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Barriers to identifying eating disorders in pregnancy and in the postnatal period: a qualitative approach.

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1 **TITLE PAGE**

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3 **Article title**

4 Barriers to identifying Eating Disorders in pregnancy and in the postnatal period: A
5 qualitative approach

6

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48

49 **ABSTRACT**

50 **Background**

51 Eating Disorders (ED) are mental health disorders that typically effect women of
52 childbearing age and are associated with adverse maternal and infant outcomes. UK
53 healthcare guidance recommends routine enquiry for current and past mental illness in
54 antenatal and postnatal care for all women, and that pregnant women with a known ED are
55 offered enhanced monitoring and support. Midwives and health visitors are ideally placed
56 to identify and support women with ED as they are often the primary point of contact
57 during the antenatal and postnatal periods. However, research on the barriers to identifying
58 ED in the perinatal period is limited. This study aimed to understand the barriers to
59 disclosure and identification of ED in pregnancy and postnatally as perceived by women
60 with past or current ED, and midwives and health visitors working in the UK National Health
61 Service.

62

63 **Methods**

64 Two studies were undertaken: mixed-measures survey of pregnant and postnatal women
65 with current or past ED; focus groups with student and qualified midwives and health
66 visitors.

67

68 **Results**

69 Five themes emerged on the barriers to disclosure in pregnancy as perceived by women:
70 stigma, lack of opportunity, preference for self-management, current ED symptomatology
71 and illness awareness. Four themes were identified on the barriers to identification of ED in

72 pregnancy and in the postnatal period as perceived by health professionals: system
73 constraints, recognition of role, personal attitudes, and stigma and taboo.

74

75 **Conclusions**

76 Several barriers to the identification of ED during and after pregnancy were described, the
77 main factors were stigma and poor professional training. Perinatal mental health is
78 becoming increasingly prioritised within national policy initiatives; however, ED continue to
79 be neglected and increased awareness is needed. Similarly, clinical guidance aimed at
80 responding to the rising prevalence of obesity focus on changing nutrition but not on
81 assessing for the presence of ED behaviours that might be affecting nutrition. Improving
82 education and training for health professionals may contribute to reducing stigma and
83 increase confidence in identifying ED. The barriers identified in this research need to be
84 addressed if recognition and response to women with ED during the perinatal period is to
85 improve.

86

87 **Key words**

88 Eating Disorders, pregnancy, barriers, disclosure, identification, qualitative research

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99 **BACKGROUND**

100 Eating Disorders (ED) are a group of mental health disorders characterised by severe
101 disturbances in eating behaviour that significantly impair health and psychosocial
102 functioning, including Anorexia Nervosa (AN), Bulimia Nervosa (BN) and Binge-Eating
103 Disorder (BED) [1]. ED typically affect women of reproductive age [2] and may affect
104 between 5.1-7.5% of women during pregnancy, if subthreshold disorders are included [3–5].
105 Women with ED tend to experience a decrease in ED symptoms during pregnancy [6–9].
106 However, there is evidence that symptoms persist [7, 8] and of postnatal relapse [6, 8, 9].
107 Furthermore, depression and anxiety symptoms are common during pregnancy and
108 postnatally for women with current and past ED [10, 11].

109

110 ED have been associated with various adverse pregnancy outcomes, for instance women
111 with AN have higher risk of infertility, unplanned pregnancies, miscarriage, prematurity and
112 low birth weight babies while women with BED have increased risk of higher birth weight
113 babies [12–17]. There is growing evidence of the postnatal impact of maternal ED, such as
114 difficulties with infant feeding [18–20], and behavioural and emotional problems in the
115 infant [21–23].

116

117 Given the evidence of adverse outcomes for women and their infants, early identification of
118 ED and appropriate antenatal and postnatal care are highly important. In the UK, National
119 Health Service (NHS) maternity care is informed by a suite of guidance from the National

120 Institute for Health and Care Excellence (NICE). NICE antenatal and postnatal mental health
121 guidance [24] recommends routine enquiry about current and past severe mental illness
122 with all women, and women with ED should be offered enhanced support and monitoring,
123 and referred to specialist care if needed. Midwives and health visitors are ideally placed to
124 identify and support women with ED as they are the primary point of contact delivering
125 routine care for all women from pregnancy until the child is aged five. In a universal
126 healthcare system such as the NHS where these regular routine appointments are provided,
127 guidelines to support effective identification and management of women with ED should be
128 implemented to reduce risk of poor pregnancy and birth outcomes, however evidence on
129 uptake and use of guidance is limited.

