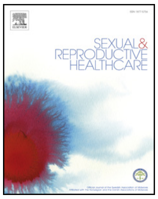
Sexual & Reproductive Healthcare 19 (2019) 31–35

Contents lists available at ScienceDirect

Sexual & Reproductive Healthcare

journal homepage: www.elsevier.com/locate/srhc



Childbearing concerns, information needs and preferences of women with cystic fibrosis: An online discussion group

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ARTICLE INFO

Keywords:
Childbearing
Cystic fibrosis
Reproduction
Information
Australia
Facebook

ABSTRACT

Objective: The life expectancy of women with cystic fibrosis (CF) has increased, enabling many to reach reproductive age. However, little is known about the childbearing concerns and information needs of women with CF or their preferences for information about the effect of their condition and its treatment on childbearing. The aim of this study was to identify the childbearing concerns and related information needs and preferences of women with CF.

Methods: To ensure access to a diverse group of women with CF throughout Australia and to minimise the risk of cross infection, an online group was advertised and convened on Facebook from October through December 2017. In a closed-group moderated discussion, participants responded to questions about childbearing concerns and the related information needs and preferences of women with CF. Non-identifiable demographic information was sought via an online anonymous survey. The discussion transcript was analysed thematically.

Results: Participants ($n = 11$) identified a number of concerns about childbearing including uncertainty about whether to have children; achieving or maintaining a pregnancy and giving birth; treatment and treatment adherence during pregnancy, breastfeeding and motherhood; and the impact of pregnancy and childbirth on future health. Women wanted information about childbearing as it related to their CF but reported difficulties accessing up-to-date accurate relevant information.

Conclusions: Women with CF want to be better informed about childbearing, and identified a need for personalised information as well as regular reviews with their CF treating team so that they can make informed decisions about having children.

Introduction

Medical advances in diagnostic testing and treatment have increased the life expectancy of women with chronic illnesses such as cystic fibrosis (CF), enabling many to reach reproductive age [1]. Women with CF are usually able to have children [2] but for women with CF, childbearing requires planning and management of their condition before, during, and after pregnancy [3,4].

Women with a chronic illness such as CF often seek reproductive information from a range of sources, including their healthcare provider, the internet, other women with the condition, patient associations and support groups, and scientific publications [5]. However, women with a chronic illness frequently report that they are unable to access reproductive information relevant to their condition easily [5,6]. Few women discuss childbearing with or receive information from their healthcare providers, and those who do receive information often report receiving insufficient information [5]. As a result, women with a chronic illness can be denied the opportunity to ask questions, discuss feelings, or make informed plans and decisions about childbearing [7,8]. The inability of women with a chronic illness to make informed childbearing decisions and achieve their reproductive goals contributes to unfulfilled life goals, altered social and family relationships, the burden of stigma, and compromised mental health [5].

Little is known about the childbearing concerns and information needs of women with CF or their preferences for the mode and timing of information about the effect of their condition and its treatment on childbearing.

The aim of this study was to identify the childbearing concerns and related information needs and preferences of women with CF.

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https://doi.org/10.1016/j.srhc.2018.11.004
Received 12 June 2018; Accepted 27 November 2018

Methods

Study design

A qualitative method was used to yield in-depth understanding of women's childbearing concerns and related information needs and preferences. Using Facebook as the online platform, a discussion group was held with women of reproductive age who have CF. We have previously used this method successfully to identify barriers to effective fertility management among Australian women and men [9]. Social networking sites such as Facebook are extremely popular and the use of Facebook as the platform for the discussion group enables participation at times that suit participants. It is also easy to access via personal computers, smartphones and tablets, removing the need for a physical venue, and is a space in which people are comfortable and open to discussing their ideas and opinions. An online discussion group also reduces the risk of cross infection for participants with CF for whom attendance at a face-to-face group may result in exposure to harmful pathogens.

Sample and recruitment

English-speaking women with CF aged 18 years or older and living in Australia were recruited via advertisements on Facebook, an article in the newsletter of a major Australian CF health service, and the Facebook pages of Australian CF organisations who 'liked' or 'shared' details of the study's Facebook page.

