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Pregnant Women's Experiences and Views on an "Opt-Out" Referral Pathway to Specialist Smoking Cessation Support: A Qualitative Evaluation

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Abstract

Introduction: Smoking in pregnancy remains an important and costly public health concern with policy makers worldwide researching methods to aid cessation. UK government guidelines recommend implementation of an "opt-out" (ie, whether requested or not) referral pathway for pregnant smokers to specialist smoking cessation support using carbon monoxide (CO) screening. This study explores the views of pregnant smokers who experienced this new pathway in one UK hospital trust.
Methods: Eighteen semi-structured telephone interviews with women who experienced the opt-out pathway were undertaken. Data were analyzed thematically.
Results: Three themes were identified relating to *expectations*, *acceptability* and *impact* of the pathway. Women were generally very accepting of the CO testing especially when it met their prior expectations and was perceived as being a routine component of antenatal care. They considered the visual feedback from the CO monitoring improved their motivation to quit. Views on the automatic referral for cessation support were divided with questions raised as to the removal of choice, with many women also expressing dissatisfaction about perceived lack of contact by Stop Smoking Services (SSS) following referral.
Conclusion: The opt-out pathway is potentially an acceptable addition to current practice. The women considered CO monitoring to be the most valuable element of the pathway. Women keen to engage with SSS desired a more efficient system of contact.
Implications: This study presents a unique insight into pregnant women's views on the implementation of opt-out referrals for smoking cessation. Introducing CO testing and opt-out referrals at the time of antenatal ultrasound examination can potentially increase motivation to stop smoking in pregnancy. The findings demonstrate that facilitating access to SSS was not always achieved, and further refinement is needed to ensure more effective contact procedures. Ensuring all women are fully informed prior to the CO testing may further improve both the impact of the opt-out referral pathway and the chance of successfully engaging with SSS.

Introduction

Smoking in pregnancy is an important and preventable public health issue causing increased risk of miscarriage, prematurity, low birth weight, and sudden infant death syndrome[1] with costs to the NHS in the United Kingdom estimated to be as much as £87.5 million[2] (132 million USD/ 122 million Euros). Approximately 12% of pregnant women in the United Kingdom and United States smoke throughout pregnancy[3,4] with a much higher prevalence reported in some European countries (eg, 30%–35% in Spain).[5]

The National Institute for Health and Clinical Excellence (NICE) guidelines for smoking cessation in pregnancy[6] recommend that all pregnant women are assessed for smoking, using routine exhaled carbon monoxide (CO) testing early on in pregnancy. Women with a CO level above the "low cut off point" should be referred to SSS unless they specifically decline ("opt-out" referral pathway). Whilst some studies have examined the impact of opt-out pathways on referral and cessation rates,[7,8] little is currently known about the women's reaction to this referral method, which is necessary to help inform implementation of the pathway.

A key element of this pathway is the use of CO monitoring to identify smokers. Previous studies have found feedback using biomarkers of smoking may increase personal risk perception,[9,10] as many smokers understand the theoretical risks of smoking but downplay the risk to themselves.[11] In contrast, other studies have not found that biomarkers are more effective than standard treatment.[12] While biofeedback impact evaluations have been undertaken, little is known about pregnant women's views of receiving biofeedback for smoking; knowledge of which is important to guide opt-out consultations and understand the acceptability from the patient perspective. The aim of this study was to explore the views and experiences of women participating in routine CO testing and an opt-out referral pathway.

Methods

Design and Procedure

Routine CO testing of all pregnant women and an opt-out referral pathway were introduced within one UK hospital trust; qualitative work reported here was part of a 6-month service evaluation of this pathway.[13] Patients who experienced the pathway were invited to participate in an interview about their experience.

The standard care prior to implementation of the pathway involved pregnant smokers and recent quitters being offered referral to Stop Smoking Services (SSS) if they wanted one ("opt-in" referral). The opt-out pathway was introduced within the antenatal clinic setting at the time of dating scan appointment (around 12 weeks gestation) where those with CO levels at least 4 parts per million were referred by the Health Support Worker (HSW) to the SSS unless they explicitly declined.

