

Parental experiences of difficult neonatal decision making

Name of Principal Investigator:

Health Care Professionals Information Sheet: the case studies

Background

The purpose of the study is to explore how we can best support parents who are facing difficult treatment decisions for their fragile newborn baby. The results of the study will help to develop a support intervention for parents on the neonatal unit who are facing difficult decisions for their newborn infant. The study has been reviewed and approved by the NHS Research Ethics committee and the Research & Development department at University College London.

What does the study involve?

Taking part in the study, for both parents and doctors, involves video recording the conversations that take part in the side room on the neonatal unit, through the use of a discrete video recorder. We would like to reassure you, that if you agree for these conversations to be recorded, they will be stored confidentially and no identifying information will be made available when presented in research environments or in training. Names will be removed from the audio recordings, the pitch of your voice will be changed, and finally your video image will be distorted by using software to convert it into a cartoon-like image, so that your face will not be recognisable. Conversation analysis will explore the interaction in the dialogue, looking at how the conversations flow. This is for the purpose of understanding the context of how parents make difficult decisions, and is not an analysis of the skills of a particular health care professional. We will also ask you to complete our data collection tool following each conversation, to enable us to capture basic demographic and clinical details to support our analysis.

There would be 2 copies of the conversation. The first copy would be for research purposes and would be stored within a secure network (as well as on encrypted hard drives), which has a dedicated computer technician maintaining security. As the neonatologist involved in the study you would have access to these recordings. The content of these conversations would also be used to develop a training package for trainee neonatologists in talking about treatment decisions with parents. The second, audio-only copy would be made available for parents to upload onto a portable MP3 player that they will be given as part of their study participation. The rationale behind this is that recent evidence in Australia by Koh et al has shown that recordings of interactions with neonatologists were listened to by both the parents and the family members. Parents who listened to the recordings (96% of the 102 who were in the intervention group) could recall significantly more information about their interactions with the neonatologists at 4 months post discharge, and parents whose infants had a poor outcome were significantly more satisfied with the conversation than those who did not receive a recording.

We assure you that the study will be conducted with the minimal of interruption to your work and interaction with the families. The parents will be aware that conversations are going to be recorded and have provided signed consent; the research team are happy to work with you to determine the best way of organising the recordings.

Do you have to take part?

It is up to you to decide whether or not to take part; parental consent for the study does not automatically give the research team permission to record your conversations with them. If you agree to take part, you will be asked to sign a consent form. Please do not hesitate to contact the research team if you have any questions.

What if something goes wrong?

If you have any concerns about the study, please contact the Chief Investigator, Professor Neil Marlow, using the details below.

Will my taking part in this study be kept confidential?

All information gathered during the study will be anonymised and will be stored in a strictly confidential way.

All information that is collected about you during the course of the research will be kept on a password protected database and is strictly confidential. All information will be confidentially archived by University College London for 7 years following the end of the study.

Health Care Professionals as well as parents are required to give their consent and agreement to treating all anonymised audio recordings made available to them in a strictly confidential manner.

What will happen to the results of the research study?

The results will contribute towards the development of a package of support, which we can offer future parents in similar situations. Results will also be published in academic journals and conference presentations, and used in training so that we can share best practice with other neonatal health care professionals. If you wish to see a copy of these articles, please inform Professor Neil Marlow.

Who has reviewed the study?

To ensure that this study meets required ethical standards, it has been reviewed and approved by the NHS Research Ethics Committee and the Research & Development department at University College London.

Thank you for your time. Please do not hesitate to contact the research team if you have any questions.

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