

From Recreation to Creative Expression: The Essential Features of an Adolescent Inpatient Psychosocial Support Programme

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Abstract

Introduction: Adolescent Inpatient Units are now an established component of leading tertiary children's hospitals in the developed world. While different methods have been used to provide psychosocial support in these settings, there is little recent literature about these programmes. We aimed to identify programme goals and to explore the features that are thought to underpin an effective programme. **Material and Methods:** A qualitative paradigm was used to identify the essential features of the psychosocial support programme within the adolescent inpatient unit, Royal Children's Hospital, by drawing on the practice wisdom of experts involved in the development of the psychosocial support programme since its inception over a decade ago. In-depth interviews were conducted that were analysed thematically following recording and transcription. **Results:** Seven out of nine identified professionals were interviewed. These staff identified that while the psychosocial support programme had focussed on different activities since its inception, the goals of the program had been consistent over time. The essential underpinning features were reported to be support for the programme and communication between multidisciplinary health professionals. When this was effective, the overarching role of the programme was reported to be the promotion of identity formation in adolescents. **Conclusions:** This small-scale qualitative investigation reveals that identity formation has consistently been the focus of the psychosocial support programme in our adolescent unit, despite the different ways the programme has been run over time. Findings about the importance of support and communication are essential knowledge for those considering the implementation of similar programmes.

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"I took the kids indoor rock climbing and for some of those cystic fibrosis patients, it was the best physio they had ever done. They loved it because it was a physical challenge and a mental challenge. It was great to see them rolling around on the ground, laughing and exhausted at the end of it. It gave them faith in themselves to complete something, to do something and to enjoy life again." (Extract from an interview describing participation in the psychosocial support programme)

Introduction

In 1984, the Royal Children's Hospital (RCH) in Melbourne, Australia opened a new ward specifically for adolescent inpatients. This initiative was the result of many years of observation, patient survey, discussion and debate about the possibility of allowing teenagers to stay in a children's hospital. Once this concept was accepted for patients with cystic fibrosis and diabetes, the door was opened for the development of a formal Adolescent

Medicine service which initially supervised the inpatient adolescent unit.¹ Growing recognition of the importance of the health care needs of young people prompted reconsideration of how the RCH might better respond to these issues. In 1991, this led to the establishment of the Centre for Adolescent Health which focuses on research, education and training, as well as the clinical care of young people.

The Adolescent Unit at the RCH is a 22-bedded ward that admits a diverse range of patients. The Adolescent Unit is serviced by medical and allied health staff and is managed by the adolescent nursing team. From its conception, the unit has tried to address much more than the medical needs of these patients: it aims to attend to the developmental, educational and social needs of young people, tacitly acknowledging the inadequacies of a hospital service that was originally designed to support babies, infants and children. In addition to standard hospital services, education professionals from the RCH Education Institute liaise

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around educational concerns and the Centre for Adolescent Health employs a full-time coordinator of a psychosocial support programme. The psychosocial support programme is implemented through the provision of daily groups, individual work and participation in various events outside the hospital.

Over the years, the focus of the programme has been operationalised through focusing on different programme elements, ranging from sports to recreation to creative expression. At any time, the balance of activities has changed according to the interests and skills of the programme coordinator. The coordinator receives informal referrals from the medical, nursing and mental health teams and approaches young people on the ward to participate in group activities in the recreation room or provide individual bedside work as appropriate. Adolescents from other wards are welcome to attend the group programme and may receive individual bedside work if requested. However, workload limitations prevent staff from taking a more proactive role outside the Adolescent Unit.

Despite the existence of adolescent inpatient units internationally, there is no recent literature describing how psychosocial support is provided in these settings. Early descriptive reports include adolescent inpatient recreation therapy in oncology treatment,² eating disorder treatment³ and general medical patients.⁴ Fisher⁴ describes a particular recreational therapy method – self charting – and describes its implementation to enhance communication between the patient and the team. However, no explanation of the broader programme is offered. Bost and Brown² discuss the humanistic model adopted in their recreation programme, but make no attempt to measure outcomes. In comparison, Collins et al³ measure the achievement of four programme goals for inpatients with anorexia nervosa, including a goal that addresses socialisation and others that focus on eating and participation in psychotherapy. They boast a 100% success rate in goal attainment in most young people, and suggest that it is the social system of the unit, including other patients and the recreation therapist, that are responsible for their success. However, generally, these reports do not provide a basis for conceptual thinking about the potential benefits of youth participation in psychosocial support programmes, which has limited the

development of more formal evaluation of these programmes.