Procedure

A 'closed' (private) group was created on Facebook. Potential participants requested permission to join the group. Once the group had been created and potential participants had been approved to become members, the status of the group was changed to 'secret'. This ensured that the identity of the group members and what they posted was only visible to members of the group.

In October 2017, an advertisement (Fig. 1) briefly describing the research and discussion group was placed on the Facebook pages of all users meeting the eligibility criteria. Age was identified from the user's profile (a mandatory field on all personal Facebook accounts), and location was established from the Internet protocol address [10].

The project page on Facebook provided further details about the research and what participation involved. Women who chose to participate requested to join the group by clicking on a link on the Facebook project page.

To develop a summary description of group members, participants were asked to complete an anonymous online survey. The survey contained questions about demographic variables (age, relationship status, country of birth, and level of education) and fertility history (ideal and expected number of children, and number of pregnancies).

Childbearing for women with CF

Sponsored

Join a study about the information women with CF need when thinking about having a baby.

Childbearing for women with CF

Community

12 people like this.

Fig. 1. Facebook advertisement.

A discussion guide was used to initiate and prompt discussion. Participants' views were sought on the childbearing concerns and current and preferred sources of reproductive information of women with CF, and their perspectives on what types of information resources would be most helpful, acceptable and feasible to assist women with CF achieve their childbearing goals.

Participant responses were read daily by the moderator (SH) and regularly discussed by the research team. The moderator asked additional or clarifying questions as appropriate and did not censor personal anecdotes. Members of the group also commented on each other's posts. The moderator posted a new question every few days.

Data management and analysis

The transcript of the group discussion was copied from Facebook and pasted into a Word document. Participants were identified in the analysis by number only. Transcripts were analysed using thematic analysis techniques commonly practised in qualitative research [12]. The analysis was conducted by the first author and interpretations discussed within the research team until consensus was reached. Quotes have been used in the text to illustrate the findings.

Ethics

The main ethical considerations were privacy and voluntary participation. Facebook allows users to determine how much of their personal information is publicly displayed. Profile security settings can be public (that is, allowing access to the complete profile by any Facebook user) or private (that is, limiting access of some or all profile information). Participation in the group was voluntary, and participants could withdraw at any time. A request to join the group was taken as informed consent to participate.

The research project was approved by the Human Research Ethics Committees of Alfred Health (Project Number 386/17, 28 August 2017) and Monash University (Project Number 10910, 29 August 2017).

Results

Participants

The Facebook advertisement reached 3225 women, 139 clicked on the advertisement (directing respondents to the study Facebook page). Eleven women who had seen the Facebook advertisement or the advertisement in a CF newsletter requested to join the group. All requests were accepted. Comments were posted by nine (81.8%) members of the group. The group ran for 3 months, from October through December 2017.

Demographic data were provided by all participants. As the survey which collected the demographic data was anonymous, it was not possible to distinguish the demographic information of participants who contributed posts from those who did not or associate demographic information with individual posts.

The mean age of participants was 32.2 years (25–46 years). Participants were mostly born in Australia (10/11, 90.9%). All participants had completed a postsecondary school qualification, and most were married or living in a heterosexual relationship (7/11, 63.6%); 2 (18.2%) had a partner of the opposite sex they were not currently living with, and 2 (18.2%) were not currently in a relationship.

More than half of the participants (n = 6, 54.5%) had tried to get pregnant, and the mean number of children was 0.8 (ranging from 0 to 3). No participants reported that their ideal number of children was none, most stated that their ideal number of children was between 2 and 4 (mean = 2.5). However, there was a discrepancy between participants' ideal number of children and their expected number of children. In general, the number of children participants thought they thought they would actually have, was lower than the number they desired (mean expected number of children = 1.6, range 0–3).

Key themes

Guided by questions posted by the moderator, the discussion focused on: 1. the childbearing concerns of women with CF; and 2. women's needs and preferences for childbearing information. Analysis revealed several themes related to each of these aspects of childbearing for women with CF.

1. Childbearing concerns

The participants identified a number of concerns that women with CF have about childbearing. These included uncertainty about whether to have a baby; concerns about achieving or maintaining a pregnancy and giving birth; treatment and treatment adherence during pregnancy, breastfeeding and motherhood; and the impact of pregnancy and childbirth on future health.

