

In the Darkness There Can Be Light: A Family's Adaptation to a Child's Blindness

Alissa A. Ulster and Beverley J. Antle

Abstract: Blindness or significant visual impairment can be very difficult for families to cope with. In this article, the authors present an in-depth case study of a family's journey through diagnosis and treatment for retinoblastoma (RB), a rare form of childhood eye cancer affecting the retina. As a part of the analysis of this family's experience, the authors examine assumptions about children's abilities to cope and predominant notions of quality of life through the experiences of one child, Alex, and his family. In spite of signs of psychological trauma, Alex demonstrated a remarkable adaptive ability and had more insights about his experiences than anticipated. Similarly, following a period of considerable worry for their child's health and his ability to adjust to blindness, the parents, too, feel their family has a good quality of life.

Misconceptions about blindness or vision loss continue to fuel popular perceptions that living with a significant visual impairment is devastating. Little is known about parents' perceived stress in raising a child who has a serious eye condition, particularly when compared to parents' experiences in raising a child with another type of physical or cognitive disability (Dyson, 1997; Hintermair, 2000; Johnson, 2000; Smith, Oliver, & Innocenti, 2001; Trute & Hiebert-Murphy, 2002; Warfield, Krauss, Hauser-Cram, Upshur, & Snonkoff, 1999).

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This article outlines an in-depth case study of the child's and parents' journey through diagnosis and treatment for retinoblastoma (RB), a rare form of childhood eye cancer that occurs in approximately 1 in 15,000 live births and may involve one or both eyes. A bilaterally affected child has an added genetic risk of a secondary malignancy later in life (Byrne, Fears, & Parry, 1995), making them a particularly vulnerable subgroup. The degree of visual impairment may range from mild to severe, and if the cancer has spread outside the eye, the disease can potentially be fatal. Medical treatment for this disease is invasive and may consist of a combination of multiple surgical interventions, systemic chemotherapy, radiation, enucleation (surgical removal of the eye), and a bone marrow (stem cell) transplant.

Clinical practice informs us that even young children's understanding about illness and disabilities is often underestimated by their parents, caregivers, and those employed in the health and disability fields. In addition, assumptions that are made about what is a "good" quality of life for families living with visual impairment may not be in keeping with children's and families' perceptions. As a part of the analysis of this family's experience, the authors examine assumptions about children's abilities to cope and predominant notions of quality of life through the experiences of one child, Alex (the child's true name has been used, as requested by Alex and his parents), and his family, who were interviewed on two occasions by the authors.

Background

It is recognized that parents of children with physical or developmental disabilities (Dyson, 1997; Hancock, Wilgosh, & McDonald, 1990; Leyser, Heinze, & Kapperman, 1996; Leyser & Heinze, 2001; Tröster, 2001) or a chronic health condition (Krulik et al., 1999) experience more stress than parents of a "typical" child. Furthermore, this stress may have "... restrictive and disruptive effects on the family ... [requiring] continual readjustment in family roles, relationships, and organization" (Leyser & Heinze, 2001, p. 37). It is thus not surprising that parents of children with a visual disability experienced higher levels of stress than parents of sighted children (Hancock et al., 1990; Leyser et al., 1996; Tröster, 2001). An interesting trend in Tröster's results (2001), although not statistically significant, was that mothers of children with low vision experienced more stress than mothers of

children who were blind. This suggests that the process of adjustment for parents is not straightforward, nor is there a clear relationship between severity of impairment and parental stress.

Strategies that parents of children with visual impairment identified as helpful in their adjustment include educating oneself about the disability (Leyser et al., 1996), accessing informal and formal supports (Hancock et al., 1990; Leyser et al., 1996), and actively helping their child to further develop his or her talents (Leyser et al., 1996). A positive finding is that some parents' emotional reactions and responses toward their child's disability appeared to improve over time (Hancock et al., 1990; Leyser et al., 1996).