A more contemporary report was authored by Viner and Keane⁵ who detailed a ‘best-practice’ model for the care of young people in hospital. They emphasised a ‘normalising’ model with a physical ward space that includes a recreation room, school room, quiet room, kitchen and laundry facilities, interview rooms and meeting room for multidisciplinary team meetings. This report accurately describes the RCH environment (which is not surprising given that the primary author was based at the Centre for Adolescent Health while writing this report). The report makes reference to the value of psychosocial support programmes, suggesting that these programmes should address educational, vocational, self-esteem and independence issues, as well as providing for leisure activities. Although the report claims an evidence-based orientation, it is apparent that there is insufficient evidence to guide a systematic assessment of the expected outcomes of these various psychosocial support programmes.

We therefore decided to rigorously investigate the underlying premises of the psychosocial support programme at the adolescent unit at the RCH, from the time of its establishment to the present day. A qualitative paradigm was selected to identify the essential features of the programme, with the hope that this might form the basis of future research using a hypothesis-testing orientation. This initial investigation draws on the practice wisdom of experts involved in the development of the psychosocial support programme since its inception over a decade ago. It identifies programme goals, and explores what features are thought to underpin an effective programme.

Materials and Methods

In-depth interviews were conducted with multidisciplinary youth professionals identified as ‘key-players’ in the development of the psychosocial programme on the Adolescent Inpatient Unit at the RCH since its inception. Seven of the nine identified participants were available for interview, providing a range of perspectives from different professional vantage points over the time-span of the programme’s existence. Participant details are described in Table I.

TABLE I: STUDY PARTICIPANTS

Name	Relevant professional information	Discipline	Participation
Dr John Court	Founding Director, Department of Adolescent Medicine, RCH	Adolescent Medicine	1984 – 1991
Ms Leanne Shea	Adolescent Unit Manager	Nursing	1991 – present
Professor Glenn Bowes	Founding Director, Centre for Adolescent Health	Adolescent Medicine	1991 – 1996
Ms Jane Jensen	Teacher	Education	1990 – 1998
Ms Gabrielle Tange	Recreation Officer, Adolescent Unit	Recreation	1995 – 1999
Associate Professor Susan Sawyer	Head, Clinical Services, Centre for Adolescent Health	Adolescent Medicine	1995 – present
Ms Christabel Quiah	Creative Expression Coordinator, Adolescent Unit	Social Work	1999 – present

Each interview was based on a series of questions designed to elicit the individual's perspective on the programme and its development over time. The interviewer (KMS) began with a broad question about the perceived significance of the programme and then moved on to detail the interviewees' beliefs about patient experiences. This incorporated questions about what they observed while other questions asked about their theorised outcomes for patients. The focus of the interviews then moved to more developmental aspects of the programme and opinions about more and less successful experiences over time. Despite the structured approach to the interviews, each evolved uniquely: some participants responded in great detail to the broad invitation of the first question and virtually required no further prompting; others preferred to respond to each specific question. In qualitative interviewing this is considered to increase rather than reduce validity, because the direction of the participants responses are authentic to their own experience and not directed by the researcher. The themes that emerge when all participants' views are considered together can therefore be recognised as coming from their actual involvement in the experience over time.

Within this investigation, the data were analysed using a phenomenological approach based on the methods proposed by Giorgi.⁶ Phenomenology was selected because of the value placed on describing an experience prior to interpreting it for meaning. This fulfilled the criteria of congruence with the focus of the inquiry and also clearly outlined techniques for exploring the data collected from in-depth interviews. A further benefit of phenomenology is that it identifies essential features of the experience as the final outcome of the investigation. This is fruitful in considering its intended use as the basis for future evidence-based inquiries into the programme, because it distils the information to small units of meaning that are considered fundamental to the programme.