Once referrals were received, SSS staff attempted to telephone each woman twice (as per standard procedures), if unsuccessful, they sent a letter inviting them to call for support. No additional resources were allocated to SSS for this study.

Participants

Women attending an ultrasound "dating" scan appointment from August to November 2013, with CO levels at least 4 parts per million, were asked for consent to be contacted for an interview. The hospital provided the research team with contact details of 47 women. Of these, there was no response from 18 women, a further four declined and two were ineligible due to having quit prepregnancy. True purposive sampling was precluded due to receiving insufficient quantity of contact details from those who had attended the referral. Participants were selected for interview to ensure representation from those who accepted the referral and those who opted out and to gain interviews from participants with a variety of smoking levels, with 18 women interviewed in total. All women were at least 16 weeks pregnant at the time of interview, with the majority being interviewed between the 17th and 24th week of pregnancy. Three women were interviewed postpartum. Eighteen participants were interviewed with an age range of 18–33 years and a mean age of 24. All women reported smoking in early pregnancy with levels ranging from 3 to 40 cigarettes per day. At the time of interview (or prior to the end of pregnancy for those that were interviewed postpartum) four participants had quit, eleven reported cutting down and three reported no change. Six participants (33%) had opted-out of the referral (Table 1).

Table 1. Participant Characteristics (Percentages Have Been Rounded so may not Equal Exactly 100%)

Characteristic	Number	%
Age band (y)		
18–21	6	33
22–25	5	28
26–29	3	17
≥30	3	17
Missing	1	6
Ethnic group		
White British	17	94
White European	1	6
Household socioeconomic classification (using NS-SEC, 8 level classification with seven being the lowest and eight unemployed)		
5	1	6
7	10	56
8	7	39
Number of previous pregnancies		
1	14	78
2	2	11
3	1	6
4	1	6
Smoking rate prior to scan and CO test (cigarettes per day)		
0	0	0
1–5	2	11
6–10	4	22
11–15	5	28
16–20	5	28
≥21	2	11
Smoking rate following scan and CO test but prior to delivery (cigarettes per day)		
0	4	22
1–5	3	17
6–10	6	33
11–15	3	17
16–20	0	0
≥21	2	11
Referral to SSS category		
Accepted referral to SSS	12	66
Rejected referral to SSS	6	33

CO = carbon monoxide; SSS = Stop Smoking Services.

Data Collection and Analysis

Participants were sent an information sheet then contacted by phone with those interested in being interviewed providing verbal consent (audio recorded) before the start of the interview. Interviews were conducted by two experienced female university researchers, MS and BB, between December 2013 and June 2014, lasted between 18 and 46 minutes and were audio recorded and transcribed verbatim.

Data were analyzed thematically[14] with preliminary coding of initial transcripts to identify emerging concepts to inform the refining of the guiding questions to gain further insight and begin to identify themes. Interviews continued until theoretical saturation was reached with no new concepts emerging.[15] The stages of analysis involved (1) immersion in transcripts, (2) identification and refinement of themes, (3) developing a coding scheme, (4) coding the data, and (5) amalgamating the extracts from individual transcripts with other examples on the same theme.[14] The framework method[16] was used for organising data and to compare results within and between groups. NVIVO 9 software was used to assist with coding and data management. KAC, KB, and FN independently analyzed 20% of transcripts to ensure consistency in coding and analysis. Particular attention was paid to deviant cases to strengthen validity of the findings.[17]

Results

Three main themes emerged from the analysis of the interviews relating to expectations, acceptability and impact of the referral pathway.

Expectations

The women reported that they expected to undergo multiple testing in pregnancy and most saw the CO test as another element of these "just in routine" (P3—opted out) tests. Almost all indicated they felt it was being done in their and their baby's best interests:

> "I know it's just something they've got to do and it's just part of what they've got to do at the hospital now. That's all I really thought." P8—Referred

However, several women expressed surprise and discomfort at the fact this particular test was new, unexpected and "rather sprung on people" (P1—opted out). A desire for more information preceding the test was expressed by several women:

> "I couldn't understand why I needed to, because I mean after all my other dating scans I've never had to sit and wait for a [CO] appointment straight after …if everyone knew everyone was getting tested, it wouldn't make smokers feel discriminated against… I kind of felt cornered if you like and singled out." P17—Referred