In spite of these positive findings among families of children with visual impairment, Ek (2002) found that children with RB, who had an eye surgically removed (enucleated), displayed obvious psychological reactions to the loss of the eye, and experienced medically related phobias. Long-term implications of vision loss due to RB could be felt in many domains, including education, reproduction, social, and employment or income attainment (Byrne et al., 1995).

There is a paucity of literature addressing the emotional adjustment and adaptation process of a child and family experiencing late-onset blindness in childhood. The majority of literature describes congenitally blind children's emotional development (Freeman et al., 1989), socialization, and play with their sighted peers (Erwin, 1994; Rettig, 1994). However, the authors' clinical experiences suggest that there are differences in experiences faced by a congenitally blind child and his or her family when compared

with a child with late-onset blindness that warrant further inquiry.

The authors present this case study as an initial step in a planned program of research investigating the adaptation of children and families with late-onset blindness. This work is informed by advances in the disability studies field that challenge dominant notions of life with a disability as inherently tragic (Antle, 2004; Beaulaurier & Taylor, 2001; Oliver, 1996) and a strengths perspective (Saleebey, 1996) that directs social workers to consider the capabilities and strengths in a client system, as well as the challenges and barriers they face.

Method

This in-depth case study of one child's journey through diagnosis and treatment is based on the authors' clinical history with this family, as well as two in-depth family interviews focused on the child at age 6 and the parents' retrospective reflections. The authors present a chronological description of Alex's journey through treatment and then provide an in-depth analysis of these experiences.

ALEX'S JOURNEY

Alex's journey began when he was not quite 7 months of age; a day, his parents say, they will never forget. On this day at a large children's hospital in Canada, Alex was diagnosed with bilateral RB. Approximately one month earlier, Alex's father had noticed a "cat's eye reflection," or leukocoria, from Alex's left eye, the most common presenting sign found in RB. After being examined by a community eye specialist, Alex was urgently referred to the RB team at this children's hospital for further assessment and treatment of his condition.

During this initial visit, Alex's parents were told that Alex's left eye, now blind due to his RB, would need to be enucleated (surgically removed) immediately due to the advanced size of his tumor and risk of tumor cells spreading outside his eye. A medium-sized tumor was found in Alex's left eye covering the macula and touching his optic nerve. Understandably, Alex's RB diagnosis came as a shock to his parents and extended family, who were not only being informed of a very poor vision prognosis, but that their only child, still a young baby, also had cancer. Without delay, and to avoid serious threat to Alex's overall physical health, Alex's left eye was promptly enucleated.

Approximately 4 1/2 years of rigorous treatment for Alex's RB followed, involving 15 cycles of systemic chemotherapy at three-week intervals, preceded by multiple focal therapy treatments (laser and freezing therapy), which were conducted under a general anesthetic. Unfortunately, these treatments were only partially effective and often resulted in pain and swelling of Alex's remaining eye, to the extent that Alex was unable to open his eye for several days following each treatment. Alex also underwent surgery for his right (remaining) eye to insert a radioactive plaque through which Alex received 50 hours of localized radiation. Alex also received 25 cycles of whole-eye external beam radiation, a therapy in which there is an increased risk of developing secondary malignancies as well as orbital anomalies. In Alex's case, this therapy resulted in a degree of facial asymmetry. Lastly, Alex received two periocular carboplatin chemotherapy treatments (a localized chemotherapy injected into the back of the eye).

Soon, however, it was discovered that Alex's 4½-year fight to save his remaining eye and vision would be lost. Alex's remaining eye was enucleated when Alex was 5 years old. Alex, who had once been partially sighted, was now completely blind. As a precautionary measure, Alex has since undergone several lumbar punctures as well as bone marrow testing to ensure that his cancer has not spread outside of his eye.