Theme 1.1: Uncertainty about whether to have a baby

Participants' desires about having or not having children appeared to reflect those of women in the general population. Some definitely wanted to have children.

> *I remember a switch almost being turned on when I was about 23... (Young yes) But it was the switch that led me to be ready to be a Mum. I literally woke up one day knowing this is what I wanted to be.* (Participant #2)

Whilst others expressed uncertainty about having children given their condition and the information that they and their families had received.

> *My whole life I have been supported to believe that carrying a child naturally was pretty much out of the question (most likely due to medical information given to my parents) to the point where my sister often would say to me she would be my surrogate. I think this has led me to be really unsure of whether I want to have children, honestly I change my mind about it daily.* (Participant #3)

Women were also concerned that their condition would be inherited by their baby or that their partner may be a carrier of the CF gene.

> *What happens if my partner is a carrier of the CF gene and what it will mean for us if he is?* (Participant #3)

Theme 1.2: Achieving or maintaining pregnancy and giving birth

Another concern identified by the participants was the ability of women with CF to conceive and maintain a pregnancy.

> *Worrying you won't be able to get pregnant because of your CF …[and] actually carry a child full term.* (Participant #8)

Having achieved a pregnancy, participants were also worried about how they would give birth and the impact of the mode of delivery on their health.

> *What happens if I were to need a caesarean delivery – how would my body cope with more surgery/the recovery/increased risk of infection etc?* (Participant #3)

Theme 1.3: Treatment and treatment adherence during pregnancy, breastfeeding and motherhood

Women were apprehensive about how they would manage their CF treatment during pregnancy and once they became a mother.

> *Will I manage being a mum/working/looking after myself and how will I mentally cope if I can't?* (Participant #3)

Participants were particularly concerned about the safety of taking their CF medications during pregnancy and breastfeeding.

> *What medications can/can't I have whilst pregnant/breastfeeding and are there safe alternatives?* (Participant #3)

One participant told of her frustrations trying to obtain reliable and accurate information about her medications and whether they were contraindicated during pregnancy as well as her uncertainties about continuing their CF medications during pregnancy.

> *I was on Kalydeco [before] I moved to Australia. [When] I found out I was pregnant … I had to make the difficult decision whether to stay on Kalydeco or not … I had no information about the use of this drug in pregnant woman as the drug was pretty new. … No one was 100% [certain] if Kalydeco was safe or not. … That to me was the hardest decision when having kids. I was worried about my own health but also the effect it might have on bubs!* (Participant #4)

Theme 1.4: Impact of pregnancy and childbirth on future health

Participants worried about potential difficulties managing parenthood and the impact pregnancy and childbirth might have on their future health.

> *Whilst I am reasonably healthy, I spend a lot of time doing treatment and exercising, rely on my partner and family to support me when I'm unwell and need regular rest weekends. … I worry how I would physically and mentally cope [with parenthood].* (Participant #3)

Women identified that having a support network would be important to assist them care for the baby and themselves.

> *I suppose my other major concern was my support network. Who was going to look after my baby when I was in hospital?* (Participant #4)

Participants were concerned about what would happen if they were not well enough to care for their child and the impact of this on their partner and children.

> *How will my partner manage if my health deteriorates?* (Participant #10)

The possibility of dying prematurely and the effect on their children was identified by the participants as an important concern about having or not having children.

> *This sounds terribly morbid but do I prepare my children for a life without me?* (Participant #3)

2. Childbearing information needs and preferences

Participants identified their current sources of childbearing information as well as their preferred types, sources and timing of childbearing information.

Theme 2.1: Current sources of information

Participants reported seeking information about childbearing from a range of sources including their CF health care providers and other women with CF. However, they also identified that only limited information was available, and it was difficult to access relevant, accurate, up-to-date information about CF and childbearing.

> *I feel there is very limited information and you really have to work hard to find it! I follow blogs on Facebook (of mothers with CF who have had child/ren), [and] have consulted with my CF team.* (Participant #11)

Theme 2.2: Preferred types and sources of information

Participants had different views about the best types and sources of childbearing information for women with CF. Women identified that information resources based on both medical evidence and the personal experiences of other women with CF would be useful. It was suggested that such resources should include information about medications that were safe to use during pregnancy, the physical risks of pregnancy for women with CF, and the importance of treatment adherence during pregnancy.

