Tell me a story ... What can paediatricians gain from reading stories?

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In our first article we considered literature for and about children, and how writing for the young has changed, reflecting different and evolving perspectives on childhood. In this second article, we will be asking whether literature can be used creatively and usefully in the training of doctors. The suggestion for the topic arose from a session we organised for paediatricians in the Communication and Management Skills module of the MMedSc in Child Health at Leeds University.

Some months ago we put out a request on the RCPCH email discussion group for suggestions of books that illustrate children’s experiences of illness and health care. We explained that we were planning a session on communication skills on the Leeds MMedSc in Child Health, and thought that insights might be gained by reading literature (we emphasised that we meant real literature, rather than the dry articles that make up most of our professional reading). There was a large response and many suggestions were made, along with the proposal that we might explore the topic further in two articles for Archives.

One might well ask why the topic of children’s literature should merit an article in a professional journal, even when children’s doctors make up the readership. We plan to address this question, and discuss why and how literature might be relevant to us as paediatricians. We begin with what we feel we can gain professionally from reading, and then go on to consider how we might utilise literature in paediatric training and our ongoing professional development.

EDUCATION VERSUS TRAINING

Secretly (if not overtly in these days of evidence based practice) we know that narrative has an influence on our work. Indeed many of us might admit that the personal experience columns in the BMJ often attract more of our attention than the scientific articles. We are naturally drawn to our colleagues’ and patients’ accounts in order to discover, or confirm our perceptions of illness and health care. Perhaps we should acknowledge this and then collect a fat fee. Doctors may also turn to for advice, comfort, and support even if their powers of healing and cure were very limited in earlier centuries.

This is not to say that doctors are portrayed as helpless and sympathetic characters. There are many illustrations and poems that poke fun at the pompousness of the profession and question doctors’ motives. Both AA Milne’s and Hilaire Belloc’s verses have illustrations showing well dressed, portly doctors running to the bedside to pronounce on patients’ conditions. They use long, incomprehensible medical terms and then collect a fat fee. Doctors may also come out less well in autobiographical accounts. Roald Dahl’s tonsillectomy in his autobiography Boy provides a particularly graphic example.

PORTRAIYAL OF ILLNESS

We commented in the previous article how in the past illness and death often allowed for reflection on character, both of the sufferer and the carer, with special emphasis on the grace that suffering brings. Children in Victorian literature are commonly confined to sickbeds, and the family (and the reader) are required to sit through endless bedside vigils. Every fever is potentially fatal and...
much of the drama of the situation arises from the fact that death may occur at any time, as indeed was the case throughout much of the nineteenth and early twentieth centuries. Infections such as typhus, typhoid, and cholera were common, and many heroes and heroines of children’s literature succumbed to these, or to terrible accidents, which either killed them or rendered them “cripples”.

It seems that modern children’s books do not dwell on sickness in quite the same way as their Victorian predecessors. These days we are more likely to read about mental illness, cancer, child abuse, or chronic conditions such as cerebral palsy, deafness, or scoliosis, reflecting the changing epidemiology and definition of disease in our developed world.

This change is particularly evident for childhood disability. In the past a child’s disability was often used for its impact on other characters. Now disability has taken more of a frontline position, reflecting changing attitudes in society. Fictional accounts are more realistic and commonly offer an insight into the way disabled children experience the world, and what they have to offer to others.

While reading fiction does not inform us much clinically about the conditions mentioned, it can reveal the child’s perspective and experience of illness, as well as insight into the trauma and suffering of the carers. Situations may resonate for us as doctors, perhaps particularly in dealing with parents of ill children whose reactions to their child’s condition is often unpredictable and sometimes even selfish. We may in addition be struck by the limitations of medicine and the relative impotence of the medical profession to relieve human suffering, whether it be in Victorian times or more recently.

LITERATURE IN TRAINING

If reading can increase our sensitivity to ourselves and the impact we have on patients, along with giving us a better understanding of illness and how it affects our young patients, might there be a value in formally incorporating reading into our professional development? It was with this thought in mind that we developed the Lessons from Literature session.

From the extensive list of suggestions that we had compiled from colleagues we selected a sample of excerpts that were varied in subject and style, and which we thought might provide a broad base for discussion. We distributed them in advance and asked participants to read them prior to the session. Included were a scene from Little Women where Beth was seriously ill, the gruesome account of Roald Dahl’s tonsillectomy at a seemingly routine visit to his GP in Norway, a chapter from Spasm, an autobiography by a sufferer of epilepsy, AA Milne’s “Sneezles and wheezles,” and “The dormouse and the doctor,” and Hilaire Belloc’s Cautionary Tale of Henry King.