130

131 To our knowledge, no previous studies have specifically investigated the barriers to
132 identifying ED in the perinatal period. Evidence suggests that women with ED are often
133 reluctant to disclose their ED to a health professional [25] and are unlikely to seek treatment
134 [26], which may be due to feelings of stigma and shame [27, 28]. One UK-based qualitative
135 study investigating women's views of antenatal care found that women were reluctant to
136 disclose their ED because they felt health professionals lacked ED knowledge and sensitivity
137 in dealing with the disorder [29]. A few studies in the US have found poor routine enquiry
138 and knowledge about ED behaviours and symptoms among clinicians, including
139 obstetricians [30–32].

140

141 Subsequently, women with ED may go undetected during pregnancy and postnatally, with
142 potential implications for adverse maternal and infant health outcomes if disorders are not
143 managed appropriately. An in-depth understanding of barriers to the identification of ED

144 during and after pregnancy which reflects the perspectives of women and health
145 professionals is needed to assess and inform practice, including implementation of relevant
146 guidelines in to practice.

147

148 **Objectives**

149 To understand the barriers to disclosure and identification of ED in pregnancy and
150 postnatally as perceived by women with past or current ED, and midwives and health
151 visitors working in the UK NHS.

152

153 **METHODS**

154 Two studies were undertaken:

155 **Study 1**

156 *Design and setting*

157 A mixed-measures survey of pregnant and postnatal women with current or past ED was
158 conducted over a seven-month period. Women were recruited via a national parenting
159 website, Netmums, which is a UK-based online parenting organisation with over 1.7 million
160 members. Ethical approval was granted by the University College London's Research Ethics
161 Committee (Ref. 3735/002).

162

163 *Recruitment and procedure*

164 The study employed convenience sampling by inviting women to voluntarily take part in an
165 online survey via a study advertisement on the organisation website. Before commencing
166 the survey, women were asked to read the information about the study displayed on the
167 website. To be eligible, women had to answer yes to "Do you have, or have you had an

168 eating disorder?”, and respond to “How many children do you have?” with either the number
169 of children or that they are currently pregnant. For women who were eligible and willing to
170 take part, consent to participate was implied by virtue of survey completion. The survey was
171 developed specifically for this study, and questions of interest were a combination of seven
172 Likert-type scale questions and an open-ended question (see Additional file 1).

173

174 ***Participants***

175 A total of 101 women completed the mixed-measures survey, the majority of whom were
176 not currently pregnant and already had children and had experienced an ED in the past or
177 currently (n=92; see Table 1). The sample consisted of women from across the UK, with a
178 range of age and educational attainment reflected.

179

180 ***Analysis***

181 Data were analysed using the thematic analysis approach described by Braun and Clark [33].
182 This approach is an inductive and iterative process involving six phases of analysis:
183 familiarisation with data, generation of initial codes, searching for themes among codes,
184 reviewing themes, defining and naming themes, and producing the final report. Data were
185 independently coded by two researchers (AB and KT), both of whom were trained in
186 qualitative research methods and analysis. The rating-pair familiarised themselves with the
187 data and independently coded the complete data set to ensure reliability and thoroughness,
188 ensuring full consideration could be given to patterns within the data. The pair discussed
189 their codes together, with an 89% agreement being achieved by the rating-pair. At this
190 stage, codes with similar information were grouped, discrepancies discussed, and
191 agreement sought before amendments were made and emerging themes sought. The

192 process was iterative throughout, with continual reference to the original data to validate
193 and refine emerging themes. The themes were then clustered into subordinate themes, and
194 finally superordinate themes. The research team contributed to the refining, naming and
195 interpretation of the themes. Quotes that were illustrative of the themes and subthemes
196 are presented in the results and additional files.

197

198 [INSERT TABLE 1 HERE]

199

200 **Study 2**

201 ***Design and setting***

202 Focus groups with student and qualified midwives and health visitors were conducted over a
203 seven-month period at participating universities and NHS hospital and community services
204 in the South of England. Ethical approval was granted by the University College London's
205 Research Ethics Committee (Ref. 3735/001) and the Joint Research and Development Office
206 for Great Ormond Street Hospital for Children NHS Foundation Trust & The UCL Institute of
207 Child Health (Ref. 11BS33).

