

Summary of QI Share & Learn: Fertility & Pregnancy – Thursday 30th November

Case Studies

Sharing decisions about reproductive health in CF: Insights from CF-PROSPER

Rhiannon Phillips, Cardiff Metropolitan University

- Knowledge is crucial in decision making; women with CF were interested to understand what they need to do to prepare for pregnancy, what options they had for giving birth, what the risks of complications would be for them and their child etc.
- Opportunity for shared decision making is very variable; women in the study said health professionals did not tend to initiate conversations about reproductive health with them.
- Insights from CF-PROSPER:
 - Create space and time for consultations about reproductive health.
 - Improve information and pre-consultation preparation for women with CF.
 - Create environments to enable shared decision making (time, training, resources, culture that welcomes patient-centred conversations).

An antenatal clinic supporting women with CF on their pregnancy journey

Imogen Felton, Royal Brompton Hospital

- As number of pregnancies increases dramatically, the Brompton CF service wanted to be guided by the patient voice in designing their support offer for pregnant women.
- Service piloted a virtual monthly reproductive and maternal health MDT, and developed a CF maternal medicine network with involvement from a specialised obstetrics physician who supports women with underlying conditions in pregnancy.
- Early discussion of pre-conception goals with women, incl. about optimal timing, and early engagement with partners for genetic counselling etc.
- Feedback from women with CF has been positive, with a drop in unplanned pregnancies.
- Hub-and-spoke model implemented, where 50% of deliveries are supported through outreach maternal health in local services.
- Brompton also offered virtual gestation-specific exercise classes for pregnant women with CF, which were very well received; these highlighted the role of having contact with peers.
- Learning and recommendations:
 - Early engagement (pre-conception) of women and their partners is key.
 - Some women with CF are now low risk and can be supported to give birth locally.
 - Brining women together, e.g. in virtual exercise classes, is beneficial for peer support
 - A UK-wide online space for pregnant women with CF could be a valuable resource.

Experience with a local joint Care Plan Pathway

Julie Knowles, Blackpool Teaching Hospitals

- Service wanted to minimise the number of appointments pregnant women with CF have to attend and improve coordination between the CF team and obstetrics colleagues.
- Appointed a link CF nurse and specialist midwife, who collaborate closely, to support the new joint pathway, which amalgamates care plans to include all investigations.
- All cases of pregnant women with CF are reviewed with obstetrics team, and CF team work closely with them to ensure adequate segregation, determine appropriate anaesthetics etc.
- Organised educational sessions for obstetrics to learn about CF and for CF team to learn about maternity care – both teams are benefitting from closer working.
- Learning and recommendations:
 - Communication and close working between different health professionals is key, ideally with a named contact for collaboration in each team.
 - A joint care plan and pathway can reduce number of times pregnant women with CF are asked to attend for investigations and improve patient experiences.

Supporting new parents with CF

Becky Kilgariff, Cystic Fibrosis Trust

- Cystic Fibrosis Trust recognised a need for new parents with CF to have support after the baby is born; however, current support offers are often generic and staff/volunteers offering support for new parents lack an understanding of CF as a condition.
- The Trust has partnered with the charity Home-Start to develop a new joint programme of work equipping Home-Start volunteers with specific knowledge about CF to support parents.
- The programme pilot has just opened for referrals in Glasgow.
- Key messages:
 - Support from Home-Start volunteers for new parents is already available across the UK and CF teams can refer new parents to the charity, though volunteers may not have any knowledge about CF.
 - The new joint programme is being piloted and it is hoped this will be expanded to other areas in the UK (contact: Becky.Kilgariff@cysticfibrosis.org.uk).

Complex Pregnancy – Case Study 1

Kate Powell, York & Hull CF Service

- Patient with several underlying issues, incl. CFRD and liver disease, with a history of poor adherence and frequent disengagement; partner shown to be carrier.
- Patient even less engaged with healthcare during pregnancy, possibly due to early discussions about termination.
- Concerns for patient and baby throughout pregnancy, multiple complications and team had to put in place emergency plans due to fears of variceal haemorrhage.
- Eventual delivery by C-section of healthy baby boy
- Learning:
 - Work closely with patient and discuss their preferences and views on pregnancy early on to reduce the risk of disengagement or non-adherence.
 - Need pre-conception planning and clear referral pathways.
 - Collaborative management and a multidisciplinary approach to supporting complex pregnancies in CF are crucial.

Complex Pregnancy – Case Study 2

Caroline Whitton, Derriford Hospital Plymouth

- Complex patient with lung transplant, GI complications and history of miscarriages
- Put in place a highly collaborative approach working across CF team, obstetrics team, transplant team, diabetes team and anaesthetists, with later involvement of ICU and NICU
- Throughout the pregnancy, patient had several blood pressure issues and admissions.
- Baby delivered by C-section due to maternal instability at 26+2 weeks with initial requirement for level 3 NICU care and mum transferred to ICU.
- Mum discharged within a few weeks of labour; daughter remained on NICU for 4 months.
- Learning:
 - Collaborative working across multiple teams and sites to support patient with CF and a lung transplant essential to support this complex pregnancy.
 - Regular communication means all specialists can learn from others' expertise and make decisions jointly with patient as to the best course of action.

Notes from the Q&A and open discussion

- What are presenters' top tips for setting up new MDTs and/or working arrangements with non-CF colleagues to support pregnancy?
 - Approach colleagues in maternity care early on, ideally directly (e.g. by heading down to their department if based at the same site)
 - Consider which other non-CF teams, apart from maternity, need to be involved and engage them early (e.g. diabetes team, transplant team, etc.)
 - Have regular touchpoints / virtual catch-ups with other relevant specialties, keeping lines of communication open and having one named contact in each team
 - Seek to understand and address concerns from other specialists/teams – and seek to learn from each other; collaborative myth busting and risk stratifying.
- What support could benefit pregnant women with CF?
 - Include the woman with CF (and partner) in decision making.
 - Women who are co-producing the service in Brompton have asked for parenthood support or a network / digital hub for women with CF to give advice and peer support.
- The All Wales Adult CF Services is heat-mapping pregnancies across the nation and working on an all-Wales pathway.
- The UK CF Registry is looking at long-term implications of remaining on Kaftrio during pregnancy and planning some data linkage work; [UK BUMPS](#) (Best Use of Medicine in Pregnancy) survey could be cascaded to pregnant women with CF.
- PhD student at Bristol is exploring female sexual reproductive health in CF. Aim is to design a digital tool with women and health care professionals to assist women with CF in decision making about reproductive matters. Currently seeking input in a survey to understand the UK clinical landscape of female sexual reproductive health in CF and opinions on a potential digital tool: <https://forms.office.com/e/pT9udKNyM4>

If you have any questions or comments, please contact QI@cysticfibrosis.org.uk