Results

Tuttle (1984) attempted to analyze blindness within the context of two overlapping theoretical constructs: the process of adjusting to social or physical trauma or both and the development of self-esteem. Although Tuttle's work emerged in the 1980s, it still forms an important framework from which to analyze adaptation to a visual impairment. Tuttle (1984) identified the seven stages whereby individuals adapt emotionally and adjust to visual impairment as: 1) trauma, physical or social; 2) shock and denial; 3) mourning and withdrawal; 4) succumbing and depression; 5) reassessment and reaffirmation; 6) coping and mobilization; and 7) self-acceptance and self-esteem. The adjustment process, as Tuttle pointed out, "is influenced by a number of factors, namely: age of onset, degree of vision, support of significant others, and the availability of professional services" (p. 55). Furthermore, he describes the model as "... a dynamic, fluid, continuous process without a fixed final "adjustment" at the end. A person may cycle back through some or all of the phases every time he encounters an unfamiliar situation or unresolved discrepancy" (Tuttle, 1984, p. 159). So, while the analysis of Alex's adjust-

ment was linear, in reality Alex and his parents moved back and forth through the phases of adjustment throughout the many changes in his health. Clearly, the transition that takes place between the stages, and the duration at each point, varies. In Alex's case, his transition between stages was more rapid than that of his parents, a phenomenon staff often observe when working with children.

CHANGES AND NATURAL ADAPTATION

In the 4½ years following Alex's RB diagnosis and ongoing treatment needs, it had been estimated by his family that Alex retained approximately 10 percent of his vision, none of which was central vision. In meeting with Alex, the authors and a team of professionals working with Alex marveled at how well he was able to function, despite his limited vision. In other words, although Alex's vision was quite limited as illustrated by visual acuities, his remaining vision was functional.

Prior to the loss of his vision, Alex coped well in a mainstream educational environment where he was supported weekly by a vision resource teacher. By age 4½, however, subtle changes in Alex's behavior were observed by school staff. These changes included increasing difficulties with mobility, such as bumping into things when previously he had not, and requests to hold the hand of a trusted teacher for guidance. Despite his recognition, at not quite 5 years of age, that his vision had deteriorated, Alex never complained. Alex would later speak of seeing "moving worms" and "spiders" in his eye, his experience of decreased vision due to vitreous seeding and further tumor growth. A few months later, Alex reported to his mother, "The

bad guys in my eye are back!” Shortly thereafter, new and concerning tumor activity was detected that had further compromised Alex’s vision, and that led to the enucleation of his eye.

Prior to his second enucleation, one of the staff ophthalmologists who had followed Alex since his diagnosis and had developed a close relationship with him, decided to tell Alex that he would soon lose his remaining eye, and thus, his vision. In attempting to break the news gently to Alex, this ophthalmologist “tip-toed” around the topic; however, Alex quickly remarked, “I know what you’re talking about!” Although angry and sad, both highly adaptive coping techniques in response to a traumatic event, Alex only asked, “Will I still be able to ride my bike? . . . Will I still be able to play the same as I do now?” To these questions, the ophthalmologist replied, “Yes, you can still do many of the things you do now, and some things you will learn to do a slightly different way.” Clearly, what Alex most wanted to know was whether he would still be able to be a “regular kid” and do the things that kids do, even when he could no longer see.

With his parents’ consent, Alex and his family were introduced to two other families, both of whom had a family member affected by RB who had lost both eyes in childhood. These connections have resulted in invaluable friendships that remain strong to this day. Alex’s mother shared the story with me that on meeting one of the adults with RB, Alex walked right up to this gentleman, poked him in the stomach, and stated matter-of-factly, “I hear you’re the guy who has no eyes!” To this day, this adult recalls this story with much laughter!

TOTAL VISION LOSS

In the few days leading up to his surgery, Alex confided in his father, expressing his fear that once he is no longer able to see, it would feel like being “in the dark” all the time. In the days just prior to his second enucleation, Alex stated that he thought it would be “okay” not being able to see, as he had many “pals” like his mother and father who will help him. He described his new adult friend with RB as “a man with no eyes but [who] can see.” Furthermore, Alex reported that although he would no longer have an eye, he will be still be able to “see” by listening to the sounds around him.