208

209 ***Recruitment and procedure***

210 A convenience sampling strategy was employed to recruit participants to the focus groups.
211 Student midwives were recruited from across three universities, and student health visitors
212 from one university. Qualified midwives were recruited from two hospital and community
213 services, and qualified health visitors from one community service. Five focus groups were
214 conducted, with one group per professional group, except for qualified midwives who
215 required two separate groups to be conducted as staff were unable to travel between the

216 two locations due to time and resource constraints. Participants provided written informed
217 consent prior to taking part in the focus group. The focus groups were facilitated by AB.

218

219 The focus group topic guide was developed specifically for this study and refined by the
220 research team and other experts, including researchers with qualitative research experience
221 and training and clinical specialists in ED, midwifery and health visiting. The guide facilitated
222 an informal discussion in each focus group on attitudes, knowledge, and clinical practice on
223 identifying ED in pregnancy and in the postnatal period, focusing on the role of midwives
224 and health visitors (see Additional file 2). Health professionals were not asked directly if
225 they had a personal experience of ED.

226

227 ***Participants***

228 Thirty-three health professionals took part in the focus groups, the majority of whom were
229 qualified health professionals (see Table 2). The sample was predominately white, female
230 and over twenty-five years of age. The majority had trained in the UK and as part of that
231 training had been educated in perinatal mental health, however only a small proportion had
232 received training specifically in ED (n=10; 29%).

233

234 ***Analysis***

235 The focus group discussions were recorded and transcribed verbatim with identifying
236 material removed. Data were analysed following the same procedure as detailed for Study 1
237 using a thematic analysis approach [33] to refine the emerging themes. The data were
238 independently coded by two trained researchers (AB and MKM) and a percentage

239 agreement of 79% was achieved by the rating-pair, with discrepancies resolved in the same
240 manner as detailed for Study 1.

241

242 [INSERT TABLE 2 HERE]

243

244 **RESULTS**

245 **Study 1**

246 Women reported experiencing some improvements in ED symptoms during pregnancy,
247 however over half of the sample reported experiencing any ED symptoms during pregnancy
248 (n=64; 63%), most common was calorie restriction and binge eating. Only a quarter (n=26;
249 26%) of the sample reported disclosing their ED to a health professional involved in their
250 antenatal care, and of the seventy-two (71%) women who did not disclose, seventy-one
251 (70%) explained their reasons for not doing so (see Table 1). The findings generated five
252 themes on the barriers to disclosure of ED in pregnancy as perceived by women: stigma,
253 lack of opportunity, preference for self-management, current ED symptomatology and
254 illness awareness (see additional file 3).

255

256 **Stigma**

257 Stigma of ED was an important theme for women's non-disclosure to a health professional.
258 Many women reported that they felt shameful and embarrassed and feared judgement.
259 Some women described feeling judged by health professionals based on their physical
260 appearance, as illustrated by one woman who stated: *"I was overweight according to my*
261 *BMI. I didn't think they would believe me to tell them I had an actual problem. I was*
262 *patronised by more than one healthcare professional who tried to educate me on nutrition. I*

263 *got the impression they thought I was just lazy and ate junk food all of the time when this*
264 *wasn't the case. I felt they were too judgemental to approach” (W42). A few women*
265 *expressed concern that a disclosure would lead to unwanted referrals to social services and*
266 *other services: “I would have been to worried to discuss with my midwife etc. for fear of*
267 *being reprimanded for it (i.e. referred to social services” (W49).*

268

269 ***Lack of opportunity***

270 Several women expressed a lack of opportunity to disclose and discuss an ED with a health
271 professional. It was felt there was limited and insufficient enquiry by health professionals as
272 *“they didn't ask and it wasn't raised as a concern” (W67). One woman expressed difficulties*
273 *in establishing a rapport with a midwife that may have facilitated a disclosure: “I didn't have*
274 *the same midwife for long enough to speak to them, it was rather stressful and upsetting”*
275 *(W21).*

