

Case study

Rachel's journey: an adolescent's need for patient and family centred care in an adult hospital environment

Abstract

Adolescence is a difficult time for the young person as they adjust to the many physical, sexual, emotional and social changes in their lives. They have unique healthcare needs and, as a result, hospitalisation can be an emotive experience for the adolescent, and challenging for the healthcare providers. Patient and Family Centred Care (PFCC) is a partnership between healthcare providers and the patient and their family. This partnership's core concepts include dignity, respect, information sharing, participation and collaboration. PFCC recognises and values the roles the patient and family have in working together with the healthcare team to achieve better health outcomes, as well as subsequent increased staff satisfaction. This paper discusses the experience of a 14-year-old female admitted to an eight-bed adult intensive care unit (ICU) following surgery at a metropolitan private hospital. It explores the concept of PFCC and how its implementation would have led to better patient and family satisfaction.

Keywords adolescent, hospitalisation, scoliosis, family, surgery

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Introduction

Adolescence is the challenging transition between childhood and adulthood. It is a time when the young person may feel vulnerable, emotional and marginalised.¹ Hospitalisation presents many difficulties for this cohort due to separation from their peers and families, restrictive routines and the perceived lack of control and independence. Admission to hospital exerts an immense amount of psychological stress due to the myriad of unwanted changes and disruption to routines.²

Background

Rachel (a pseudonym) was a 14-year-old girl with a history of adolescent idiopathic scoliosis (AIS) admitted for an anterior spinal fusion, with the second stage thoracolumbar fusion 1 week later. She was fit and well with no other significant medical history. Rachel had nil known allergies and was on no regular medications.

AIS is a structural lateral curvature of the spine of greater than 10° accompanied by vertebral rotation. AIS develops in healthy adolescents around the time of puberty and affects 1–3% of children between 10–16 years of age. It is more

common in females and, although it may pose no immediate health concerns in mild or moderate forms, it is associated with cosmetic concerns. There is no clearly defined aetiology for scoliosis, but it is believed to be familial (Figure 1).³

Treatment of AIS is dependent on the severity of the curvature with the goals of preventing progression of the curvature and preserving respiratory and neurological functioning. Options include exercise programs, bracing or surgery. Surgery involves fusing the bent part of the spine in order to straighten it and prevent further abnormal growth. A bone graft, or substitute, is placed in the affected inter-vertebral spaces and secured with rods or screws, providing an internal support while the bones fuse and the graft heals. An anterior approach involves accessing the spinal column from the front of the spine and is used for thoracolumbar curvatures. Due to the length of the surgery this treatment is commonly undertaken in two stages, 7 days apart (Figure 2).⁴

During appointments with her surgeon, Rachel and her mother had been provided with the details of the proposed surgical procedure along with postoperative recovery expectations. It was explained to them both that Rachel would be required to spend at least two nights in the intensive care unit (ICU) following her surgery. Rachel also supplemented this information by researching the internet for other adolescents' experiences following this surgery. When the time for her admission to hospital arrived, Rachel was confident that she was fully prepared for her experience. However, it was interesting to note that at no time was there contact made with the ICU to discuss the anticipated experience nor the facilities that would be available for Rachel and her mother during her admission to the unit.

Narelle Luczynski

RN, BN, Prof Hon (Paediatric Nursing), MCN (Paediatric Nursing)
Clinical Nurse Educator, Mater Hospital
North Sydney, NSW
Email narelle.luczynski@svha.org.au

