

Hearing the Voice of a Shadow Child: Healthy Siblings Experience of Cystic Fibrosis and Other Life-Threatening Conditions

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Abstract

Cystic fibrosis (CF) is a chronic, life-threatening disease, similar to other chronic life-disrupting pediatric conditions, and this creates physical and psychosocial problems for parents and the healthy sibling/s of the sick child, who often become sibling carers. It is feared that, despite good intentions, professionals fail to hear the authentic voice of those intimately involved, especially these sibling carers, who can feel they became a “shadow child.” This study is a partnership between an academic and a former CF sibling carer, who wrote a “fairy story” for his children about the Uncle they never knew. It is an effort to hear the “voice of shadow children” who can feel left behind and unseen as families and professionals focus upon their ill sibling.

Keywords

caregiving, medical education, patient/relationship centered skills, patient perspectives/narratives, relationships in health care, patient feedback

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The healthy siblings of children who have brother or sisters with cystic fibrosis (CF) or other chronic life-threatening conditions can sometimes become part-time sibling carers, supplementing their parent’s support for the ill child. One consequence is that the healthy child may sometimes feel relatively ignored due to the necessary extra attention their ill sibling must receive, almost making them feel like a “shadow child,” standing in the background, not clearly seen.

This paper is a partnership, of such a “shadow child,” A.C. who was a sibling, whose brother died from CF and now as an adult is able to reflect back, with greater understanding what was happening to him and his family, as in effect, he had become a part-time sibling carer to his brother.

It is recognized that this is the personal experience of but one such “shadow child” and we cannot generalize from this one experience. Yet it is believed that the story may speak to others in the situation of being a “sibling carer.”

The following story of A.C. was written in response to a counselling course requirement, seeking examples of attachment theory and neuroscience to identify developmental interruptions that happen during childhood. He used a “fairy story” format and saw it as an opportunity to speak to his children of the Uncle they never knew.

A.C. shared this with an academic C.P., who realized that so much research in this field, lacked the psychosocial integrity of the sibling carer’s perspective. Both authors recognize the clinical progress made with CF but appreciate that there is a need for a better understanding, by practitioners, of the psychosocial impact upon the “shadow child.”

Cystic fibrosis is a chronic multisystem disease, especially impacting upon lung function and if of autosomal genetic origin. The condition is found in every Western world country, while in the United Kingdom, there are more than 10 000 people living with the condition (1). In the mid-20th century, C.P. remembers that most children with CF died well before their fourth birthday, but today, the average life-expectancy is into the 40s and onward. Indeed, in Britain and the USA, there are now more adult than pediatric people with CF (2). This has been said to be one of the most successful medical

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interventions in the Western world (1–5). The progress has been made on focusing on the underlying CFTCR gene and modifying its impact, and current developments of this approach aim to seek to develop a personalized treatment that crucially will prevent the chronic breathlessness and the development of respiratory infections (6–8).

To develop, the condition requires that parents are carriers of the CF gene, which means they will learn that their child will have a limited life span which even in the 1980s often meant that many children did not reach adolescence (9). As if this grim prognosis was not enough. Studies from around the Western world have found that they, the parents and crucially their healthy siblings, face major psychical and psychosocial demands in their everyday family living (10–17). Though of course, such situations are mediated by personal socioeconomic circumstances and the extent of supportive services in different societies.

Cystic fibrosis has its own physical demands. As daily, the lungs exude a “defensive” mucous, which can become pathological, reducing oxygen absorption and a site for secondary infections, which can make the person feel as if they are drowning. The impact upon the ill child, as the condition starts after birth and worsens over time. Furthermore, because of the increasing breathlessness–respiratory insufficiency, this reduces the child’s mobility, bringing with it its own psychosocial limitations. This brings on early exhaustion and shortness of breath, while the secondary infections associated with the deterioration of the condition can create life-threatening crises, often leading to emergency hospital admissions.

For the parent, this means they need to provide morning and evening physiotherapy to clear the child’s lungs, which is physically as well as emotionally demanding. Indeed, home care is maintained while ever possible, and while parents need help, they can often become the primary “experts” in dealing with their own child (18). Perforce, the ill child becomes the center of the family’s daily functioning and everything needs to be arranged around the daily treatment. This is quite apart from hospital appointments and the increasing emergency hospital admissions as acute attacks and the consequences increase as the lungs are accumulatively damaged (9–11,15,16).