276

277 ***Preference for self-management***

278 Some women reported not disclosing their ED to a health professional as they did not need
279 or want specialist care and preferred to self-manage their disorder: *“I don't like to talk about*
280 *it and think I can manage on my own” (W26), and “I just wanted to deal with it myself”*
281 *(W36). In some cases, this feeling appeared to relate to how long their ED had been*
282 *undetected for: “I don't really like to talk about it I have had some sort of disordered eating*
283 *for a very long time it is very much part of me and no one else's business” (W27).*

284

285 ***Current ED symptomatology***

286 For some women disclosure was dependent on their current mental health status and
287 perceived need to disclose a history of an ED to a health professional. A few women who
288 experienced ED prior to becoming pregnant did not think it necessary to raise this with a
289 healthcare professional: *"I didn't think it was relevant as I have been OK for a few years*
290 *now"* (W23). Other women reported improvements in ED symptoms during pregnancy so
291 similarly did not feel it relevant to disclose: *"It wasn't affecting me during my pregnancy, it*
292 *helped"* (W50) and *"I felt like I was a lot better when I fell pregnant"* (W30).

293

294 ***Illness awareness***

295 For several women, disclosure of an ED was dependent on their awareness of ED and
296 acknowledging that their symptoms were that of an ED. This was particularly notable in
297 women with BED as retrospectively some considered that they had dismissed their binge
298 eating behaviours as general over eating:

299

300 *"Binge eating doesn't seem like that big of an issue and I've never seen it as an eating*
301 *disorder before"* W4

302

303 *"I have only really just recognised that I have an issue & at the time I was pregnant did not*
304 *realise. I just thought I was a greedy person"* W34

305

306 **Study 2**

307 Four main themes emerged on the barriers to identification of ED in the perinatal period as
308 perceived by health professionals: system constraints, recognition of role, personal
309 attitudes, and stigma and taboo (see additional file 4).

310

311 **System constraints**

312 System constraints and associated sub-themes were the dominant theme affecting the
313 identification of ED among health professionals. All the professionals reported receiving
314 minimal, if any training on ED as part of their pre or post-registration clinical education, as
315 one participant described: *"I know what an eating disorder is but I've not come across it
316 through my health visitor training"* (P7). Some health professionals felt knowledge had to be
317 inferred from other taught topics as ED were not specifically addressed, as illustrated by one
318 qualified midwife involved in midwifery education: *"it wouldn't be a module...it would be
319 linked into mental ill health or BMI"* (P22). Several qualified and student participants
320 reported receiving training, but considered that this was a general introduction to ED which
321 was not specific to women during or after pregnancy and did not clarify their clinical role in
322 identifying or managing ED: *"I don't know whether it was actually mentioned apart from
323 refer to a dietician, there wasn't really any practical advice of what we need to do"* (P17).
324 Some student midwives felt that module and programme leads expected knowledge of ED
325 to be gained from self-directed learning or 'learning' in clinical practice: *"I think university
326 often relies on us learning this kind of thing in practice that obviously we've got so much
327 learning in the three years"* (P4).

328

329 Across all groups, most participants felt that the media was their main source of ED
330 knowledge, with personal and previous clinical experience and training less likely to be
331 described as a source. Most participants expressed limited understanding of ED beyond
332 food-restriction associated with AN and self-induced vomiting associated with BN, and were
333 not aware of implications for maternal and infant health. Some reported a lack of awareness

334 that ED was classed as a mental health disorder, as one qualified health visitor explained: “I
335 have a very limited knowledge about the, those terms as in Bulimia and Anorexia, I’ve heard
336 the words being thrown round quite a lot...but what I know as well is that it’s kind of
337 linked...to mental health issues” (P30). Consequently, many health professionals lacked
338 evidence-based knowledge on ED which impacted on their confidence in enquiring and
339 identifying ED. One qualified midwife described: “it’s really hard when you’ve, when people
340 give you information but you don’t know anything about it or there’s nothing much you can
341 do” (P17), and likewise this feeling was expected to affect disclosure by women: “It’s that
342 kind of feeling that, like a bit awkward and stuff like you don’t really know what to say and
343 then it’s not going to help the women open up and discuss anymore with you” (P4).

344

345 Health professionals related their poor awareness of relevant policies, guidance, care
346 management plans and referral pathways to their lack of relevant training on ED: “If it’s in
347 the trust policy and guidelines I haven’t found it yet because I haven’t sort of come across it
348 or it hasn’t been emphasised in the training” (P3). Several qualified and student
349 professionals reported not routinely including ED when asking women about their history of
350 mental health problems: “I never mention those words, I don’t think I ever ask a question
351 that you know” (P11). However, several midwives that had asked women felt “there’s no
352 point in asking the question if you don’t know what to say next” (P13) referring to the lack of
353 awareness on care pathways.

