A Patient and Public Involvement investigation into healthy eating and weight management advice during pregnancy.

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Abstract:

Objective: To conduct Patient and Public Involvement (PPI) to gain insight into the experience of healthy eating and weight management advice during pregnancy. Design: PPI in the planning and development of health interventions; aiming to ensure patient-centred care. Optimum nutrition and weight management are vital for successful pregnancy outcomes, yet many services report poor attendance and engagement. Setting: Community venues in Liverpool and Ulster (UK). Participants: Two PPI representatives were involved in all aspects of the study: design, interview questions, recruitment and collection/analysis of feedback. Intervention: Feedback was collected via note taking during group discussions, two in Liverpool (n=10 & 5); two in Ulster (n=7 & 9) and an interview (n=1, in Ulster). Results: Data were collated and Thematic Analysis identified three themes: 1) Weight gain is inevitable in pregnancy; 2) Healthy eating advice is important but currently lacks consistency and depth; 3) Expectations regarding the type of knowledge/support. Conclusions: PPI provides opportunity to enhance research design and offers valuable insight towards the needs of healthcare users. Pregnant women want positive health messages, with a focus on what they can/should do, rather than what they should not do. Midwives need to consider their communication with pregnant women, to ensure that their unique relationship maintained, especially when the topics of diet and weight management are addressed. A well-designed digital intervention could improve access to pregnancy-specific nutrition information; empowering midwives to communicate patient-centred, healthy eating messages with confidence. This has the potential to change dietary and weight management behaviour in pregnant women.

Introduction

In the last 20 years, there has been significant progress in efforts to ensure that healthcare interventions are more patient-centered, by involving patients and public in the planning and development of National Health Services (NHS) [1]. Referred to as 'Patient and Public Involvement' (PPI), it aims to empower those most affected by the intervention, to play a part in shaping the intervention [1, 2,]. This is particularly true for research involving 'Complex Interventions' (CI) and funding bodies such as The National Institute for Health Research [3, 4] and The Medical Research Council [5], have published guidelines regarding the importance of PPI at all stages of the research process. CI's are "*interventions that contain several interacting components"* [5, p2]. The components of CI usually involve the organisation or delivery of behaviour/behaviour change, (such as the delivery of a healthy eating intervention aiming to improve eating behaviour). It is often difficult to determine the 'active ingredients' of a CI [5, 6]; this can create difficulties in evaluating its effectiveness due to problems of developing, identifying, documenting and reproducing the intervention; that is which aspects of the intervention 'made it work?' [3]. Therefore, the involvement of potential participants in the design of CI is a critical component of its possible success. Studies that conduct PPI report improvements to the design of the intervention and the success of subsequent research [7].

Optimal nutrition and weight gain during pregnancy is vital to successful pregnancy outcomes. The World Health Organization (WHO) [8] identifies that health professionals, especially midwives have a crucial role in communicating nutritional messages to pregnant women, improving pregnancy outcomes. The UK National Institute for Health and Care Excellence (NICE) [9] states that all pregnant women should receive advice about healthy eating from a midwife during antenatal care. Pregnancy is thought to be a powerful 'teachable moment' for behaviour change [10, 11], as pregnant women are reported to have increased motivation and are more likely to seek advice about their health [12]. However, Atkinson *et al.,* [13] found that many overweight pregnant women declined or failed to

engage with weight management services; poor/no explanation of referral and/or a perception that the service would not meet their need were cited as the main reasons for this. It is therefore essential to determine the relevance, accessibility and appropriateness of future interventions with the proposed target audience. This may not only help with compliance issues, necessary for improving maternal and infant health, but it also assists in recruitment and retention of participants in future research.

Aim

To conduct PPI investigations with pregnant/postpartum women to gain insight into their experience of healthy eating/weight management advice during pregnancy.

Methodology

To ensure the PPI work complied with INVOLVE and GRIPP2 guidelines [4, 14], two PPI Lead Representatives (PLRs), both postnatal previous service users were recruited. The research team briefed the PLRs regarding the purpose of PPI and their role as collaborators. The PLRs were involved in all aspects of the project including project design, interview questions, recruitment and collection of feedback. Both PLRs contributed to edits of this paper, are named co-authors and received a fee according to INVOLVE guidelines [4]. PLRs recommended group discussions as preferred method of data collection; the research team suggested workshop questions and the PLRs refined and added to them. All women interviewed were either pregnant or less than 12 months postnatal and were recruited from various community venues in Liverpool and Ulster. As a PPI study, exempt from ethical approval, women were approached by the PLRs to participate, and as part of the PPI workshop procedure women gave verbal consent for their views and possible verbatim quotes to be used in publications or grant applications.

