

4. The relationship between parents and clinicians is critical to the care of seriously ill children. A breakdown in the relationship can have lasting consequences for both families and clinicians. Through our research, we have identified key factors that bear on the success of consultations and the maintenance of the essential relationship between parents and clinicians as well as factors leading to a breakdown of the relation 34,35,36,37.

We have disseminated our results in major journals and at major conferences leading on to incorporation into medical and nursing education and training both within PPC and across paediatric specialities where seriously ill children are seen (e.g. oncology, cardiology, intensive care).

5. Advance care planning (Do Not Attempt Resuscitation Orders, Ambulance directives, plans and preferences in place of care and place of death) is widely endorsed by policymakers and institutions; however, parents are often resistant to engage in such discussions. The result is that parents are distressed by being confronted with issues which they find painful to discuss, and clinicians feel inadequate in the performance of their job.

Our research uncovered the bases for such resistance and proposed solutions based upon an approach to advance care planning not as the completion of an agenda but as the sensitive, individualised initiation of the exploration of painful but unavoidable issues^{38,39,40}

Because of our unique relationship with the clinical team, there was not the usual time lag between such discoveries and implementation in practice and education. Having the results immediately and directly from the academic researchers, not having to wait until publication (often a year or more between submission of an article and publication), the clinical team was able to alter practice and incorporate the findings into education and training including their well evaluated oversubscribed simulation course on end-of-life care.^{41,42}

6. Prognostic information about seriously ill children is challenging for clinicians to reveal and painful for parents to receive. Yet it is something that many argue is something parents must know in order to make informed decisions about their

provide any or even adequate prognostic information. They report further that what information is given is poorly understood by parents. Our studies of the actual on the ground conversations between oncologists and parents of children with high-risk brain tumours (audio-recorded and transcribed verbatim) at diagnosis has revealed that an essential issue for parents is not the lack of information or poor information, but rather how to apply complex, often general and statistical information to their specific, unique situation³⁶

100. We are currently analysing consultations as the disease progresses and will, as is our practice, propose clinical guidance based on our findings.

There are indications that our findings apply to clinicians and parents of children with other illnesses including complex cardiac condition; those in intensive care or

awaiting transplant. Part of the work of the PPC Team is helping the parents to understand prognostic conversations and their impact on decisions going forward.

7. As more children survive what were once fatal illnesses more research is focusing on to the impact of their illness and its treatment on their quality of life as survivors. PPC also stresses the importance of quality of life for children who will not survive their illness. However, what quality of life means to clinicians, children and parents and how it figures into their decisions has not been explored.

Beginning with a study of children with high-

shows that most parents and children welcome the opportunity to participate, and some report benefits from their participation.

Working as an integrated Centre we have been able to develop, implement and evaluate a number of approaches to increase invitation and access to research studies⁵⁸.

research; something which parent and children want to do, and we have an obligation to provide. Continued work in parent public involvement and engagement in research will help to ensure the development of this most precious resource.

10. Known for the depth and breadth of our clinical practice as well as cutting edge, foundational research the LDC is a destination point for professional development^{26,59,60,61}.

References [Current or previous LDC staff members or honorary associates are in bold]

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