354

355 Midwives reported that time constraints in antenatal clinics would be likely to impact on
356 their ability to enquire effectively about ED, with opportunities to screen for physical and
357 mental health risk often limited to the initial pregnancy ‘booking’ appointment: “these really

358 *big questions you know which can't just be rushed over"* (P15). Some health visitors reported
359 they would ask about women's mental health at a 'new baby' visit which was usually
360 allocated more time than other routine clinic appointments, but there was less focus on this
361 being the main opportunity as *"when you see them for the first visit...you know the chances*
362 *are you won't see that person again...I've got someone who comes to clinic...the health*
363 *visitor probably never saw her again anyway, whereas now it would be much more*
364 *appropriate for me to say to her"* (P31).

365

366 In all groups, poor sharing of information about a woman's physical and mental health was
367 reported to be problematic. Qualified and student midwives reported limited means of
368 relaying sensitive information or raising concerns about a woman's mental health between
369 colleagues. A woman's pregnancy and medical history was expected to be documented in
370 the woman's handheld maternity notes, with concerns about confidentiality if a woman's
371 history of ED was included. Several midwives used domestic violence as an example of the
372 limitations of using women's handheld notes: *"obviously because they are handheld notes*
373 *we're very careful of what we write in them"* (P3). Communication between services
374 particularly within primary care, for instance between the family doctor (GP), midwives and
375 health visitors, was described by some qualified health visitors as limited, with services
376 increasingly fragmented across acute and primary healthcare sectors: *"there was one*
377 *midwife in every Sure Start and we were all attached so we would always be able to liaise*
378 *with that midwife and they would liaise with us...now it's like five midwives, like different*
379 *midwives' every time and they, they don't build up that kind of rapport"* (P26). Sure Start is
380 a UK parenting support programme, with centres primarily across England with slightly
381 different versions in Wales, Scotland and Northern Ireland, but funding cuts have led to

382 many of these centres closing in recent years [34]. Clinicians felt there were few
383 opportunities to be involved in shared care as part of a multidisciplinary team, resulting in
384 limited access to mental health expertise within or between services, particularly within
385 health visiting: *“if you had some supervision around those sorts of issues, any sorts of issue*
386 *where you’re just feeling like you’re holding something but you haven’t necessarily got the*
387 *skills”* (P26). Furthermore, a few health visitors described poor awareness about ED
388 generally among health professionals and not isolated to health visiting: *“I do really think*
389 *that if we had it everybody else in the community teams would need it too because there*
390 *would be no point in just training us if it then stopped with us”* (P27).

391

392 **Recognition of role**

393 Many clinicians were in favour of enquiring about ED but several considered their
394 confidence and competence to identify complex mental health problems was limited, and
395 their role should be more advisory and supportive. This was illustrated by one student
396 midwife who described: *“we tell people what not to eat but not how do you eat”* (P3). Some
397 qualified midwives felt that the primary focus in antenatal care was physical wellbeing of
398 the woman and the fetus rather than the woman’s mental health: *“We would be just*
399 *making sure that the baby was growing adequately... and then leaving the woman well*
400 *alone in a way just focusing on the wellbeing of the baby”* (P11). The focus on the infant
401 after the birth was similarly expressed by some of the qualified health visitors. A few
402 student midwives considered whether women’s perceptions of their clinical roles could
403 support or hinder a discussion about ED as *“a midwife...usually it’s for normal pregnancies,*
404 *normality, and also is a figure that only she’s for the women and babies and the doctors*
405 *maybe they seem, or the mental health services don’t sound probably very nice...maybe it’s*

406 *easier because they know that this, the midwife is gonna follow them through the*
407 *pregnancy” (P2), whereas “the health visitors kind of some were viewed for the baby and*
408 *kind of for the child’s sake not someone to support the mum” (P4).*