As anticipated, the days and weeks following Alex’s second enucleation were emotionally taxing and physically draining for Alex and his parents. Initially, Alex was depressed and withdrawn, crying because he could no longer see. He stated things such as, “I can’t see. . . . Why is this happening to me?” Alex also would ask, “Why did the doctor have to take my eye?” It was at this time that Alex’s mother realized that a more direct and age-appropriate approach was required to further explain the situation to her son. Whereas previously he had understood his illness in the context of “the bad guys in his eye,” now Alex’s mother began to use more concrete terms, for example, the word “cancer.” She, in particular, worried that “a part of Alex had died” since losing his only eye, as he had become “clingy” and dependent. This was a “frightening” prospect to her and Alex’s father, as Alex had previously been a fiercely independent child. Remarkably, only several weeks later, Alex (now age 5) commented, in response to the loss of his remaining eye, “I was in a race with the bad guys in my eye.”

For a while they were gaining on me but they tripped at the finish line.” Alex was expressing his feeling that despite his loss of vision, he had come out the winner.

The health care team began to see that Alex had much to teach us about the strength, perceptiveness, and adaptability of children. The authors also will admit to underestimating just how much Alex was able to understand about his illness and blindness. Furthermore, Alex could also identify that being blind did not feel the same as the sensation of being in the dark and seeing black, but rather, that the color appeared gray. In response to a question about what he would say if someone was asking what is it like to be blind, Alex stated: “Um, . . . it’s very dark. You can’t see anything . . . and . . . it doesn’t slow me down. . . .”

As expected, Alex experienced many ups and downs, the first year in particular, as a newly blind child coming to terms with his permanent loss of vision. Initially, Alex was quite resistant to exploring his environment using touch, as he had previously relied heavily on the vision that he did have. In addition, Alex’s play became rougher and more intense (for example, playing with swords), which provided an outlet for expression of his feelings of anger, frustration, and sadness about his loss of vision.

According to Alex’s parents, Alex, at age 6, speaks very casually about his blindness. Most important, Alex retains the same qualities that defined his personality as a bright, perceptive boy with a great sense of humor. Alex is first a child and second a blind child who has learned over time to “see” through his sense of touch, hearing, smell, and taste. When asked what he likes to do outside of school hours, he replied,

“Sometimes I sit down in my chair and watch TV. . . . I follow them because I know what they’re doing. . . . I can’t see the TV, but I do listen.”

FROM DARKNESS THERE IS LIGHT

Although Alex has a tendency to surprise most people he meets, as he often comes across as mature and perceptive beyond his years, it is the authors’ belief that this observation is only in small part due to his lived experiences. Before returning to school following his second enucleation, Alex made several short speeches to students in higher grades to explain his recently acquired blindness. Like many children who have a physical disability, Alex continues to cope well in a mainstream school setting. He excels in braille, and receives instruction from an itinerant teacher of students who are visually impaired. When Alex was asked what was now different about school for him, he remarked, “I can’t see none of the stuff,” and mentioned obtaining help from his peers: “I get help from the kids. Sometimes I can find my way around, too. . . . I just ask somebody or I just keep on going until I figure it out on my own.”

Alex reports that he now uses a white cane both on and off the school grounds and when climbing up or down stairs, but not in his classroom, as he is able to navigate there quite well without it. Initially, Alex sat in between two “classroom helpers” who provided assistance when needed.