Of course, the child is not always acutely ill, and their parents seek to provide as normal a life experience as possible. But when considering the physical impact of CF upon the child, who is often underweight, their life experiences are very different from their age peers (14,17,19).

For the child, school brings its own challenges, though today it is recognized that the child needs to be involved in decision making (12,20,21), as many appear to manage their condition well, equally becoming personally “expert” as many are living longer lives (16).

The focus of this study will be primarily upon the perspective of healthy young people whose sibling has a chronic, often life-threatening condition whose voice is often not heard. Who we describe as “shadow children,” as they often feel unseen, obscured by the necessary demands required to support their ill sibling.

This can occur not just with children with CF but a range of conditions such as cancers, mental illness, hemophilia, epilepsy, sickle cell disease, and neurological disorders as research shows that the intra-family dynamics are very similar (13,14,19,21).

One psychosocial feature of living with a CF child can be anger and resentment, even in older adolescents, as the sense of accumulative neglect and unfairness, where everybody is expected to put the ill child first (10,11,13,15,22).

A systematic review by Chudleigh et al is somewhat critical of a number of studies that explored unaffected siblings experience, which were often reported via parents, feeling that the *authentic voice of the sibling is not heard* (22). They stressed the vital importance of hearing direct from the healthy child, their views of their unique situation. This cri de coeur encouraged us to offer this paper to enable professionals to better hear the voice of an often mixed-up, confused, angry, guilty, emotional young person whose brother or sister is a child with CF.

For the professional involved with the family, we need to remember parents face the nightmare of every parent, that their child might predecease them. Moreover, because of the genetic origin of the disease, parents can sometimes carry a degree of guilt and blame, which can bring its own special dynamic. From the perspective of the people living with the reality of CF, especially the sibling, while appreciating professional’s good intentions, our approach may seem a little too “clinically detached” and we fail to hear the voice of the shadow child.

The following story of A.C. proved to be a cathartic journey as he sought to explain the half-chaotic remembered feelings of the “shadow child.” What he experienced and the turbulent and painful emotions he then felt. His story provides an authentic voice of reality of the healthy child in the chronic ill situation, so that we can hear the “shadow child,” as well as the tribute to both brother and parents. A.C.’s “fairy story” goes far beyond that which is outlined in academic papers as it reflects the perspective of many shadow children.

“It’s not your fault”: a therapeutic puppy dog’s tail.

Once, not that long ago, in a town by the sea lived 2 happy, beautiful puppy brothers called Blim and Blam. They loved each other deeply and for the first few years of their lives they were inseparable playmates. Blim was older than Blam by a little way and had to keep an eye out for his excitable brother. Blam was lovable and mischievous, but there was something else—he had been born with wonky breathing and was sometimes unable to run around with Blim, having to stay at home with their parents, tucked up in his basket.

Blim hated it when Blam was too poorly to play. He was worried about his brother but, at the same time, he felt like Blam always got the attention from their Mum and Dad.

As time passed, the puppies grew into young dogs and the times that Blam was ill became more frequent and lasted longer. Blim’s feelings toward his brother grew more

resentful: “He always takes up all of Mum and Dad’s time, it’s not fair. What about me?”

Blim hated that he felt like that but did not know how to stop the feelings from growing bigger and more intense. Eventually, Blam was unable to leave his bed at all, his breathing became more difficult and his playful nature seemed to vanish. Such a distance developed between the brothers by now that all Blim could feel now was anger and frustration to the point that he wished his brother would just hurry up and die so that he could have some attention from his parents again.

Reading this you might think that Blim was not very pleasant young dog, but all he was just young and unable to understand the feelings he was experiencing.

Then, one horrible morning, Blim went to wake Blam for breakfast but the vital spark that animated his beloved brother had gone and all that was left was an empty shell.