409

410 ***Personal attitudes***

411 The majority felt that health professionals needed to be empathic and positive so that
412 women felt comfortable to raise and discuss their mental health problems: *“there is no*
413 *room for negativity in midwifery” (P12).* However, one health visitor did express that she
414 would feel uncomfortable to enquire about ED with women who were overweight
415 compared to women who were underweight. One midwife discussed the need to recognise
416 the health professional as an individual: *“we make assumptions that we all will deliver that*
417 *health promotion message when actually attitudes and beliefs are integral to who we are,*
418 *influence how we ask the question” (P22).*

419

420 ***Stigma and taboo***

421 Health professionals in all groups discussed the stigma of ED, with some referring to it as a
422 ‘taboo’ subject for women and clinicians, with less experienced midwives and health visitors
423 describing greater anxiety about asking women. As one student midwife said: *“it does feel*
424 *kind of sometimes like it’s one of those taboo questions a bit like domestic violence...but you*
425 *kind of like skirt over like ‘you haven’t ever had any eating disorders, have you? No right*
426 *moving on” (P4).* One qualified midwife explained: *“one needs to be sensitive about these*
427 *things, mental health issues equals social services take away baby” (P15).*

428

429 **DISCUSSION**

430 This is the first research to specifically explore the perspectives of women and health
431 professionals on the barriers to identifying ED during and after pregnancy. Our main findings
432 were that perceived stigma had a major impact on women's disclosure of their illness, and
433 health professionals had low confidence in identifying ED as they lacked evidence-based
434 knowledge and training. The discussion will mainly focus on these outcomes as they were
435 the most prominent, and have direct implications to support effective identification of ED
436 during and after pregnancy.

437

438 Consistent with general and pregnancy ED research, women were often reluctant to disclose
439 their ED to a health professional [25, 29]. Stigma was a key barrier reported by the women
440 in this research, and health professionals similarly felt it hindered discussion and enquiry
441 about ED. Stigma is consistently implicated as a barrier to disclosure and treatment-seeking
442 in the ED and wider mental health literature [27, 28, 35]. The term stigma involves
443 perceived and experienced stereotyping, prejudice and discrimination to the detriment of
444 the targeted group [36]. The stigma of mental health is widely recognised, but it can be
445 greater for ED as sufferers are perceived as more responsible and in control of their ED
446 behaviours [37, 38]. The stigmatising attitudes towards BED specifically are comparable to
447 attitudes towards obesity and overweight status [39]. Weight stigma is well recognised and
448 reinforced by some of the more pervasive anti-obesity campaigns [39]. Given the
449 association between BED and obesity [40], the stigma women with BED experience may be
450 compounded by their weight status. Stigmatising attitudes can contribute to feelings of
451 shame and guilt, which cause an individual to feel personal responsibility for their
452 behaviours. As a consequence, an individual may want to hide their disorder [41], avoid
453 disclosure and show reluctance to seek help for their ED [27–29].

454

455 In the UK, several campaigns have been launched to raise public awareness and reduce
456 stigma about mental health, such as the 'Time to Change' campaign [42], and several
457 initiatives have been launched to address perinatal mental health awareness specifically,
458 such as the 'Better Births' initiative [43]. Similar anti-stigma programmes exist in other
459 countries, such as 'Beyond Blue' in Australia [44], 'Mental Health Commission of Canada'
460 [45], and 'Bring Change 2 Mind' in the US [46], and these, along with other campaigns, have
461 formed a global alliance to reduce mental health stigma [47]. However, ED continue to be
462 largely neglected in these mental health awareness campaigns. BED is also not considered
463 and neither is the broader issue of weight stigma within the anti-obesity and healthy eating
464 campaigns and clinical guidance [48–50]. The campaigns and clinical guidance [48–50]
465 aimed at addressing the rising prevalence of obesity focus on changing nutrition but not on
466 eating disorder behaviours that might affect nutrition. Considering the high level of
467 comorbidity [40], the identification of ED perinatally may subsequently support obesity
468 prevention in pregnancy and postnatally. Initiatives are needed to specifically target and
469 address the broad range of ED to reduce stigma, prevent discrimination and raise
470 awareness. Only by raising the profile of ED and reducing stigma will disclosure and open
471 discussion with health professionals be encouraged among women during and after
472 pregnancy who suffer these mental health disorders.