ALEX’S PARENTS’ JOURNEY AND REFLECTIONS

It goes without saying that the 4½ years of uncertainty, anxiety, fear, and worry since Alex was diagnosed with BP have

taken an enormous emotional toll on both parents. Alex's mother, in an interview conducted approximately one year after the removal of Alex's remaining eye, reported being unable to eat, and experienced significant sleep disturbances before each of Alex's eye examinations that were conducted under a general anesthetic, fearful that she would be told that Alex had suffered another recurrence of his cancer requiring the removal of her son's remaining eye. An additional stress for Alex's parents was that both had different preferences for the course of treatment they wished to pursue for their son, a stress experienced by many parents who have children living with chronic health conditions and requiring ongoing and invasive medical treatments. Despite these differences, their mutual respect enabled them to bridge this gap and support each other in the difficult choices that they each had to make. A constant worry for both parents was the degree of psychological trauma that their son experienced as a result of his frequent and ongoing treatment requirements. Both expressed a strong desire to be able to endure their son's pain for him, rather than sitting back helplessly, unable to change the course of events. Both also grappled with their feelings about being the parent of a newly blind child and caring for him.

In light of the ongoing complications of RB, the parents began to realize that the outcome of Alex's fight to retain his eye that they had prayed for, was not to be. Alex's parents reported two great fears: first, fear of the unknown, that their son's cancer had spread throughout his body, compromising his life, and second, that Alex's blindness would "break his spirit." Alex's mother described this time as a par-

ticular low point for her family as a result of physical and emotional exhaustion. Alex's mother recalls that when she and her husband realized just how close the cancer had come to jeopardizing her son's overall health, they "couldn't wait for the eye to be removed, as waiting meant that the cancer could be spreading."

Despite Alex's medical outcome, his mother reports that she knows she would not have "done anything different." Ultimately, she wanted Alex to retain his remaining vision as long as possible, to give him an opportunity to understand the meaning of visual concepts. Following Alex's enucleation, the parents reported feeling that finally Alex "didn't belong at [the hospital] anymore, as he was just blind, and no longer sick." In retrospect, she notes that neither she nor her husband truly understood just what battles they and Alex would have ahead of them in coming to terms with their son's blindness, nor could they fully prepare.

Years after Alex's surgeries, they report that they still grieve Alex's loss of vision, a process they emphasize is ongoing, but they believe that their son now has a much better quality of life. Furthermore, Alex's mother reports that both she and her husband take much comfort in the fact that as Alex once had vision, he has the advantage of being able to "picture items in his mind." Both now marvel at how well Alex is able to function quite independently. More than anything, both want other parents to know that "blindness is not such a barrier" nor is it "the end of the world." In other words, "through darkness there can indeed be light."

When the authors asked Alex's mother what she feels has aided her family in their emotional adjustment to their son's blind-

ness, she reports that it was the emotional support they received through other families who had coped with RB, the RB team at the children's hospital, and a support group for parents of blind and significantly visually impaired children that were most valuable. More than anything, she expressed that a family needs ongoing emotional support. When Alex's father was asked what he would like other fathers and family members to learn about his family's experience, he stated, "Life does go on" and "Life can be normal" even when a child is blind. It is his strong belief that Alex now has a much better quality of life as a blind child than as a partially sighted child who required ongoing and invasive medical treatment with the ongoing threat that his cancer could have spread.

Implications for professionals

Alex's personal journey raises questions about how professionals define quality of life. Although the authors are confident that the medical decisions were made in the best medical interest of this child, there is an unintentional yet implicit message that to be blind is a fate to be avoided at all costs, except the cost of life itself. Several authors (Eiser, 1997; Eiser, Havermans, Craft, & Kernahan, 1995) have begun to study children's quality of life after prolonged medical treatment, and recognize that "... statistics based on survival may not accurately reflect the degree to which quality of life is compromised in the longer term, given the incidence of both physical and psychological difficulties reported by some survivors" (Eiser, 1997, p. 350). The balance between therapeutic benefit of a treatment and the potential psychological trauma and compromises to quality of life caused by that treatment is a delicate one that must be continually reevaluated.