For topicality we also included Roald Dahl’s account of his daughter’s death from measles, and his plea for immunisation back in the 1970s.

Most of the group read the excerpts prior to the session, and actively joined in the discussion. The group varied from those who had spent their childhood reading avidly to those who had barely opened a book. Not surprisingly the debate appealed particularly to the “bookworms” especially when similar tastes in reading were uncovered. We discussed whether the seizures in Spasm were indeed epilepsy, laughed over the portrayal and illustrations of doctors, and pondered over the impact on children of reading gruesome tales from Belloc, and on Dahl himself following his unexpected assault by tonsillectomy.

The session was not restricted to reading published literature alone. The second half was devoted to participants trying out some creative writing themselves. They were asked to write a personal account of a child’s experience of illness or health care, and were given only 30 minutes to do so. The results were quite extraordinary, with clear talent emerging from a few, and sensitive accounts by all. Some chose to describe their own medical encounters when young and others described their experience of caring for their own children through ill health. All volunteered to read their accounts to the group. To our surprise, the participants had not confined themselves to prose. A few brave individuals attempted poetry with considerable success.

We heard about a visit to the dentist together with a twin sister. The experience graphically drew out not only the child’s reaction to dental care but also and especially the complexity of the sibling relationship. One could empathise with both the stoical twin and her attention needy sister, and see how the family dynamics were reflected in the described visit. It even allowed us to consider what impact the medical attention we give to our patients may have on their siblings.

Particularly moving were side by side accounts from two senior paediatric registrars of very similar reactions to receiving medical care when young. One had been brought up in rural Uganda and the other in middle class Britain. One had suffered a foot injury while playing barefoot in the fields, the other was subjected to repeated visits to hospital for scoliosis. Both described their feelings and impressions, the endless waiting to be seen, the experience of being x rayed and their reactions to the doctors and nurses. The universality of the child’s reaction to experiencing health care was striking, despite the completely different settings in which they occurred.

Participants did not restrict themselves to their own childhood experiences, but also chose to recount their experiences as parents. Only the previous weekend, one senior paediatric
FEEDBACK AND EVALUATION
There was no doubt that the session was well received, and subsequent feedback was positive. We felt that we had achieved our aims of exploring issues related to child health and demonstrated that reading together was useful. We subsequently spent some time reflecting on our choice of material. Our aim had been to “get inside” children’s experiences of ill health and medical care. We realised that we had not considered the obvious—that literature is invariably written by adults. We had only been able to view literary accounts of childhood illness through the filter of the adult author’s experience. In interpreting our reactions we need to be aware of this limitation.

We were also struck by the realisation that we had largely drawn on literature that we had read to our own children or had enjoyed ourselves as girls growing up in London. The selection had been unnecessarily limited. Given the opportunity to conduct this sort of session again we would attempt to tap the diversity of backgrounds present, and ask participants to bring readings of their own to share.

REFLECTION
Our experience in running these sessions has strengthened our sense that reading literature can benefit us in our work. Through shared reading and writing we managed to explore a number of issues that in all likelihood might not otherwise have been touched on. We only began to see how this might be developed, and there are no doubt other ways that we can enrich ourselves through literature. Reading clubs already exist in some hospitals, and a multidisciplinary group focused on childhood might be a novel approach. Perhaps our professional literature might provide a further forum, with personal accounts and reviews.

Sensitivity to children’s experiences of illness and doctors is an important quality for paediatricians to acquire. There are clearly many routes to achieving this. It seems to us that reading and creative writing is an effective one, with the added benefits that it is enjoyable, and can be carried out without special expertise in the area, but simply a love for reading.

Dr Sarah Gilead, an expert on children’s literature, told us that “Narrative is one of the primary ways we all comprehend ourselves and the world, and not only comprehend, but actively engage in the world”. We would like to encourage more narrative based learning in our work, through reading books, writing and sharing our own accounts, and engaging our patients in describing their experience under our care.

AFTERWORD
We began this article by telling of our request to the RCPCH email discussion group for suggestions of books that illustrate children’s experiences of illness and health care. The response encouraged us to pursue our thoughts as to how stories might benefit us in our work. We have compiled these suggestions and they are now posted on the ADC (www.archdischild.com) and PIER websites11 (with due acknowledgement). We would like to thank the numerous respondents and suggest that the list might be used as a starting point for those who might like to take these ideas forward, either on an individual level or with others.

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The booklist can be viewed on the ADC website (www.archdischild.com/supplemental)

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RECOMMENDED READING
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