Four sessions were held in community locations; two in Liverpool (n=10 & 5, all postnatal) and two in Ulster (n=7 postnatal & n=9 3rd trimester of pregnancy) and an interview (n=1 pregnant, in Ulster). Sessions (approximately 1 hour in duration) were conducted in both Liverpool and Ulster to collate views across different areas of the UK. We adopted focus group style methdology to bring together a variety of views at once [15]. Participants were aware of the aim of the sessions, consented to notetaking, and agreed that such notes could be used in publications or grant applications. The decision to not use a digital recorder was made so that participants could speak freely and openly [16]. Conversational evidence [17] was captured by hand-written field notes made by the PLRs during the workshops in Liverpool, and a PhD student who supported the workshops in Ulster. Field notes recorded the discussions chronologically, and these notes were coded during the workshops [18]. Checks were made with participants during, and at the end of the workshops, to validate understanding and clarify comments. Additional field notes were made by the research team (including PLRs) immediately after each session, these notes captured reflections, feelings and evaluations of the discussions [19, 20, 21]. Thematic Analysis (TA) has been used extensively across health and well-being research and is particularly relevant to applied research settings [22]. The data were subjected to TA, informed by Braun and Clarke's step-by-step guide [23] to explore the patterned meaning across the data. Field notes made during the PPI sessions were coded initially by the PLRs, and validated by the participants themselves. Additional coding and collation of themes occurred post sessions between all authors (including PLRs). Our analytical strategy was inductive and data-driven, focusing upon identifying and discussing the salient themes repeated within field notes. Themes were defined, and where applicable relevant quotations were selected from field notes as evidence to support interpretation.

Results

There were no major differences in the opinions of women from Liverpool and Ulster. Three themes were identified: 1) Weight gain is inevitable in pregnancy; 2) Healthy eating advice is important but currently lacks consistency and depth; 3) Expectations regarding the type of knowledge/support

1. Weight gain is inevitable in pregnancy

The majority viewed weight gain as an inevitable part of pregnancy, with variable amounts of weight gain being reported. Some women viewed pregnancy as an opportunity to 'relax' previous dietary regimes - using pregnancy as an excuse to gain weight '*without feeling guilty*'. Early weight gain was often hindered by pregnancy sickness.

"I only went up about half a stone from my normal weight."

None of the women interviewed were aware that there are currently no specific weight gain guidelines in the UK, but did speculate that up to 2 stones was acceptable; one woman suggested that there should be some variation:

"It sort of depends on your BMI doesn't it?"

Women were only weighed at their initial antenatal appointment. There was no opposition to being weighed routinely during pregnancy or for research, but the women wanted to be informed about the significance and importance of regular weighing:

"It would be ok to be weighed if it is for baby's health."

Alternatively, it was considered as a way of monitoring own progress:

"I find it useful being weighed regularly because it gives me a chance to keep track of it."

However, they felt it needed to have a purpose and were opposed to routine 'weight watching'.

"We live in a society where weight is such a big issue. It can be difficult putting on weight and thinking about it too much and stressing yourself."

"It could be a bit shaming like at weight watchers, 'right get up on those scales now'".

Figure 1 - here

2. Healthy eating advice is important but currently lacks consistency and depth

Some women reported receiving healthy eating advice during pregnancy, but described it as 'minimal' and only at the booking-in appointment. Many were advised not to 'eat for two', but consultations mainly focused on food safety and foods to avoid as opposed to positive messages about what they should be eating:

> *"They told me not to be eating a lot of eggs, and what to limit, like food safety, liver and soft cheeses that sort of thing".*

Some of the midwives asked questions relating to supplement use but did not expand on dietary sources of micronutrients:

> *"They asked did I take vitamins but didn't really give more knowledge about the foods to get them from".*

There appeared to be no continuity regarding healthy eating advice; some women were given booklets or leaflets with general information; others were not. There was a feeling that the midwives lacked either the confidence or knowledge to provide specific advice:

> *"Some of them just weren't interested in nutrition at all. It wasn't helpful at all. May be it was lack of knowledge as well, they may be didn't feel comfortable and were just skimming over it".*

This was particularly true when women were following diets that were more restrictive (either by choice or due to changes in appetite/nausea during pregnancy):

"I'd been watching documentaries and am aware that dairy isn't that great. I'm not a vegan, but I tried to limit it, but the midwife didn't really know what to advise me".

"If you are unwell for the first 12 weeks of your pregnancy and can't even eat… you'd rather know from the midwife about what supplement, Pregnacare or whatever that you could take to make sure you were getting all the nutrients."