473

474 Health professionals considered an important barrier to identifying ED was their lack of
475 evidence-based knowledge and training, which subsequently impacted on their confidence.
476 This finding was not unexpected as ED are not currently specified in the core clinical
477 competencies required as part of pre-registration training of midwives and health visitors in

478 the UK [51, 52]. This reflects poor integration of available guidance in to pre and post-
479 registration training [24]. Future curriculum revisions need to educate about the complexity
480 and range of ED and ED behaviours, and include the changes in symptoms that may be
481 experienced during and after pregnancy [3, 6–9]. Research is needed to explore facilitators
482 to disclosure to identify acceptable means of enquiry and management that are sensitive
483 and responsive to the needs of women, and findings need to be incorporated in to future
484 training. Training also needs to address individual attitudes about ED given the expectation
485 for health professionals to deliver care in a consistent manner.

486

487 Other system level barriers to identifying ED in pregnancy and postnatally were identified,
488 specifically poor continuity of care and poor communication between health professionals
489 and women, and between health professionals. Women and health professionals described
490 the lack of opportunity and time within routine antenatal and postnatal care contacts to
491 discuss ED in a comfortable way to encourage disclosure, with midwives advocating the
492 potential benefit of a ‘case loading’ model of midwifery care. This model of midwifery care is
493 considered to promote better continuity of care in pregnancy and is advocated in UK policy
494 and guidance [53, 54] and other countries with similar healthcare systems such as Australia
495 [55]. Case loading models of midwifery care have been associated with better maternal and
496 infant outcomes, patient satisfaction, and cost effectiveness in comparison to other models
497 of maternity care [56–58], yet provision remains variable [59, 60]. Poor communication
498 between health professionals was similarly an important barrier as methods of relaying
499 concern about women were complicated by the need to balance communication of crucial
500 information with respecting the sensitive and confidential nature of disclosure. The issue of
501 communication of risk between acute and primary care services is increasingly affected by

502 fragmented and poorly integrated maternity services, particularly in primary care settings
503 with services central to coordinating healthcare [61]. Addressing these system level barriers
504 could promote an environment conducive to open discussion and support the role of the
505 health professionals in the identification of ED in the perinatal period.

506

507 **Strengths and limitations**

508 Strengths of this research include the exploration of experiences from both women and
509 health professionals, with consistency in the findings between the two groups. Research
510 findings are likely to be relevant for women who have ED regardless of place of birth, with
511 issues for health professional training likely to be relevant in settings where women can
512 access care from midwives and health visitors or an equivalent health professional.

513

514 There are several limitations to the research to be taken in to account when considering the
515 implications of the findings. Convenience sampling was necessary for logistical reasons
516 however, it limits the representativeness of the sample and generalisability of the findings.

517 There may have been recall bias as most women were reflecting on past experiences of
518 antenatal care. The single eligibility question may have been ambiguous in the absence of a
519 clinical diagnosis and did not distinguish between past or current ED. However this type of
520 self-report indicator was used primarily for practical reasons, further it has been validated in
521 an antenatal sample [62] and no ED screening measures have been validated in pregnancy.

522 Future research could focus on women who have been clinically diagnosed with ED.

523

524 **CONCLUSIONS**

525 There are several important barriers to the identification of ED in pregnancy and the
526 postnatal period. Stigma had a major impact on women’s disclosure of their illness, whilst
527 health professionals had poor confidence in identifying ED as they lacked evidence-based
528 knowledge and training. The need to identify perinatal mental health problems has been
529 increasingly recognised, however ED continue to be neglected and it is important to raise
530 awareness with health professionals. Similarly, clinical guidance aimed at responding to the
531 rising prevalence of obesity focus on changing nutrition but not on ED behaviours that might
532 affect nutrition. Improving ED education and training for health professionals may
533 contribute to reducing stigma and increase confidence in identifying ED. The barriers
534 identified in this research need to be addressed if recognition and response to women with
535 ED during the perinatal period is to improve.

536

537 **Abbreviations**

538 Eating Disorders (ED)

539 Anorexia Nervosa (AN)

540 Bulimia Nervosa (BN)

541 Binge Eating Disorder (BED)

542 National Health Service (NHS)

543 National Institute for Health and Care Excellence (NICE)

544

545 **DECLARATIONS**

546 **Ethics approval and consent to participate**

547 Ethical approval for the research was granted by the University College London’s Research

548 Ethics Committee (Ref. 3735/001 and 3735/002) and the Joint Research and Development

549 Office for Great Ormond Street Hospital for Children NHS Foundation Trust & The UCL
550 Institute of Child Health (Ref. 11BS33). Women’s consent to take part in the survey was
551 implied by virtue of survey completion. All participants in the focus groups provided written
552 informed consent prior to taking part.