> *It would be great to have fact/research based resources to read as well as anecdotal discussion with other CF patients*. (Participant #8)

Participants also identified the importance of having personalised information for women with CF given the differences in severity of CF that women experience as well as access to generic information about childbearing and CF.

> *I think it's very difficult as there's so many variations and severities of CF but some sort of baseline booklet or website would have been amazing compared to nothing*. (Participant #8)

Theme 2.3: Preferred timing of information

Women's preferences for the timing of childbearing information varied. Some women preferred to receive information just before needing it, such as when considering pregnancy, whilst others would have liked information at puberty.

> *I wish I had more information, right from an early age (puberty and for my parents when I was younger)*. (Participant #3)
> *I would have liked to talk about it with my team prior to getting pregnant but it sort of felt like there was never a chance to discuss. Clinics always seem to be about 'reactive' treatments (how can we stop this cough, how can we gain weight, how can we improve lung function, what scripts do you need etc) which leaves little room for 'proactive' treatments or topics that relate to the 'future'*. (Participant #8)

Participants also commented that they would welcome the opportunity to have regular reviews and discussions with their treating team about their personal goals including fertility options and childbearing.

> *Maybe pregnancy and fertility should come up annually? It doesn't need to come up at every clinic but maybe it would be good to brush over the topic once a year to see what the individual feels/thinks*. (Participant #8)

Discussion

This study found that women with CF have concerns about childbearing and want to be better informed but find it difficult to access up-to-date accurate relevant information. Women identified a need for personalised information as well as regular reviews with their CF treating team so that they can make informed decisions about having children and achieve their reproductive goals.

In common with most women, women in this study wanted to have children and similar to other women in Australia reported that their ideal number of children was two to three [13,14]. However, consistent with other studies of women with a chronic illness they often identified their health as a barrier to having children and expressed concerns about childbearing [5,15–17].

In order to make informed childbearing decisions, women in this study wanted and needed relevant information about childbearing. Other studies have also found that women with CF require information about reproduction and childbearing [2,15,18] but often find such information difficult to obtain especially from their health care providers [18].

Strengths and limitations of current study

This was a small study that included participants from diverse locations in Australia. Participants were recruited via advertisements on Facebook as well as in the newsletter of one Australian CF adult health service. Women may have been more likely to participate in the study if they received care from this service and therefore, the findings may not reflect the experiences or needs of women who attend other health services, although similar findings have been found in other Australian studies [2]. Women currently contemplating childbearing or who have recently had children or fertility difficulties may have also been more likely to participate in the study.

Implications for policy/practice

The findings of this study suggest that women with CF would benefit from appropriate personalised fertility-related information to assist them make informed decisions about childbearing. Interventions could include regular reviews with CF treating team about fertility and childbearing, provision of both personalised and general information about childbearing and CF, and access to the 'childbearing stories' of other women with CF. Such interventions could include information delivered in ways that take advantage of new technology, including the internet and social media, as well as printed materials and videos.

Many women in this study expressed particular concern about the safety of their CF medications during pregnancy. This highlights the need for health care providers to advise women with CF about which medications are contraindicated for use during pregnancy, and to monitor and regularly discuss treatment and treatment adherence.

The findings also indicate that CF healthcare providers need to continue to be alert to the individual childbearing and information needs of women with CF taking into particular consideration women's current life stage and age.

Conclusion

Women with CF have concerns about childbearing but find it difficult to access accurate information.

Women would like personalised information as well as regular reviews with their CF treating team about childbearing. Without adequate information about the effects of CF on childbearing, women may find it difficult to make informed decisions about if, when and how many children they have.

Acknowledgements

The researchers thank all the women for their generous participation.

Funding

This study was supported by a Monash University Advancing Women's Research Success grant awarded to SH.

Declaration of interests

The authors declare that they have no competing interests.

Appendix A. Supplementary material

Supplementary data to this article can be found online at https://doi.org/10.1016/j.srhc.2018.11.004.

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