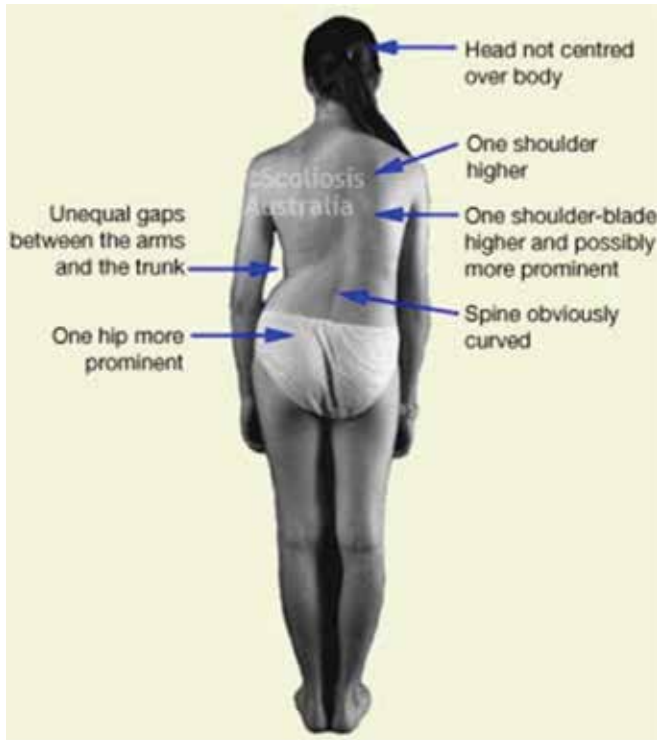


Figure 1. Presentation of AIS³

Rachel was admitted the night before her surgery directly to the ICU. As this is primarily an adult unit there were no provisions for Rachel's mother to stay overnight. Due to current renovations, private cubicles were not available and a curtain for privacy separated the bed spaces. There was only one bathroom for the eight-bed unit and this was situated at the end of the unit. Observing this environment for the first time, Rachel became quite anxious and overwhelmed and this set the tone for the duration of her admission.

Recommended by her surgeon as the standard procedure for her degree of AIS⁵, Rachel underwent the first stage T12–L3 anterior scoliosis correction, including thoracotomy and cages L1–2 and L2–3. This was performed under general anaesthetic along with an intercostal nerve block via a left thoracic abdominal approach. As per her surgeon's protocol⁶, Rachel returned to the ICU following her surgery with intravenous therapy, an indwelling urinary catheter, along with a left intercostal chest drain on low suction. A patient controlled analgesia (PCA) of oxycodone 1mg boluses with a background infusion of 1mg an hour, in conjunction with a paravertebral naropin 0.2% infusion at 6ml an hour, ensured Rachel's pain was manageable on return to the ward. All wound dressings were intact with minimal ooze and her vital signs were within the recommended parameters.

Although the procedure was more than 5 hours' duration, there were no surgical complications. However, during the procedure Rachel developed a short-lived episode of facial and generalised muscle spasm or seizure associated with a rise in blood pressure and heart rate. A neurologist was consulted and subsequent electroencephalogram and magnetic resonance imaging (MRI) of her brain were normal.

During the initial 48 hours following her surgery, Rachel became pyrexial with decreased oxygen saturations. She required extensive chest physiotherapy and high flow oxygen;



Figure 2. Surgical treatment of AIS⁴

however, she was reluctant to use it saying she "hated it... hated everything". By day 3 Rachel had developed a left pleural effusion, primarily due to a blockage of her chest drain, with associated upper respiratory tract infection. Her chest drain was replaced and she continued on intravenous antibiotics.

During this postoperative stage Rachel became more visibly distressed each day. Her mother remained with her as much as possible. However, with only a chair available, along with limited space for visitors, time spent with Rachel was only intermittent throughout the day. As the use of mobile phones was not permitted at this stage, Rachel felt lonely and isolated from her friends and extended family. She did not engage with staff and the messages her mother brought from home appeared to exacerbate Rachel's feelings of isolation. At this stage Rachel felt she had little or no control over the situation she had been placed in. Staff described her behaviour as "unco-operative" and "belligerent". Extensive reassurance was provided to both Rachel and her parents and, ultimately, the staff gained her cooperation. Over the coming days, Rachel made constant progress. Her catheters and PCA were removed and she was allowed to sit up in bed. By day 5 Rachel was able to mobilise short distances with the use of a forearm support frame, along with assistance from the physiotherapist, and she was able to have her first shower.