553

554 **Consent for publication**

555 Not applicable

556

557 **Availability of data and material**

558 The datasets generated and analysed during the current research are not publicly available
559 as individual privacy could be compromised but are available from the corresponding author
560 on reasonable request.

561

562 **Competing interests**

563 JS is an Associate Editor for BMC Pregnancy and Childbirth. The other authors declare that
564 they have no competing interests.

565

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579

580 **Authors' contributions**

581 All authors contributed significantly to this work. AB and NM conceived and designed the
582 studies, with input from JS, DB and AE. AB carried out the data collection. AB and MKM
583 analysed the data. All authors contributed to interpreting the findings. AB drafted the
584 manuscript, and all authors read and approved the final manuscript.

585

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594

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772 **Table 1. Study 1: Sample characteristics**

Characteristics N (%)		N=101
Age	≤24	21 (21%)
	25-35	55 (55%)
	≥36	24 (24%)
	<i>Missing</i>	1
Parity	Currently pregnant	9 (9%)
	1 child	39 (39%)
	2 children	37 (37%)
	≥3 children	16 (16%)
	<i>Missing</i>	-
Location	England	
	London	16 (16%)
	Midlands and East of England	18 (18%)
	North England	26 (26%)

	South England	24 (24%)
	Wales	6 (6%)
	Scotland	5 (5%)
	Northern Ireland	3 (3%)
	<i>Missing</i>	3
Education	GCSE or equivalent	27 (27%)
	A level or equivalent	28 (28%)
	Degree or above	44 (44%)
	<i>Missing</i>	2
Type of eating disorder	Anorexia Nervosa	34 (34%)
	Bulimia Nervosa	16 (16%)
	Binge Eating Disorder	24 (24%)
	Eating Disorder Not Otherwise Specified	25 (25%)
	<i>Missing</i>	2
Any eating disorder symptoms experienced during pregnancy	No	36 (36%)
	Yes	64 (63%)
	<i>Missing</i>	1
Eating disorder symptoms experienced during pregnancy	Purging	12 (12%)

	Binge eating	29 (29%)
	Calorie restriction	31 (31%)
	Excessive exercise	14 (14%)
	Low weight	17 (17%)

Eating disorder symptoms that

improved during pregnancy	Purging	16 (16%)
	Binge eating	21 (21%)
	Calorie restriction	27 (27%)
	Excessive exercise	12 (12%)
	Low weight	15 (15%)

Health professional aware of

eating disorder	Yes	22 (22%)
	No	62 (61%)
	Unsure	16 (16%)
	<i>Missing</i>	1

Informed health professional

about eating disorder	Yes	26 (26%)
	No	72 (71%)
	<i>Missing</i>	3

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784 **Table 2. Study 2: Sample characteristics**

Characteristics N (%)		N=33
Age	≤24	4 (12%)
	25-35	11 (32%)
	≥36	12 (35%)
	<i>Missing</i>	7
Gender	Female	32 (97%)
	Male	1 (3%)
Ethnicity	White	24 (73%)
	Black	5 (15%)
	Asian Indian	1 (3%)
	Mixed ethnicity	1 (3%)
	<i>Missing</i>	2
Professional category	Student	Midwife 5 (15%)
		Health Visitor 5 (15%)

	Qualified	Midwife	14 (42%)
		Health Visitor	9 (27%)
Training for current post in			
the UK	Yes		28 (82%)
	No		3 (9%)
	<i>Missing</i>		3
Previous nurse training			
	Yes		19 (56%)
	No		12 (35%)
	<i>Missing</i>		2
Received training in			
perinatal mental health	Yes		24 (71%)
	No		5 (15%)
	<i>Missing</i>		5
Received training specifically			
in ED	Yes		10 (29%)
	No		21 (62%)
	<i>Missing</i>		3

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796 **ADDITIONAL MATERIALS**

797 Additional file 1.docx

798 Study 1: Mixed-measures survey

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800 Additional file 2.docx

801 Study 2: Focus group topic guide

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803 Additional file 3.docx

804 Study 1: Themes with illustrative quotations

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806 Additional file 4.docx

807 Study 2: Themes with illustrative quotations