

FOR PARENTS / CAREGIVERS OF PATIENTS WITH ACUTE LYMPHOBLASTIC LEUKAEMIA

How much information is retained following the diagnosis discussions?

Dr Amy Irons and Dr Tristan Pettit | Children's Haematology and Oncology Centre, Christchurch Hospital

INTRODUCTION

Parents/caregivers of children with Acute Lymphoblastic Leukaemia (ALL) have a broad range of new information explained to them at the initial diagnosis discussions, during a formalised meeting with their paediatric oncologist. The end of treatment meeting is similar, where surveillance plans and late effects assessment are discussed.

During this meeting, the topics discussed at the initial diagnosis are revisited. Although the initial conversation must take place prior to treatment commencement, the conversation is occurring at a time of emotional distress, so information may not be adequately understood and remembered.

OBJECTIVE

Develop an understanding of what information is understood and retained by caregivers from the initial meeting, in order to identify any unmet information needs and set priorities for what should be discussed at the end of treatment.

METHOD

A questionnaire was developed, based on the themes that are discussed at the initial diagnosis meetings. Themes included:

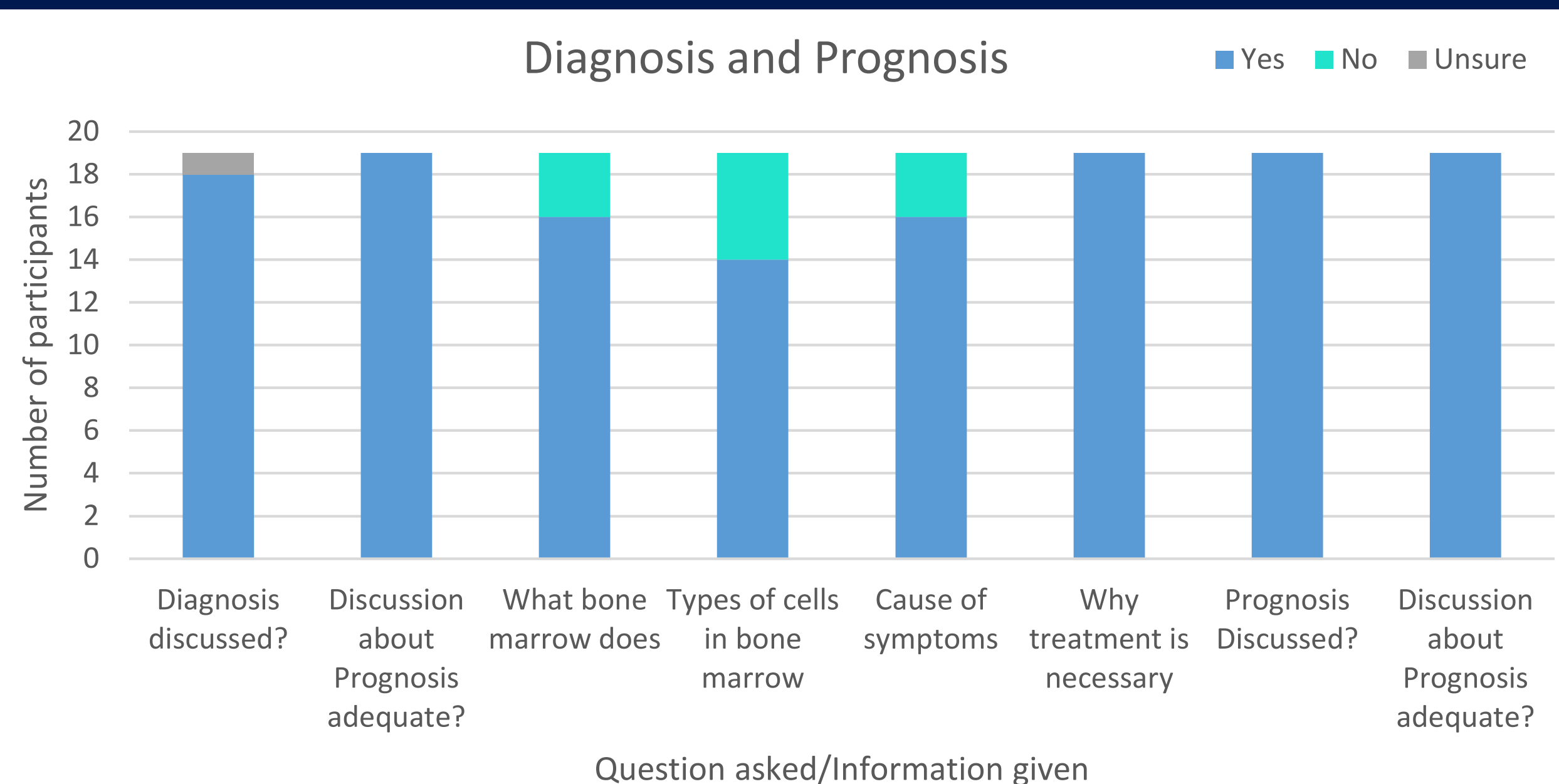
- Diagnosis
- Treatment
- Clinical Trials
- Side effects (short term, long term), Fertility, Second Malignancy
- Prognosis

Parents/caregivers of children (aged <16 years old at diagnosis) currently undergoing maintenance chemotherapy for Acute Lymphoblastic Leukaemia through the Christchurch Children's Haematology and Oncology Centre (CHOC) were invited to participate. The questionnaire was administered online.