Following further assessment by the intensivist and neurologist the decision was made to proceed with the second stage of Rachel's surgery – stage two thoracolumbar fusion T5–L1 posterior spinal fusion. Rachel tolerated this second procedure better and progressed well with no complications. She was compliant with all procedures and tolerated her chest physiotherapy well. Rachel mobilised on day 3 following this second procedure and was transferred to the orthopaedic ward the following day. As per her surgeon's usual protocol, she was discharged home 3 days later.

Discussion

Florence Nightingale first acknowledged the value of the hospital environment suggesting it be therapeutic to enable healing and recovery, with Dodds⁷ describing the adult ward as “frightening” for adolescents. Therefore, what were the implications for Rachel in the ICU? The hospital unit influences the behaviour of any patient; however, when an adolescent is admitted to an adult surgical environment, not only adult patients but also adult staff surround them. Would Rachel be able to relate to the staff or would she view them as authoritative figures who would not be able to joke with her or treat her as an equal? Would the staff understand and respect Rachel’s needs?

Frequently the needs of the unit or the healthcare team supersede the needs of the patient and there is an expectation that the adolescent will conform and abide by adult norms and policies.⁸ The routines and restrictions may be especially distressing for the adolescent at a time when they are attempting to assert their own independence. From her admission, Rachel struggled with her hospitalisation. She needed to adapt to the healthcare team’s routines but was not only isolated from her peers but also did not have access to her social network. At this time mobile phones were not permitted in the adult ICU and there was inconsistent WIFI access due to the renovations in progress. All of these, along with the unfamiliar sounds in the ICU, had the ability to cause a detrimental effect to Rachel’s recovery and overall wellbeing.²

Due to her pleural effusion, Rachel was required to remain in the ICU 2 days longer than expected, although this did not extend her overall length of stay in hospital. Once Rachel was transferred to the orthopaedic unit, she progressed quickly to meet the expected goals of her recovery. It was here Rachel had access to her social network, whilst friends and family were able to visit throughout the day. She also had her own room along with private ensuite. The staff on the unit interacted with Rachel, engaging her with conversations regarding the movies she was watching on her laptop or the music she had been listening to. Rachel described the staff on this unit to her mother as “really fun!”.

So how much did this different environment contribute to Rachel’s recovery and overall wellbeing? Rullander et al.⁹ describe how an adolescent’s hospital experience may be classified into three main areas – emotional, physical and social.

Emotional: Their qualitative study suggests that pre-operative anxiety places the adolescent at risk of post-traumatic stress disorder following the experience, with the potential of impeding their social development and physical health. Rachel was not provided with the opportunity for a pre-admission visit to the ICU. This pre-operative preparation would have allowed staff to ascertain Rachel’s current coping mechanisms in stressful situations in order to develop appropriate interventions for her stay in the ICU. Her knowledge and awareness would also have been able to be addressed at this stage. Pre-operative education would prepare Rachel for the physical sensations following the surgery, including pain, listlessness and fatigue. She would have been provided with the opportunity to meet with other members of the multidisciplinary team who would

assist in her recovery. As adolescents may still require parental support⁹, facilities for Rachel’s parents to stay would have been beneficial and might have decreased her anxiety.

Physical: Although pain and immediate mobility restrictions are important issues, the adolescent is also concerned about physical scarring following the surgery and the long-term implications for social and sporting activities.⁹ Would Rachel’s peers notice her scar when she changed her clothes at sport time? Would she be self-conscious in summer clothes or at the beach in her swimmers? An accomplished netball player, would Rachel need to find a new sporting activity and consequently not only be a beginner again but also risk losing contact with her current team mates? These are all valid concerns for the adolescent that should be addressed.

Social: In a study by Hutton¹⁰, adolescents described the lack of privacy, isolation and the loss of perceived status amongst her peers as possibly the worst aspects of hospitalisation. In Rachel’s case, the enforced visiting hours of the adult ICU and the inability to use her mobile phone restricted Rachel’s peer support. Additionally, Rachel was apprehensive having her friends visit as she felt exposed with all her lines and catheters. Her concern for her peers also meant she did not wish to expose them to the confronting sights of the ICU.

