16th January 2018

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Re: BMFMS/TAMBA Bursary

Twin pregnancies With complications; Impact on Neurodevelopment Study (TWINS)

Interim Progress Report

First of all we would like to thank both the BMFMS and TAMBA for funding our proposal for the neurodevelopmental assessment of the complicated monochorionic twin pregnancies. One of the main criticisms of the existing limited literature is its retrospective designs with its inherent risk of bias. Therefore, we have decided to recruit the participants prospectively from the UK Complicated Multiple Pregnancy Registry (funded by TAMBA and St George's University of London; set up at the end of 2015). Concern was raised about approaching the pregnancies where the twins were lost, and therefore we have to ascertain the pregnancy outcome before approaching these women to participate in the neurodevelopmental follow-up assessment. The centers which are taking part in this registry include King's College Hospital, St George's Hospital, Liverpool Women's Hospital, University College Hospital, Queen Charlotte Hospital, St Michael's Hospital (Bristol), Birmingham Women's Hospital, Southern General Hospital (Scotland) and Royal Maternity Hospital (Northern Ireland). Furthermore, Southampton Hospital and Leeds have expressed interest in joining the registry.

Current state of the registry

- Total of 419 pregnancies in the registry

- 257 consented for follow up studies
- Twin-to-twin transfusion syndrome (TTTS) (n=210; 55 with outcomes; 157 consented for follow up, 29 with outcomes)
- Selective fetal growth restriction (sFGR) (n=82; 17 with outcomes; 47 consented for follow up; 7 of whom have pregnancy outcomes)
- Discordant anomaly (n=31; 14 with outcomes; 10 consented for follow up; 5 of whom have outcomes)
- Single intrauterine death (sIUD) (n=10 cases; 4 with outcomes; 5 consented for follow up; 3 have outcomes)
- Twin anaemia polycythemia sequence (TAPS) (n=5; 2 with outcomes; 2 consented for follow up; 1 has outcome)
- Twin Reversed Arterial Perfusion (TRAP) (n=6; 2 outcomes; 4 consented for follow up; none with outcomes yet)
- Uncomplicated monochorionic twin pregnancy (n=53; 0 with outcomes; 20 consented for follow up)
- Triplet pregnancies (n=22; 0 with outcomes; 5 consented for follow up)

One suggestion was to seek CRN support in order to provide local research support to the clinicians seeing these multiple pregnancies in the participating centers. Moreover, in order to maximize the use of the research midwife's time (in view of the limited funding), we felt that it would be more appropriate to recruit the midwife in post once we have enough numbers of participants in the various categories we aimed to include (TTTS, sFGR, TRAP, TAPS, sIUD). We have successfully recruited the research midwife, who is due to start in February 2018. We anticipate that the study should be completed at the end of 2018.

Causes of the delay

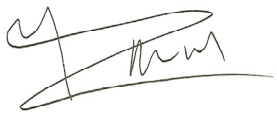
- Registry set up in each centre
- Application for CRN Portfolio support of the registry, which would enable us to have research support in each centre participating in the registry
- An average interval of 12-18 months between entry of the pregnancy in the registry and the appropriate time of the neurodevelopmental assessment at the age of 1-2 years (we have to wait for the children born to the mothers participating in the registry to be at the age of one year).

Professor Asma Khalil, St George's Hospital University of London

I hope this report outlines the progress so far and the timeline of the planned study.

Please do not hesitate to contact me if you have any queries.

Yours Sincerely,



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