RESULTS

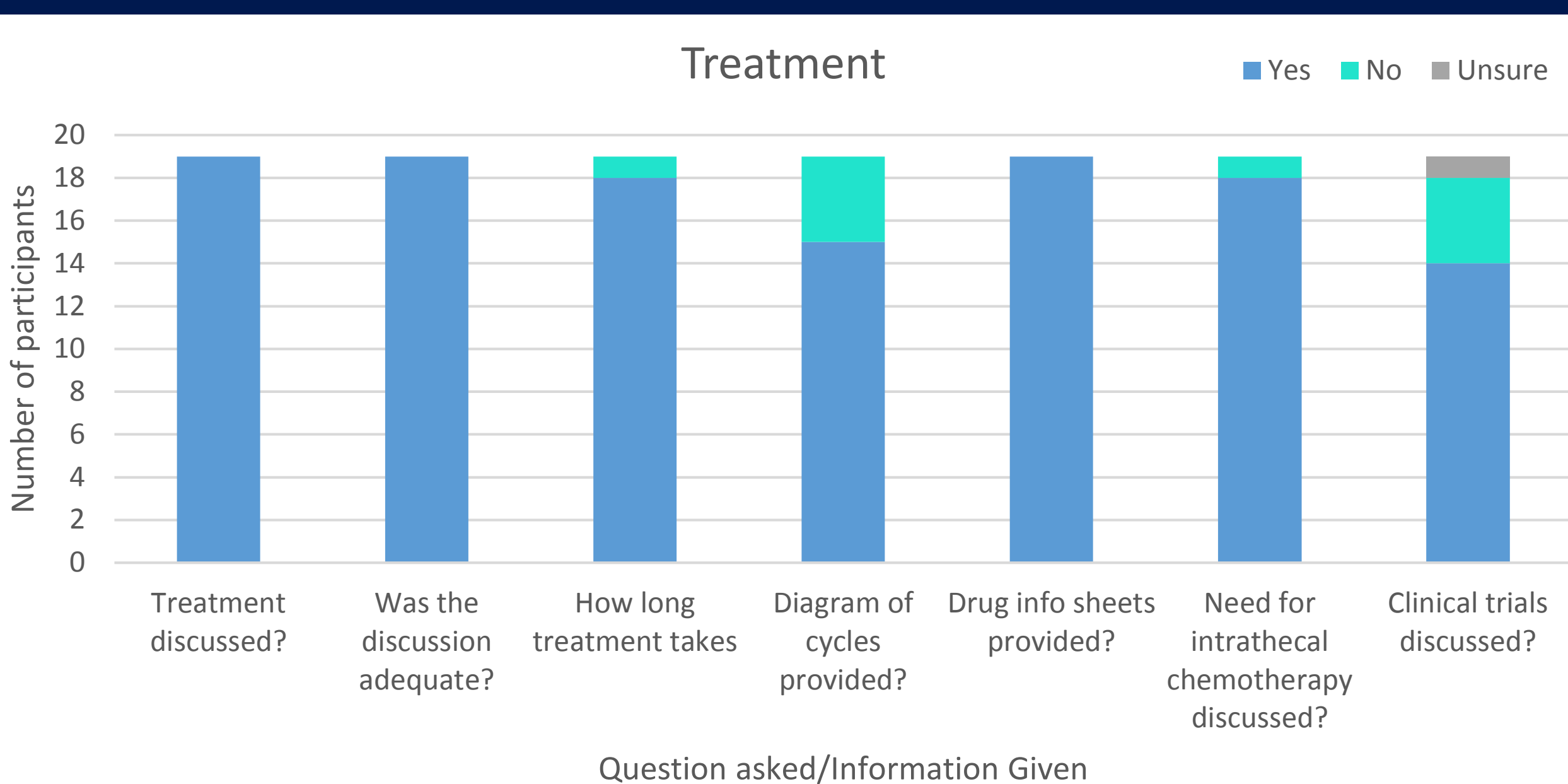
24 eligible patients were identified and emailed a personal link to the survey. Of these, 1 was found ineligible due to diagnosis at a different centre. Of the 23 remaining, 19 completed the survey (82.6%, 18 mothers and 1 father).