In an adult ICU, the implications for adolescents of bathrooms being at the end of the ward should not be undervalued. Hutton¹⁰ describes the embarrassment adolescents felt when having to walk past other patients or staff to use the bathroom. At a time when she is embarrassed by her changing body image, Rachel was fearful about being scrutinised in her nightwear, advertising her need to use the bathroom and losing control over her privacy.

Along with privacy, Rachel required time for solitude; to be alone with her thoughts and feelings. As a result, Rachel became more withdrawn. Unfortunately, many healthcare workers do not recognise this need, not its subsequent benefits, and continue to enforce hospital routines.¹⁰ It is at this time that the needs of the adolescent and healthcare providers are in conflict. The adolescent needs to have their own privacy and independence whilst in an adult ICU, yet the nursing staff need to ensure the patient is safe and medically cared for. Staff should negotiate with patients such as Rachel to create an opportunity for her to have this privacy, allowing her to exert some control over her care during her stay in the ICU.

Rachel’s close proximity to the nurses’ station presented further privacy issues. She was acutely aware that the nursing staff could hear her conversations. More distressingly, Rachel could also hear the healthcare team discussing her progress, including personal information such as elimination.

Without these basic needs of solitude and privacy, which are vital for all hospitalised adolescents⁷, Rachel did not feel in control throughout her admission to the ICU, leading her to feel hopeless and emotionally distressed. She was exposed to an environment of multiple physical attachments and immobility along with sensory overload and sleep deprivation. The indifferent attitudes of the healthcare team, along with the use of medical jargon, left her feeling dehumanised or invisible. Rachel needed support and comfort.

Nurses need to be aware of the social and emotional consequences hospitalisation brings for the young person. Hospital routines render the adolescent powerless and, for Rachel, being confined to bed she “felt trapped, like being in prison”. Regular treatments, such as changing her dressing may be perceived as intrusive and a further invasion of her privacy and personal space.¹¹

Patient and Family Centred Care (PFCC)

In order for us to meet the needs of future patients like Rachel, we should ensure the implementation and practice of Patient and Family Centred Care (PFCC). Involving primary carers and extended family, PFCC is a holistic model of care that enhances clinical outcomes and patient satisfaction by reducing stress, anxiety and the associated effects of hospitalisation (Figure 3). PFCC recognises the family as the expert in the care of their child. By exploration of the patient’s experience, beliefs, difficulties and their goals, it promotes dignity within the hospital experience.¹² It is especially important during adolescence when lifelong attitudes to healthcare are formed and should therefore be implemented in a way that meets the unique needs of the adolescent.¹³

A qualitative study by Coyne et al.¹² showed that although nurses may have the knowledge of PFCC, they lack the communication skills required to effectively practise it with patients and families. Meert et al.¹⁴ describe how PFCC can be implemented in daily practice with effective communication. Identified as a critical component of PFCC, information exchange and communication have been associated with higher quality care by patients and their families.¹⁵ Rachel spoke of how she would have felt more comfortable and safe if the nurses were less formal, spoke in colloquialisms, shared their stories or even provided non-verbal communication such as touch. She also felt that the interactions with staff were always rushed, with little time to ask questions.

Rachel and her family frequently expressed concerns that although the staff kept them informed about Rachel’s

treatment plan they did not explain the reasoning behind the interventions nor actively involve them in the decision-making. Time was not taken to ensure they understood the plan of care. In their qualitative study, Coyne and Gallagher¹⁶ describe the adolescent’s need to be included in decisions about their daily care. Many of those in the study did not feel listened to as the staff spoke with their parents and did not identify the right of the adolescent to participate in any decision-making. Interestingly, the adolescents believed that they had no other options except to comply with the routine and treatments rather than risk causing trouble by being non-compliant. They also felt the extent they were able to communicate depended wholly on the attitude and behaviour of the staff.