Acceptability

Almost all participants reported that the CO test was very easy, non-invasive and quick:

> "It was actually quite easy, all you had to do is blow into a tube for 30 seconds and it's done" P4—opted out

As the women were already at the hospital for their scan and appointment, they reported feeling that it was not an inconvenience to do an additional quick test. However, several women identified that although the CO element of the opt-out procedure was quick and convenient, the chance of them attending the subsequent appointment with SSS was unlikely, particularly for those with other children:

> "It would depend whether I remembered to go or not [to the SSS appointment] and if I could fit it in around everything…I don't think I'd go" P17—Referred

The issue of trust appeared to be strongly linked with the perception of lack of information regarding the test. A significant minority expressed the view that the tests were introduced to check up on whether they were being honest about their smoking:

> "The feeling is that you're being, it's another thing you're being checked up on…I don't think anybody has any objections to it from what I've read [on pregnancy forums], it was more the fact that nobody was told why and what…Is the whole point to find out if people are lying? What is the whole purpose of it cos I don't think it's ever been explained? P10—Referred

The majority of women reported feeling very comfortable undergoing a CO test with their HSW and felt that the HSWs had been helpful and nonjudgemental. They stated that they thought it would be a positive measure in obtaining the "truth":

> "I probably wouldn't have told them the truth because I smoke that much… would say that I smoked less than what I normally do" P16—Referred

Conversely, a small minority perceived the CO testing as negative and damaging to the relationship between themselves and the HSW.

One of the women who had told the HSW that she was not smoking prior to the CO test then recorded a reading above 4 parts per million, was unhappy at the perceived lack of trust in her verbal claim to have quit, even though she subsequently told the interviewer that she had not been truthful about her smoking to the HSW:

> "Big level of trust isn't it, like, you know, trusting people and trusting what they say…it's not a nice feeling to be, like, told well you might not be telling the truth we want you to prove it" P1—opted out

The perception of the level of choice given in undertaking the CO test and subsequent referral was the most emotive issue identified from the interviews. While almost all participants stated they were happy to be CO tested, many expressed concern at the automatic referral to SSS. This is summarized by one participant who had worked in health care herself and very much disagreed with the automatic referral:

> "I know it's [CO testing] just routine. I know it's all in the best interests of the baby so I just kind of, I just expected it really but she never asked me if I wanted to [be referred], she just told me that she was referring me to [local SSS]…she made me feel like I had no choice…like I didn't have a voice…but then, you know I should have a choice whether or not I want to go. There was no discussion…it was just basically I'm referring you and it made me feel a little bit hopeless like she'd already made her mind up that I wouldn't be able to do it myself" P2—opted out

Although reaction to the removal of choice for the referral did not appear to differ by smoking status or whether they accepted the referral or opted out, the participants fell into two distinct groups based on their opinions of this issue:

1. Those who were unconcerned about the lack of choice because they either wanted the help, did not feel unduly pressurized to

accept or perceived the lack of choice to be a positive introduction to "push" them/others in to quitting:

> "well I didn't really get a choice about it or anything really, I wasn't that bothered seeing as though I wanted it anyway. I think it's quite good really because it doesn't give people the choice…because then it's sort of pushing them towards it isn't it?" P13—Referred

2. Those who appeared displeased (or felt others would be displeased) with the opt-out system ranging from those a little unhappy with the lack of choice to those who expressed feelings of powerlessness, resentment, and disempowerment:

> "There's people out there who don't like being pushed into something and if they are being pushed into something will react in a bad, like violent way…I've actually seen at [Hospital] this bloke got told he had to go to this appointment…and he ended up punching the nurse" P4—opted out

It became apparent in several interviews that some women felt they had received insufficient information to be able to make their own decision on the new system, highlighted by one participant's concern about the perceived absence of informed choice:

> "I think it's the whole informed choice thing again isn't it. It's about having the information there and being told right this is why, this is what we're doing, why we're doing it and this is why it's been brought in place and then you can make an informed decision… because at the moment nobody can object because they don't understand it" P10—Referred

The women's perception of the method used by the individual HSWs to explain the opt-out pathway seemed important in influencing the attitudes of their patients. Around half of participants perceived they had been given a clear choice and reported a more opt-in method explained to them.