Diagnosis and prognosis:



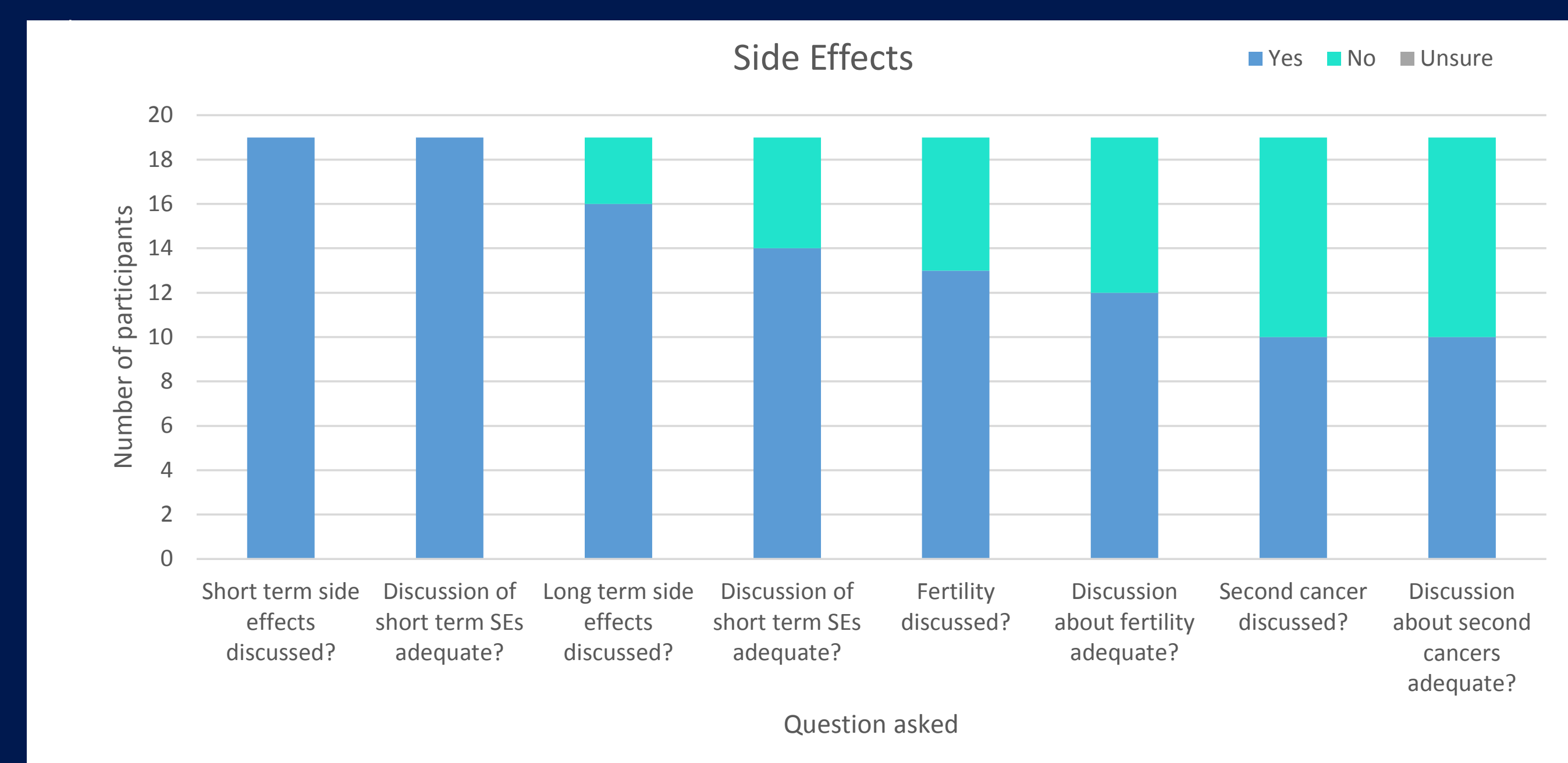
"To be honest, my brain was still in shock that my son was sick. A lot of info and new things were taking place. I was just coping."