Unfortunately, this is exactly the scenario Rachel initially found herself in and she was labelled non-compliant by the staff assigned to her care. If staff had included Rachel in communication and the decision-making process, not only would there have been enhanced provision of information between patient and the healthcare team, it would have led to Rachel feeling valued and having a degree of control. Healthcare professionals, and sometimes even parents, underestimate the adolescent’s need and ability to participate in decisions regarding their own care.

Implications for practice

The goal of PFCC is to engage in a partnership with the patients and their family. Adolescent patients need to feel valued, included and recognised as person, not the ‘patient over there in bed 6’ or the ‘scoliosis patient’. To provide effective PFCC nurses require appropriate resources, education and ongoing support from management and the multidisciplinary team.¹² Implementation may require re-organisation of current practice to maximise the benefits, and management should understand that caring for families and adolescents impacts on nursing workload.

Implementing PFCC requires input from the patient, their family and staff. The situation needs to be seen from the patient’s and family’s perspective. They need to be allowed to participate in their adolescent’s care as much or as little as they wish.¹⁴ Parents need to be viewed as an integral member of the healthcare team and vital to their adolescent’s recovery.¹⁴ They encounter constant barriers whether it is from staff dismissing their concerns for their adolescent or simply the lack of facilities available for their personal needs. Barriers such as these undermine the parents’ role within the team and suggest that hospital routines may be more important than the adolescent.¹⁷ Parents should be recognised as vital to their adolescent’s recovery.

Baird et al.¹⁷ explored the effects the restrictions of ICUs have on PFCC in their study. Families described how they were expected to realise how busy the staff were and understand care priorities; they too needed to know the ICU routine and be compliant. They felt their behaviour was often being labelled or judged by the staff; however, there was no allowance made for the stress of the hospitalisation nor the unfamiliar ICU. Unfortunately, they felt powerless and isolated; that the staff knew their child better than they did.

A practical step in promoting PFCC for the ICU would be consideration of open visitation for Rachel’s parents and



Figure 3. PFCC as a holistic model of care

siblings. At the time of her admission, visitor restrictions for the ICU were in place. This meant that only one visitor at a time was permitted for each patient and only during certain hours of the day. Although allowances had been made for Rachel's mother to have unlimited visiting, Rachel's father and siblings were required to adhere to the restrictions. Whilst there may be concerns with space restrictions or the emotional distress the ICU may cause to the parents or siblings, current research suggests that the family values close proximity to their young person.¹¹

As there were no kitchen or lounge facilities available for visitors, providing areas for Rachel's family to rest or make a cup of tea without needing to leave the ICU would allow the family to be together and support each other. Rachel's family valued and appreciated the psychological support provided by the pastoral care team during her stay in the ICU. However, they were not aware that there was also an on-call pastoral care team available out of hours, a time when Rachel felt the greatest need for emotional support (Figure 4).

Effective PFCC in the ICU requires a collaborative approach amongst all members of the healthcare team whilst also recognising the skills and specialty of the unit. The core concepts of PFCC remain dignity and respect, information sharing, participation and collaboration. It is a partnership and negotiation of care, with many of the difficulties in implementing PFCC arising from communication.¹⁸ It has been effectively implemented in adult ICUs with enhanced patient outcomes and should therefore be implemented for all adolescents in our care. Family is the constant in an adolescent's world and effective PFCC reflects our facility's commitment to providing the best possible care for our young people.

Conclusion

PFCC has been shown to improve safety in healthcare. Along with improved patient flow due to decreased length of stay and effective discharge planning, PFCC promotes better health outcomes and patient satisfaction. It allows for better understanding of the patient and overall improved communication among the healthcare team which ultimately leads to improved staff satisfaction. PFCC requires a multidisciplinary approach, involving co-coordinating communication and education amongst all health professionals. Health professionals must be aware of the psychological and



Figure 4. The importance of emotional support

emotional needs of their adolescent patients. They must go beyond the medical aspect of treating adolescents to improve the implications of hospital distress.

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Conflict of interest

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