Several months prior to Alex's second enucleation, the authors were informed by an RB team member that Alex had entered the operating room on one occasion wearing a toy plastic protective shield and mask, and holding a sword, items he refused to let go of until he was anesthetized. Clearly, in addition to making efforts to try to protect himself from physical harm, Alex was also attempting to assert his autonomy. His toys were symbols that "you can't have full control over me!" Two years after his surgery, Alex continues to exhibit signs of psychological trauma, manifested in expressed feelings of anxiety, fear, and complaints of nausea when entering the hospital, a common experience of children requiring ongoing and invasive medical treatments, incidences that have long-term quality of life implications. The experiences of children like Alex teach us to not underestimate the need for, and importance of, preparing the child and his or her family to the extent that is possible, to help facilitate the adjustment process. Furthermore, medical teams need to consider with each other, the parent, and the child, if he or she is old enough, how to best manage treatment options in the context of a long-term quality of life.

With respect to treatment decision-making and potential outcomes, in Alex's case the first goal of treatment was to save his life by curing his cancer. The second goal was to maintain, if possible, his eye. The third goal was to optimize any remaining vision. It was only when Alex's overall health and potential life was felt to be in jeopardy that the decision to enucleate his remaining eye was proposed. If, for example, the limited vision that Alex did have had not served a functional purpose for him, the decision to enucleate the re-

maining eye would have come at a much earlier date. In Alex's case, both parents were actively involved in the decision-making process. It is important to recognize that both health care professionals and family members are deeply moved by the experiences of children like Alex. In speaking with one of Alex's ophthalmologists recently, it was apparent that lingering feelings of sadness remain, not simply because Alex can no longer see, but as a result of the trauma he experienced.

Finally, inherent in Alex's journey are parenting issues and considerations. Prior to Alex's return home after his second enucleation, Alex's father reported feeling extremely helpless as a father, not knowing how to best help his son. Initially, he contemplated moving all of their household furniture against the walls so that Alex would not bump into things and hurt himself. Reflecting back, he now chuckles at this thought when observing a very independent Alex wander throughout the house without difficulty. He emphasizes that he does not feel that his role as father has changed, though he acknowledges having difficulty seeing his son struggle.

Alex's mother, responding to whether she feels her overall parenting style has changed since Alex's blindness, reported that although she feels that she is now more protective of her son, she feels strongly she would have been a protective parent in any case, so her style of parenting has remained essentially the same. She acknowledges having a tendency to "get her back up" more quickly if, for example, she sees others staring at her son, which makes her quite angry. She has also learned to talk more to Alex to provide more detailed descriptions to compensate for his lack of vision. Both Alex's need for this dialogue,

and his parents' incorporation of this dialogue into their daily lives has been a significant adjustment for the family. Alex's mother believes this is an adjustment that many other families have also had to make.

Conclusion

Alex's journey, while remarkable, raises important issues for health care providers' everyday practice. First, as professionals we must respect and support each child and family in their journey, no matter what route is taken and what outcome is reached. Second, we must recognize that children are children first, and are far more than just their eyes. Even without sight, children have remarkable perception. Third, we must not underestimate the awareness, understanding, and adaptability of children, no matter what obstacles and challenges they may encounter. Fourth, we must be prepared and willing to challenge dominant notions of normality so that implications for a child's quality of life are fully explored in the context of the community in which people live happily and successfully with vision loss every day. Last, we would like to call on other professionals who work with blind or visually impaired children to document these "lived" experiences so that others can benefit from this valuable information.

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Alissa A. Ulster, M.S.W., R.S.W., social worker, Ocular Genetics Programme, Department of Ophthalmology and Vision Services, Hospital for Sick Children, 555 University Avenue, Toronto, Ontario, M5G 1X8 Canada; e-mail: <alissa.ulster@sickkids.ca>. Beverly J. Antle, Ph.D., R.S.W., academic and clinical specialist, Social Work, Hospital for Sick Children, and adjunct associate professor, University of Toronto; e-mail: <beverley.antle@sickkids.ca>.

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