> "They just basically told me what it is and asked if I would like to do it or not, gave me the option and I said 'yeah that's fine" P12—Referred

Impact

CO Monitoring

Most participants expressed the opinion that seeing their CO reading had a larger impact on their motivation than just being given smoking cessation advice. For others the impact was reduced as they felt they had insufficient explanation of the results. Among a small minority, who reported little desire to quit, a reading lower than anticipated appeared to reassure them that they did not need to change their smoking behavior:

> "If it's non-smoker level then there's no reason for me to quit! …if the reading was high then yeah I would be ashamed but because it was quite low it didn't bother me as much" P3—opted out

The most common reaction to a high reading was a strong emotional response such as "felt sick," and "wanted to cry" with many also reporting that the test had increased their motivation, especially amongst those reporting the strongest emotional responses:

> "It makes it a lot better actually seeing the numbers than just being told…I just knew as soon as I saw that reading that it would have to be something that I had to do…that I knew I would have to do it a lot quicker" P5—opted out

One woman reported that she and her husband likened the test to an alcohol breathalyzer test and found the analogy of being "over the limit' a powerful motivator:

> "It's just physical proof it can harm the baby… you can read on the side of the packet what it's got in it but until you see it you don't know…and it's like every time I go for a ciggie now it's like you're over the limit" P11—Referred

Although some women felt well informed and reported receiving detailed explanations of the results of the CO test, the amount of information given following the test regarding the CO reading was perceived to be insufficient by several others. This reduced the impact as some were left unsure as to the health implications:

> "I asked because nobody actually explained what the numbers meant…we didn't get a sheet or anything like that, I think that would have been helpful…yeah it's telling them I'm a smoker but what's the point if like all it's going to say is yes she's a smoker. Well I've told you that! I came back and googled it" P10—Referred

Contact by SSS

Over half of the women selected for interview had accepted the referral to SSS and the majority of these reported that they were unaware of any contact attempts from SSS, either by phone or letter. Some women expressed disappointment and anger with many stating that their motivation was highest in the period directly after their CO test. They felt this lack of contact hindered their chances of quitting as many reported that they had received little or no cessation advice from the HSW and were awaiting support from the SSS.

> "I thought the phone call was going to come really quickly, just to help me like start everything off you know…quite gutted now. You know, I've been trying to do it on my own, I've cut down quite considerably from what I used to … I just need that little extra push, that encouragement" P11—Referred

However, it was implicit from the interviews that although many had accepted the referral and were actively waiting for support, others had little intention of answering the calls or attending.

> "I don't answer numbers what I don't know, it's not very often I do" P16—Referred

Opinions were divided as to whether the automatic referral had a positive impact with several participants stating that internal motivation was paramount and any external support would have little impact.

> "I think at the end of the day if people want to stop smoking, like it or not they do it on their own anyway…I think it is good but at the same time if people don't want to stop they won't so I think it's a bit of a waste of time referring people that don't want to and aren't going to" P1—opted out

Many participants used the word "pushed." This included those who perceived the "push" as motivating and helpful and those who were concerned at the perception of the removal of personal choice.

> "I think it [the new 'opt-out' pathway] will help more, I think it'll like push more people out there to stop smoking" P16—Referred

Discussion

This is the first study to have explored pregnant women's perspective of an opt-out pathway to specialist smoking cessation support. The use of CO testing to identify smokers and initiate the referral was perceived by the vast majority of participants as highly acceptable and was identified as a source of increased motivation to change smoking behavior. In contrast, discussions about the automatic referral highlighted concerns from some women. These included issues surrounding the perception of informed choice and the difficulties in obtaining subsequent support once referred. This study highlighted the importance for further information to be provided both before and after the CO test so that patients can make an informed choice and exercise their right to opt-out. This issue has been identified in other areas of healthcare, for example where an opt-out pathway for HIV testing in Kenya was misunderstood by most pregnant women as something they were unable to opt-out of and only a small minority felt they received sufficient information to make an informed decision to decline.[18]

The reported increase in motivation among some of the participants following CO testing has been observed in other studies.[10] While many participants attributed an increase in motivation to the CO test feedback, given that the hospital visit when CO testing took place included an ultrasound of the fetus, other antenatal tests and health discussions, it is possible that multiple factors contributed to improved motivation. An outcome evaluation of the opt-out referral pathway[13] found that the implemented pathway as a whole doubled the number of women setting a quit date and stopping smoking. However, it is difficult to determine the impact on these outcomes of the CO test compared to the automatic referral or whether both are necessary to increase engagement with smoking cessation via the SSSs.