Blim was hit by a tsunami of emotions: guilt, loss, and shame swamped his being so deeply that he could hardly breathe. He felt worse than his brother had ever been—how could he have wished Blim dead? Why could he have not been there for him more? Blim could not even share how he felt with Mum and Dad as they had no idea how he was feeling or what he had been thinking.

Blim carried these feelings for a long time and they began to slowly suck his own joy from his very core. He left his family home, his Mum and Dad and comfortable basket and set off into the world.

He wandered here and there, never able to settle, become more and more a victim of the shameful burden that he carried. His own health began to unravel until he was a shadow of the healthy young dog he had been. Finally, one cold and rainy night, he felt he had come to the end of his tether—his fur was patchy, his ribs showed through his coat, and he was as scrawny as a scarecrow. He found space between 2 bins in a stinking alley and lay down, not caring if he was to wake again.

That night, he was visited in a dream by his long-passed brother. In the dream, Blam was young and full of health, vim, and vigor. He had no troubles with his breathing and gave off a feeling of calm and contentment. Blim was woofless with wonder—he knew his brother was dead but felt this was too real to be just a dream. They were in a field filled with grass and flowers, Blim could feel a breeze ruffling his fur, which was no longer mangy and flea-bitten, and smell the familiar puppy breath of his brother.

Time passed silently but for the buzzing of bees lazily pollinating the meadow flowers. It was a comfortable silence like the ones they had shared as young pups but finally Blim spoke.

“I’m so sorry Blam”. As he spoke 2 he felt 2 fat tears welled up and spilled down his muzzle. It was like a dam breaking and all the pent-up sorrow made his body shake. Blam let his brother howl his grief out for a while then slowly moved towards him and gently licked his face.

“You don’t need to blame yourself, none of it was your fault. It was not your doing that I was born ill, not your fault that you felt the way you did. You never did me wrong and you always loved me no matter what you told yourself. None of us can help how we feel Blim but we can forgive ourselves for the feelings that cause us shame.”

Blim was stunned by his brother’s words. “How do you know that my resentment of you was not stronger than my love?” he asked.

“Because I live in your heart. I always have and I always will and that is where I am speaking to you from now. I love you too brother and I want you to live without shame and guilt that has dragged you down. Now, wake up!”

In the alley Blim awoke. The rain had stopped and the sun was rising. Blim got shakily to his paws, stretched and shook himself. He felt different. Lighter. Ready for a new day to move forward in.

In the shared writing of this study and subsequent review, questions were raised as to motive for the study and what of any outcomes as initially A.C. did not consciously begin with a project that might be of value being shared with others in similar situations. But then he was brought to realize that it had such a value. For A.C.’s children, it was informative and for them at a young age, gave them some idea about their Uncle but of course, children find it hard, to see their parents as once being children and sometimes vulnerable. He shared his story with a few families in similar situation and was urged to give it wider exposure. It can prove one gentle way of sharing the guilt and anger of the “shadow child” of the time, which might help others living with the demands of the chronically sick child.

Perhaps best of all, is a sense that sharing this experience with others, out of the reality of a too-often lived tragedy, something positive has emerged. Most of all, this has helped to bring a closure to all the family. As the mutual forgiveness between Blim and Blam is an absolution and homecoming and the child can now leave the shadows behind.

Authors’ Note

A.C. is the serving sibling referred to in the study and gives consent for him to be identified as the “sibling” of his brother with cystic fibrosis. This confirms his consent to be both author and subject in the paper.

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Author Biographies

Andrew Cox is the younger sibling in the story, had a turbulent youth but became a school teacher within the State system and has become a specialist to help integrate troubled young people into education. He brings his own life experiences in an empathetic way to help problematic youngsters realize that the current stress need not be permanent - "Naught is good or ill but thinking makes it so" (Hamlet), which is the foundation of cognitive behavioural therapy.

Colin Pritchard's practice background is in psychiatric social work but he has been research professor since 1998 and uses his social science background to cross over into health care fields, highlighting social and environmental impacts on human health publishing in such diverse areas as *British Journal of Neurosurgery*, *Child Abuse & Neglect*, *Acta Neurologica Scandinavia*, *British Journal of Psychiatry* and *Public Health*. He is Emeritus professor School of Medicine, University of Southampton & currently Research Professor Bournemouth University UK.