

## **LIFE: QUALITY VERSUS SANCTITY**

**Jodi Picoult, *My Sister's Keeper*, Washington Square Press, Washington, 2005, 448 pages**

*Reviewed by Anita Wambui.*

*“And if your parents have you for a reason, then that reason better exist. Because once it's gone, so are you”.*<sup>1</sup> These are the haunting words of thirteen-year-old Anna Fitzgerald in Picoult's novel, *My Sister's Keeper*. Set in Rhode Island, the novel follows the emotional roller-coaster that is the life of the Fitzgerald's family, weaving up the most heart-wrenching story while contemporaneously grappling with legal and ethical issues that come about.

Picoult's book features the middle-class family, of Brian and Sara Fitzgerald, dealing with three children who differ in every aspect. Jesse, the oldest, is their rebellious teenage son whose disillusionment stems from the fact that his parents have ignored him for the last thirteen years. Kate Fitzgerald is the second child, who suffers acute promyelocytic leukaemia (APL), is often at the centre of her parents' attention – at least when she does not have to share it with her younger sister Anna. Anna is at the centre of the family crisis, and though the youngest, she takes us on the most exhilarating and heart-breaking journey.

The story of how Anna came to be started with the misfortune that befell Kate (APL). Kate was first diagnosed with APL when she was two and she needed a transplant. Her case was peculiar and a transplant from a non-related donor would increase her risk of mortality. Neither her parents nor Jesse were an identical match to Kate thus Kate's parents decided to conceive another child who would be genetically programmed to be an organ donor for Kate. When Anna was born, her umbilical cord blood was used for the transplant. After that, Anna donated to Kate lymphocytes, bone marrow, granulocytes, and peripheral blood stem cells. Now, Kate's kidneys are failing and as usual, her parents turn to Anna. Fed up, Anna decides she wants to get medically emancipated from her parents and seeks out a lawyer, Campbell Alexander, who is all too eager to take the case because it's a sure win – donation cannot be compelled – but as the intricacies of the case are revealed to him, and the complex family dynamics come to life, Campbell's purported straight and narrow road to victory splits into various little paths, all seemingly right but all shrouded with uncertainty.

Jodi Picoult undoubtedly spins one of the most heart wrenching stories ever with enough medical jargon to scare anyone into grasping the critical nature of the situation. If this was her strength, then her weakness was her analysis of the legal issues, which was superficial at best. The story is woven across three main themes: love, best interests of a child and dignity.

*“We loved you even more ... because we knew what exactly we were getting.”*<sup>2</sup> These were Sara's Fitzgerald's words of consolation to her daughter, Anna, every time she asked how babies came to be – how she came to be. Whether these words hold water when “what exactly we are getting” is an organ bank for another child is doubtful. True love involves putting another's needs before one's own, seeking their advancement, and expecting nothing in return. Throughout the novel, the ferocious intensity with which Sara fights for Kate is undoubted. She loves her and she is willing to go above and beyond for her – even to the extent of designing for her a ‘saviour sibling’. However, this love and the desire to keep her daughter alive, clouds her judgement when it came to her other children. Anna was in and out of the hospital just as much as Kate, but all the fuss was on Kate's recovery. Jesse who had no physical role to play in Kate's recovery was ignored all together.

In all actions concerning children, loving them is inextricably linked with considering what is in their best interests. While Anna's best interests would bring about a conflict of interest between the quality

of one daughter's life versus the sanctity another daughter's life, the only time this came up as a dilemma to Sara was in court, during the emancipation suit. The obvious plan of action for her was always to prolong Kate's life, the quality of Anna's life notwithstanding. She had known that Kate was going to die eventually, but with every procedure that worked thanks to Anna's tissues and organs, she got greedier to have her daughter live longer. What she failed to realise was that for every procedure that prolonged Kate's life, the quality of Anna's life diminished. Anna was the ship genetically condemned to sink with her sister's every storm.

Anna, despite her macabre purpose, was still a child, and still craved to enjoy her life like other children did. Her demands were few and reasonable – a hockey game here and a chance to go 3

camping there. She had long accepted that she would never, at any one point, be in school long enough to make any friends beyond her sister Kate, but she still did want a life of her own. Anna was eventually kicked out of the team because of missing many a training session. This was very telling about the scales of love that Sara used, that were permanently tilted to one side.

Dignity – a word that does not even come up once in the entire novel yet is so fundamental in making a judgement in this case. Dignity denotes a right of a person to be respected, valued, and treated ethically because they are human. Dignity is an unqualified right that every person is endowed with from birth and it persists till death – some say even beyond death. It therefore did not matter that Anna was conceived through genetic programming and it certainly did not matter who her parent's intended for her to serve a subservient purpose. Her dignity remained, and with dignity comes free will.

Free will denotes the ability to make free choices uninhibited. The fact that they labelled this organ donation as 'a gift' often only serves to manipulate sibling donors into donating out of guilt and compulsion. However, informed consent should always be a standard procedure before sibling donor's organs are harvested. Anna's parents exemplified how parent's entitlement to the organs of the saviour sibling only serves to demean and devalue the saviour sibling's life. Anna was young, but she understood what she was put through for her sister's sake. At thirteen, when her sister needed a kidney, her parents did not deem it necessary to ask her. After all, what sister with two working kidneys would be inhuman enough to deny her sibling one? Anna was therefore suing for the rights to her own body. She wanted out of this compelled donation, which was often masked as altruism, but was much closer to objectification.

The concept of designer babies is becoming increasingly common in the advent of technology and medicine. The use of preimplantation genetic diagnosis to select embryos is neither inherently unethical nor is it illegal, but how individual parents choose to use this technology may be. Picoult demonstrated how parents, even with seemingly good intentions, can abuse the process of preimplantation diagnosis. The fact that Anna's sole intended purpose was to serve as a donor to Kate devalued her life, violated her dignity, and robbed her of a normal childhood.

In the end, Anna was granted a medical emancipation from her parents. However, on her way from the courthouse to the hospital to meet Kate, she was involved in a road accident that rendered her brain dead. With no chance at life, her kidney was taken and given to her sister, whose health 4

drastically improved afterwards. What were her words again? “*And if your parents have you for a reason, then that reason better exist. Because once it's gone, so are you*”.<sup>3</sup> Maybe it didn't matter which came first because once Anna was gone, so was intended her reason for life – to save Kate. Anna's short life had been filled with unhappiness. She often felt undervalued, unseen, and alone, though surrounded by family. But the family unit should never be anything short of a safe haven to children – all of them in equal measure.

And when reproductive technologies are used to the constant detriment of one child in favour of another, surely the 'saviour' child's views need to be taken into consideration. Writing about donations from incompetent persons, Cheyette cautions readers to avoid organ harvests from children and the mentally disabled because using them to cushion our pain from the suffering of a loved one is very unfair to them.<sup>4</sup> Such donations cannot and should not be considered altruistic. When they are sought, however, children should be asked how they feel about it. Should any legal action on competing interests be instituted, guardians ad litem should be appointed. And since the interests of saviour children are often overlooked, an independent physician for the donor child should also be sought, to ensure that their best interests are considered with every procedure.