The HSWs' explanation of the procedure was perceived to affect the level of acceptance towards the pathway. The most well received method of referral seemed to be when the HSW gave the appearance of an element of choice and was presented as just part of the routine. Several studies have detailed how a patient centered approach can improve the possibility of a positive relationship with the midwife.[19] Although our study found the shock of a high CO reading was perceived to improve motivation to quit, other studies report that the feeling of guilt engendered by smoking in pregnancy could be a trigger to smoke.[20,21] It is therefore important that any intervention or referral process takes into account these emotions and potential triggers.

In line with other studies, our findings have shown that pregnant smokers are a challenging group to contact when attempting to engage them in specialist cessation support. In other evaluations of opt-out referral pathways a substantial minority of referred smokers were not successfully contacted by the SSS, despite an increase in resources to do so.[7] We found that some women report accepting a referral to please the midwife but had little intention of taking it up. In addition, we found examples of women who did not routinely answer calls from "unknown" or "withheld" numbers, which are usually how telephone calls from healthcare organizations appear. Although the outcome evaluation[13] shows that there was sufficient contact to make an overall significant difference to quitting, the number of women who reported not being contacted by the SSS raises the question as to whether greater resources are required to increase the chances of successful contact following referral. This is in line with the findings from a qualitative study of the views and experiences of the HSW's and SSS staff implementing this pathway.[22] They reported an increase in workload and concluded that appointing an additional SSS staff member may mitigate the problems experienced.

The most acceptable way of introducing the pathway may need more consideration with more information and clarity concerning the ability to opt out potentially leading to greater engagement. The reported increased motivation from the CO test at the time of their dating scan and the expressed desire for more immediate support suggests the optimal window of opportunity for contact could be better identified and utilized with the "dating scan" being an ideal time to offer immediate cessation support. HSWs also need to ensure that those with very low CO results in relation to their self-reported smoking level do not see this as justification to continue smoking. Relying on SSS to give in-depth cessation advice means that these women and those who have no intention of attending SSS appointments will not receive help so an additional option of immediate advice and provision of the contact details of SSS and other support services may be beneficial.

These are important findings that require consideration for further wide-scale UK implementation and are relevant to other developed countries looking at methods to reduce smoking in pregnancy.

This study had several limitations. It is possible that responders had stronger feelings (positive or negative) towards the pathway than non-responders. However, participants with varied characteristics were selected for interview to maximize the chance that a range of experiences were represented. It is uncommon in qualitative research to attempt to recruit a representative sample of the population of interest and there was much consistency in the experiences reported by participants with deviant cases examined in detail to improve the credibility of the findings. In common with most qualitative studies, we were reliant on the participants' recall of events. This may have been an issue in particular for those women who had accepted a referral to the local SSS as there was a relatively long-time delay before it was confirmed that the appointment had/had not occurred. It is noteworthy that many participants could still very clearly recall their experience of the CO test and its emotional impact several months later. The length of time taken to receive women's details and the subsequent difficulties in contacting women for interview also meant that there was no consistency in gestation period between interviewees with most interviews taking place from mid pregnancy to several months postpartum. This hospital had a team of HCAs who were solely responsible for the implementation which may have resulted in a more cohesive team approach to implementation than might occur in other healthcare settings.

Conclusion

The high level of acceptability and impact reported from CO testing used at the point of the antenatal ultrasound examination, suggests that it may be valuable in increasing motivation to quit by its provision of direct visible biofeedback, in addition to its role in screening for the referral.

The perceived lack of contact from SSS was a major issue identified by the women in this study.

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Declaration of Interests

None declared.

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