Figure 2 - here

3. Expectations regarding the type of knowledge/support

All women agreed that positive, healthy eating advice was essential and that it should be delivered consistently to all women. They suggested that all pregnant women should be asked about their specific dietary needs at booking in appointments. Furthermore, women agreed that midwives were the preferred healthcare professional (HCP) to give this advice but expert advice from dietitians should also be integrated:

"And even just to bring in professionals to talk about what you're eating, like a dietitian, to chat and give you advice and tell you this is what to expect."

Time was a limiting factor, particularly at booking in appointments, but women also admitted that leaflets/books were often not useful and seemed to be overused. The value of group sessions, such as additional Parent Education or Sure Start classes were identified:

"Groups are good because there is also a social aspect to it too, you can exchange experiences, what worked/what didn't work. Chatting to people face to face is always valuable."

Some women reported that nausea and vomiting in early pregnancy resulted in reduced/limited dietary intake, which often impaired their intentions to eat healthily. Emotional issues, anxiety about weight, lack of time and struggles with childcare were cited as barriers to healthy eating. Such restrictions may also dissuade many women from attending group sessions and/or weight management services if referred. However, women wanted practical advice such as cooking/recipe ideas; suggestions for coping with pregnancy sickness and with the first few weeks postpartum, particularly for breastfeeding; dealing with tiredness, hunger and the challenges of implementing healthy eating during these challenging times.

> *"Classes for nutrition maybe with cooking to show you what you can make when you are pregnant would be good."*

Further suggestions included using YouTube videos, showing videos in clinic waiting rooms (although it was acknowledged that they would need to be from a reliable source). However, the women gave their most overwhelming support for the development of a digital aid such as downloading an App; this was for a number of reasons:

1) The App could provide prompts, encouraging healthy lifestyles
2) The information would be current, regularly updated and reliable (as opposed to conducting an online search)
3) The information could reinforce or provide further detail to advice given in clinic
4) Advice should be tailored to individual needs

Figure 3 - here

Discussion

A key finding was that service users' preferences differed from the perceived priorities of health professionals and academics; the latter relate obesity proportionally to risk in pregnancy. Antenatal

clinics only offer specialist support to women with the highest BMI (>40 kg/m^2 for example), whereas women with BMI 25.0 to 39.9 kg/m^2 are only offered standard antenatal care [24]. This phenomenon has been reported elsewhere regarding other services [25, 26], but this study identifies such issues within maternal nutrition and so provides insights that could improve antenatal practices and thus improve health outcomes for both mothers and their infants.

Previous research exploring attendance at weight-management services, has suggested issues with poor communication, timing and location of sessions, stigma, work commitments and other social barriers led to poor engagement [13, 27]. However, in our study women reported limitations, both in receiving specific in nutritional guidance and in terms of what information was available. Women were motivated to make dietary changes during pregnancy but reported insufficient knowledge regarding healthy diet and a lack of support from their HCP to do so. Despite known risks associated with obesity and excess gestational weight gain (GWG) in pregnancy [8], and in agreement with Atkinson et al., [13], women considered weight gain as 'inevitable' and therefore assigned this as the reason for not monitoring weight. Both international [8] and UK guidelines [28] state that all pregnant women should receive advice about healthy eating from a midwife. The women did acknowledge that midwives advised them about food safety (e.g. foods to avoid) and promoted folic acid, but the advice received did not go beyond this. Women did not have their weight monitored or discussed, and no 'positive dietary' advice was offered regarding healthy eating (advice focused on 'what they shouldn't do' rather than what they 'could do').

UK NICE guidance [28] advises against routine antenatal weighing (except to establish initial BMI) as it 'may produce unnecessary anxiety with no added benefit'. Despite this, the women recognised the value in 'weight monitoring', if conducted sensitively and with potential for appropriate dietary and lifestyle support, as opposed to 'weight watching' (weighing with no intervention) which could cause the women 'stress'. This concurs with another study exploring dietetic services for maternal obesity,

suggesting that women 'considered weight monitoring to be motivational for behaviour change and requested more frequent weighing' [29].

