Understanding experiences of childhood cancer: a fresh perspective

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In this lecture I aim to show how study of experiences of childhood cancer can benefit from a multidisciplinary approach that recognises the contribution of the range of social sciences, and that is informed by a sound understanding of the clinical issues in the diagnosis and management of childhood cancer. There are important reasons for revisiting the social science study of childhood cancer at the present time. First, a well-founded social science perspective on childhood cancer is necessary not only for researchers, but also to inform policy and practice in relation to the care of children with cancer and their families. However, some of the most important contributions to the field (e.g. Bluebond-Langner’s classic study of the private world of dying children, published in 1978) were written during a period when childhood cancer had poor outcomes, and a majority of children died of the disease. Now, most children survive, and questions must now focus on living with and surviving childhood cancer.

Second, the social science study of childhood in general is burgeoning (James et al 1998; Jenks 1996; Lee 2001; Mayall 2002), with the emergence in the last two decades of a “new” sociology childhood. This has taken the route of distinguishing how a sociology of childhood might differ from a psychology of childhood, and it has been successful in identifying previously ignored questions and encouraging the application of methods consistent with those questions. With the development of the wider field of childhood studies there are opportunities for refreshing and deepening our understanding of experiences of childhood cancer. However, it is also important to offer a critique of some currently dominant approaches within childhood studies, particularly those informed by a libertarian perspective.

Third, there is now a substantial body of empirical research on experiences of childhood cancer. Though the quality of this work is variable, it is important to begin to synthesise it to begin to produce an integrated and holistic account of the evidence, to identify where the gaps might lie, and to identify an agenda and directions for future research. It is also appropriate to synthesise the work on childhood cancer with empirical and theoretical work in other fields. For example, the sociology of adult illness has much to offer in terms of a theoretical approach to experiences of serious chronic disease, particularly in the absence of a more fully elaborated sociology of childhood illness.

I will argue that it is increasingly important that social science accounts of children’s experiences must go beyond assessments of psychological morbidity. Children and young people with cancer should be taken seriously as social agents in their own right, and be seen as active in giving meaning to their own experiences. They are also active participants in the emotional, biographical, and physical work of having childhood cancer, including its strategic management. I will also suggest, however, that some recent libertarian arguments about the potential role of children and young people in decision-making go too far.

I will suggest, for example, that the insistence that there must be “open communication” with children, and that children should be involved in decisions about and able to consent or refuse medical treatments, has very serious implications. I stress the appropriateness of adopting inflexible and rigid approaches to communication (whether in the direction of full disclosure or the reverse), particularly in the striking absence of research about the priorities and preferences of children in this sensitive and difficult area. The potential consequences of
open communication and involvement in decision-making are largely unknown, and there are many uncertainties about how disclosures of information and children’s expressed views should be managed. How seriously the objection of a very ill child to being subject to a painful, frightening or distressing but necessary procedure should be taken into account needs to be considered within this very specific context. To argue that the often agonised efforts of parents and staff to gain children’s cooperation are simply the actions of an oppressive majority is to risk offering a crude and simplistic account of a highly complex situation. Similarly, to argue that information is withheld from children through taking advantage of an unequal balance of power coupled with the paternalistic instincts of adults does not do full justice to the complexities of situations in childhood cancer and the positioning of the parties involved. For example, there is a need to recognise the ways in which children are strategic in their use of silence in consultations, and in their use of parents as envoys and communication buffers. I propose that imposing certain forms of uniform “rights” on children in relation to information and decision-making is in fact potentially oppressive (effectively functioning as a prior determination of their best interests).

Much more needs to be done to explore the extent to which (individual) children really wish to be decisive and the long term outcomes of those decisions, their preferences regarding the form of their relationships with professionals, and how their needs, including emotional and informational needs, can be better met. In this, there is a need to be clear that some issues are not easily tractable; once the explanation that it is not simply lack of will that holds adults back from sharing information and decisions with children falls away, other explanations demand far more complex and demanding solutions.

These issues highlight the need for theorising of childhood illness to take account of the science of development, to avoid, for example, confounding the general social competence of children with specific competences in medical decision-making. Here, the damaging consequences of the caricaturing of developmental psychology that has dominated some recent work in childhood studies is most apparent. Developmental psychology is much more sophisticated and diverse than its critics have given it credit for, and has a vital role to play in informing not only debates about the characteristic cognitive processes of children at different ages, but also in the assessment of individual competences. Study of these important aspects of childhood cancer is likely to involve approaches that integrate contributions from sociology and psychology, and that use methods including ethnography and conversation analysis as well as directly accessing the views of children and their families. The roles of health professionals other than doctors will be a key interest of this future work.

I will argue that social science inquiry into the nature of parents’ and families’ experiences must also go beyond a narrow focus on psychological morbidity. The experiences of parents are especially important and interesting, though attention also needs to be given to siblings and other socially adjacent people. Lupton (1997) describes how parents have acquired a whole series of obligations in relation to their children, particularly in relation to their health and welfare. Childhood cancer serves as a particular form of the intensification of parenthood. Parenting a child with cancer needs to be re-characterised to draw attention to how parents’ identities and social obligations position them in relation to the medical world, to highlight the emotional work carried by parents, and to show how becoming and being a parent of a child with cancer invites surveillance of parenthood. I am conscious, of course, that most research has focused on accounts of mothers, and that there is risk that research could (unwittingly) reinforce aspects of motherhood as “natural” and non-negotiable, rather than reflexively produced in response to dominant social and discursive constructions. Clearly the ways in which family members come to recognise and adopt norms and roles in relation to childhood cancer will be an important aspect of future research. So too will be exploration of different forms of families, including children who are in the care of social services who whose parents are unable or unwilling to accept the roles that are socially prescribed for them.
I will illustrate many of the points raised in this lecture with reference to a series of empirical studies in which I have been involved, including in particular a project funded by the UK Economic and Research Council’s Science in Society Programme on childhood cancer tumour banking. Using in-depth interviews with 81 parents and children, I will show how we need a sophisticated and theoretically rigorous approach to understanding issues of information, sharing decision-making, and consent.

Many of the issues I raise reflect the absence of a properly elaborated sociology of childhood illness to complement the psychology of childhood illness. Current social science work in childhood cancer is of variable quality, and much of it is disappointing. This poses major challenges for those attempting to theorise in a specific area such as childhood cancer. There is an urgent need to begin to distinguish in what ways a sociology of childhood illness might draw on constructs already developed within the sociology of adult chronic illness, and to identify where completely new forms of theorising are required. There is some evidence that many existing constructs have considerable explanatory value as far as experiences of chronic childhood illness is concerned, but much more needs to be done to explore and develop these and others. In taking the specific field of childhood cancer forward, it is clear that there is a particular need to attend to the different subgroups. Different forms of tumours may have very different effects, and there is a real need establish the extent to which they should be seen as different diseases. Much more, too, needs to be done to understand the experiences of children of different ages. I suggest that much more thorough, rigorous, and sophisticated empirical research and theorisation is required. An interpretive interdisciplinary approach is likely to offer the most fruitful way forward.

References