data could be mapped to the framework) and a refutational one (to check if any of the
242 data could not be mapped)¹³. The data from all the studies could be mapped to this final framework. The
243 subthemes developed in step two were all supported by data from at least one of the studies in step
244 three, except for availability of services.

245
246 -INSERT TABLES 1 and 2

247 **What matters to women**

248
249 A positive pregnancy experience emerged as a composite outcome from our results (Table 1). This was
250 informed by four sub-themes or components (Table 1) that mattered to women in pregnancy, across
251 countries, cultural groups, and varying socio-demographics, namely: *maintaining physical and socio-*
252 *cultural normality; maintaining a healthy pregnancy for mother and baby* (including preventing and
253 treating risks, illness, and death); *effective transition to positive labour and birth*; and *achieving positive*
254 *motherhood* (including maternal self-esteem, competence, autonomy).

255
256 The findings also informed a proposed design for a revised, women-centred ANC service, comprising three
257 domains: clinical care/therapeutic practices (biomedical interventions and tests, integrated with spiritual
258 and religious practices, where appropriate); relevant and timely information (physiological, biomedical, as
259 well as behavioural and socio-cultural); and support (social, cultural, emotional, and psychological) (Table
260 2). The final data set arising from the analysis concerned the attributes of formal and informal care

261 providers, including both positive interpersonal behaviours and skills and competencies; and health
262 system requirements, including the quality and accessibility of the health system within which ANC was
263 provided
264

265 **Discussion**

266 **Main findings**

267 The findings of this review confirm that women from a wide range of cultural and socio-economic contexts
268 expect positive wellbeing for themselves and their newborns to be the main outcome of pregnancy.
269 Beyond this apparently common-sense conclusion, the analysis reveals that positive pregnancy experience
270 has four distinct components, that could be operationalized in research, guidelines, and ANC provision.
271 The findings challenge the tendency for antenatal care to be focused on the identification and treatment
272 of potential or actual pathology, without paying attention to the maintenance and promotion of positive
273 health and wellbeing. This study therefore contributes to the on-going CROWN maternity care outcomes
274 initiative⁶², in proposing a new composite measure to capture wellbeing.
275
276

277 The data suggests that routine service provision might provide only a small proportion of what matters to
278 women (and, by extension, to their partners and families). This is especially so if routine provision cannot
279 flex around the expectations, beliefs, needs, and resources of intended service users, and where it is
280 largely or entirely focused on clinical detection and treatment of potential or actual pathology. In addition
281 to the tailored (rather than routine) use of biomedical tests and interventions, the findings imply that ANC
282 would be better able to deliver a positive pregnancy experience if it incorporated three key domains:
283 local practices and knowledge where these are effective, as well as appropriate biomedical tests and
284 treatments; social, cultural, emotional, and psychological support throughout; and the provision of
285 relevant, appropriate and timely information. These latter two domains have been present in previous
286 antenatal guidelines, but as underpinning principles, rather than as interventions to be given equal weight
287 with clinical treatments and processes³.
288

289 The data also indicate that the characteristics, attitudes and behaviors of formal and informal care
290 providers are important to pregnant women. This includes positive interpersonal behaviours, and clinical,
291 cultural, and social skills and competence. Finally, women required that the health system they were
292 accessing should enable ANC to be available, safely accessible, affordable, good quality, and that it should
293 enable enough time for each woman to ensure her particular needs were met, in private spaces that
294 permitted social exchange between women and staff, and between pregnant women and their peers.
295

296 **Strengths and limitations**

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

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

308 **Interpretation**

309 As part of the core dataset of maternity care outcomes and current WHO-led initiatives to improve quality
310 of care for pregnant women and newborns⁶⁶ we propose that ‘positive pregnancy experience’ should be
311 operationalized, either by mapping to existing tools and techniques that measure the four components
312 identified, or by developing new instruments. These may include individually tailored Quality of Life tools
313 such as the Mother Generated Index⁶⁷. These indicators should then be used for the evaluation of any
314 future guidelines, interventions or programmes developed for antenatal care provision.
315

316
317 We suggest that the active provision of social support should occur both in formal care settings, and in
318 communities. This could be done by including service design (incorporating the environment where care is
319 delivered) and delivery approaches that provide psycho-social and emotional support for staff and service
320 users, and that enhance physiological processes, hope, and positive feelings, to help women to
321 understand and deal with normal changes in pregnancy, and to prepare actively for labour, birth, and
322 mothering.

323
324 We also propose that provision of information in pregnancy should include physiological, behavioral,
325 social, cultural, and biomedical components, and it should value embodied and cultural knowledge, as
326 well as biomedical evidence. It should be tailored to the needs of the particular woman at the specific
327 time in her pregnancy when that particular information is needed, and it should be given in a manner and
328 through a medium that is comprehensible and accessible for her.

329
330 Our interpretation of what might work to deliver a positive pregnancy experience is compatible with the
331 new WHO quality of care framework for maternal and newborn health⁶⁶, which incorporates evidence-
332 based practice for routine care and management of complications, effective communication, emotional
333 support, respect, and dignity, provided within a functional health system that allows access to care, with
334 the aim of increasing desirable people-centred outcomes. These elements also underpin the Lancet
335 Quality Maternal and Newborn Care framework⁶⁸, suggesting that they might apply across the maternity
336 episode, and not just in the antenatal period.

337
338 There is some *a priori* evidence that the three proposed ANC domains identified in Table 2 (care practices,
339 information and support) might be acceptable to pregnant women, on the basis of positive evaluations of
340 group antenatal care, which is designed to maximize social support as well as clinical provision⁶⁹. Indeed,
341 community women’s groups that are set up in pregnancy and continue postpartum have delivered
342 remarkable results in reducing neonatal and maternal morbidity in a range of low-income settings⁷⁰.
343 Examination of the active mechanisms of these groups suggest that they include health education,
344 confidence building, information dissemination, and increasing community capacity for action⁷¹. A shift
345 towards an integrated ANC model that gives equal weight, resources, and time to tests and interventions,
346 information and support, may, therefore, have positive effects on both physical and psychosocial
347 wellbeing.

348 349 **Conclusions**

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

359 360 **Acknowledgements**

361 This paper was written as part of the Adding Content to Contact project, which was made possible by
362 Grant Number OPP1084319 from the Bill & Melinda Gates Foundation, and was a collaboration between
363 the Maternal Health Task Force and Department of Global Health and Population at the Harvard T.H. Chan
364 School of Public Health, HRP/WHO, and ICS Integrare.

365 366 **Disclosure of Interest**

367 None

368 369 **Contribution to Authorship**

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

373 374 **Details of ethics approval**

375 Not required

376

377 **Funding**

378 Grant Number OPP1084319 from the Bill & Melinda Gates Foundation

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