None of the women in our study recalled referral to dietetics or weight management services, despite reporting concerns regarding food cravings, comfort eating, portion size and what foods to eat to remain healthy. Some women reported difficulties controlling their lifestyle (diet and exercise) because of limited time, asserting that referral to weight-management services would be useful, but time to attend appointments might be problematic. Pregnant women felt that there was insufficient time and attention given to promote positive healthy eating messages; they wanted more detailed, pregnancy-specific healthy eating guidelines. They acknowledged that different women might require different advice depending on their circumstances, (underweight compared to overweight for example); so messages need adapting to accommodate differing needs. Overall, the women valued their relationship with antenatal midwives; emphasising midwives as the most appropriate HCP to deliver healthy eating and weight management advice. The vital relationship nurtured between midwives and pregnant women is reported as a critical skill of professional midwives [30]; A recent (2016) systematic review found that pregnant women receiveing midwifery-led care were more satisfied with their care and interventions were less likely during delivery [31]. Despite this, our earlier work [32] and that of others [33] found that midwives were often reluctant to approach the topic of weight and/or healthy eating for fear of causing offence and spoiling this unique relationship. Furthermore, none of the midwives interviewed reported receiving any undergraduate or post registration training regarding weight management or healthy eating [32].

As healthy eating and weight management advice are identified as part of a midwife's role [8, 9], there needs to be greater emphasis regarding pregnancy-specific, in-depth nutritional information embedded in the curriculum for undergraduate midwifery training. If dietitians with pregnancy expertise delivered this, it could significantly enhance the nutritional knowledge and, empower midwives to support pregnant women. Training should also help midwives develop skills to engage

women in lifestyle behaviour change. To date, research exploring GWG suggests that goal setting and self-monitoring may be the most effective behaviour change techniques [34, 35, 36]. To achieve such it is imperative that the attitudes, expectations, knowledge and behavioral intentions of pregnant women are assessed. The Theory of Planned Behaviour (TPB) [37], is an example of a psychological theory that can be used to illustrate the complexities of such behaviour processes (e.g. dietary, physical activity and weight control) [38]. For instance, the TPB proposes that a behavioural intention is a primary determinant of actual behaviour. In this context, using the TPB as a theoretical framework, a pregnant woman's behavioural intention to engage in a recommended (actual) behaviour may be negatively influenced if their attitude to, for example the evaluation of a weight management referral or dietary advice, is negative. A woman's subjective norms maybe influenced if she perceives advice as a 'pressure' to engage in a recommended behaviour and, perceived behavioural control would be minimised if a pregnant woman believed she had no control over GWG during pregnancy. This theoretical framework highlights how important it is that midwives, as the main point of contact for pregnant women, are able to assess and respond to pregnant women's interpretations of behavioural intent. Consequently future interventions should consider psychological theory and utilise behaviour change intervention mapping in their design to ensure advice offered is truly meaningful and patient-centered care.

As suggested by PPI participants, there is a need to ensure consistent messages, whilst personalising healthy eating and weight management advice during pregnancy, to address individual needs. In addition, midwives themselves need to feel knowledgeable and confident to raise and address this topic with pregnant women. One suggestion was to develop a digital intervention, such as an App (mHealth application) which could be utilised as a resource for both pregnant women and midwives. Such an initiative would ensure that both groups could access relevant, reliable and up-to-date information, while empowering midwives and strengthening the midwife-patient relationship, by increasing knowledge and self-confidence to give personalised advice. Moreover, midwives could use the resource during appointments to signpost women to information relevant to their nutritional and

dietary circumstances (e.g. overweight, underweight, vegetarian). However, research on digital interventions to promote healthy eating and appropriate GWG during pregnancy is limited and further research to develop, test, and implement are required [39].

A strength of this PPI study is the recruitment of PLRs, who contributed to all aspects of the study, ensuring a patient-led approach [4, 14]. We as a multi-disciplinary research team have acknowledged the link between NHS dietary and weight management interventions during pregnancy to psychological theory, although there is also a need for future research to conduct intervention mapping and development. However, we acknowledge possible study limitations and recognise that this study was conducted in only two areas of the UK so may not be representative of other regions; maternity care pathways often vary within and outside the UK. It is also noteworthy that as a qualitative study attempts to ensure quality were taken. For example researcher triangulation was conducted to minimise researcher bias in data collection and analysis; analytical interpretations of data were challenged through discussions within the research team, which included the PLRs. Throughout this process, we (the research team) remained sensitive to context [40].

Conclusion

PPI provides opportunity to enhance research design and offers valuable insight towards the needs of healthcare users, in this instance pregnant women reflecting on the appropriateness of healthy eating advice and weight management interventions. Our study suggests that pregnant women want to receive *positive* messages about health, with a focus on what they can/should do, rather than what they should not do. Midwives need to consider the psychological processes involved in their communication with pregnant women, to ensure that the unique relationship nurtured between midwives and pregnant women is maintained, especially when the topic of dietary change and weight

management is addressed. A well-designed digital intervention could improve access to pregnancy-specific nutrition information, it could empower midwives to communicate healthy eating messages with confidence and help them to tailor patient centred advice, and therefore, we propose, has the potential to change dietary and weight management behaviour in pregnant women.

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