Treatment:



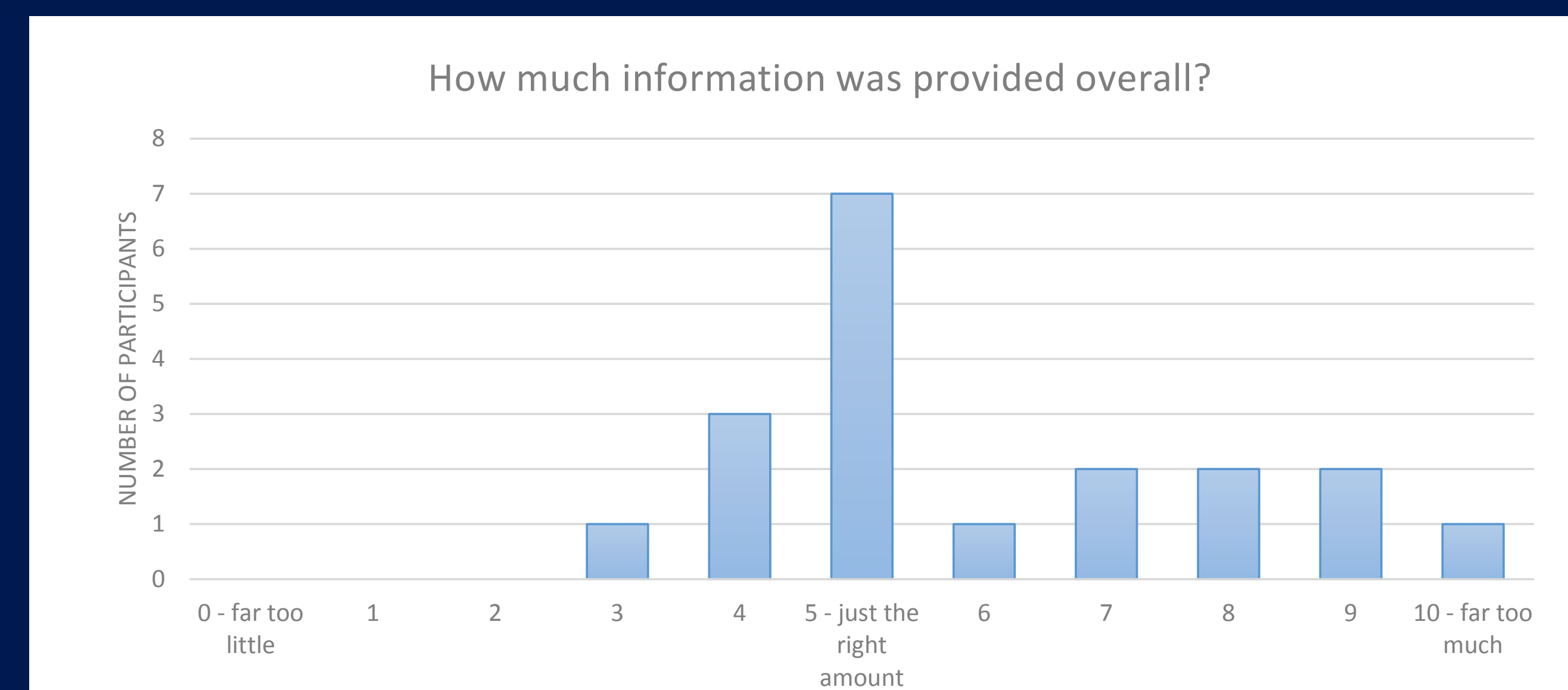
"It was all very overwhelming at the time but having the handbook of information & printouts about all the drugs & side effects to read and refer back to was extremely helpful."

Side effects:



"I don't think we were told about the long term side effects.... I had to read all the papers (Information sheets) I was given. Maybe we because we didn't ask...?"

OVERALL



"Honestly, we were given a lot of info when diagnosed which was great, although our brains were totally overwhelmed with the whole situation... We have a lot of praise for the choc team and how we have been informed from the beginning and still now"

"Yes, I'd like more information now about the risks etc. In the beginning when we were inpatients and in induction we were processing so much, it was hard to take all the information in."

CONCLUSION

Results show that the initial education provided on the CHOC unit has specific areas of strengths and weaknesses. Parents are generally satisfied with the explanations given regarding the diagnosis, prognosis and treatment that will be provided. There is less satisfaction with the education regarding side effects beyond the short term - particularly regarding fertility and the risks of second cancer. These longer-term side effects will be particularly important areas to discuss at the end of treatment.

There was significant variability between families regarding the total volume of information - some would have preferred to have less information to deal with, while others felt they had to ask questions continuously in order to get the answers they wanted. Different personalities and family dynamics will impact how much information is desired, which shows that this process needs to be individualised to families in order to address their needs.

There was a general theme that parents report being overwhelmed and stressed at this time. There is a significant degree of emotional distress at the time of diagnosis, which can make understanding and remembering the initial diagnosis discussions more difficult. Some parents reported feeling that there was a long time until the next formal meeting with their oncologist (usually held once maintenance begins), during which time they developed many new questions which remained unanswered.

Consideration could be given to an additional formalised structured conversation later in the early treatment period, e.g. after 3 months of treatment. This may address unmet information needs at an earlier time point than the end of treatment, which could potentially improve shared decision making and compliance throughout the rest of a child's therapy.