Upon completion of the interviews, each was transcribed and the information was then explored using a distilling process based on Giorgi's model.⁶ Each interview was worked through in the following way. First, the interview was read in full. Next, information was highlighted that specifically discussed the participant's experience of the psychosocial support programme on the Adolescent Unit. This information was extracted from the text and re-grouped into structural categories based on the topic of discussion. Further reading of the structural categories was then undertaken in order to gain a deeper level of understanding of the information and contemplate other possible experienced meanings. Finally, this information was organised into further discrete categories related to meaning rather than structure identified by headings in the participant's original language.

Following this exploration of each individual's contributions, the material was re-explored to focus on the identification of similar themes across the different participants. Each individual meaning category was thus categorised with similar statements by other respondents until combined categories were created that represented shared opinions. The researcher then returned to the individual interviews and confirmed that the sentences had not been taken out of context of their original discussion, and reorganised any categories accordingly. After being satisfied that the individual's opinions were represented authentically, each category was given a heading that represented the material gathered within it. These categories were then explored to identify the essential elements of the experience.

It is noteworthy that the psychosocial support programme has functioned diversely over the timeframe of this investigation. The perspectives solicited from these professionals therefore represent experiences at different points in time, from initial experiments with the therapeutic benefits of recreation (Court), to an increasingly professional and integrated programme (Bowes, Jensen, Shea), to a cohesive curriculum facilitated by both recreation and education specialists (Jensen, Sawyer, Shea, Tange). The current creative expression programme is run by a youth professional supported by a team of highly skilled volunteers (Quiah, Sawyer). Quotes from these participants are used to illustrate key points (with participants named in parentheses).

Results

The three essential features of the psychosocial support programme on the Adolescent Unit that were identified in this study were support, communication and the promotion of identity formation.

1. The Importance of Support for the Programme

A consistent underpinning element of effective functioning of the psychosocial support programme for adolescent inpatients was recognised to be cooperation across the hospital as a system. In order to support young people in their journey through identity formation, it is felt necessary that the programme itself receive assistance from a diverse range of sources. Funding support, supervisory support, medical support, nursing support, allied health support, volunteer support, the provision of resources and ongoing professional development were all described as necessities for the programme to maintain a high level of cohesion and innovation. Unlike other programmes in the hospital, there is no pre-existing hierarchical support structure: rather, the programme functions by drawing together the entire adolescent medical

care team. Adolescents are complex beings, transitioning between concrete, child-like functioning and the supposed maturity and ideologies of adulthood. It was felt that programmes designed to support this transition needed to be equally flexible. This requires various forms of assistance, such as the provision of a safe environment and the facilitation of innovative service provision.

The creation of a safe environment: The need for a safe environment in which adolescents can access psychosocial support during their stay was recognised from its conception.

“We looked around for places to set up a facility for the adolescents. The advantage of the third floor was that we had the balcony space where we could set up the recreational facility for the adolescents and for a school.” — Court

However, healthy development requires more than a physical space, relying also on the safety provided by emotional containment.^{7,8} The professionals involved in this programme felt able to provide this through a range of supportive strategies.

“It was an environment that was familiar to them and it was a place away from the hospital where any discussions with the doctors and nurses had to be taken out.” — Jensen

A good relationship between the broader health team providing medical care on the unit and the youth professionals who run the daily programme was thought to provide a sense of safety to the adolescent patients. The security of this environment was felt to be enhanced further by strategies used to integrate young people within the programme, with more experienced participants being supported to work with more recent patients. This was recognised as occasionally proving difficult.

“And I suppose that’s one of the traps of the programme as well, in that it sometimes becomes too safe. The hospital itself becomes a safe haven, they (the patients) understand what happens here, there’s rules, regulations, consistency... and they might not get that at home.” — Tange

Interviewees discouraged this level of dependency. However, chronically ill patients have been known to manipulate their medical needs in order to coincide with visits by particular peers or to ‘escape’ their home environment. The support provided to patients within this environment is thus effective, but occasionally too effective.

Providing integrated and innovative services: An integrated team approach was generally accepted as a superior model for designing an experience of care for

young people and their families. In this case, the psychosocial support programme represented this commitment to the adolescent patients.

“The observations that they (programme coordinators) make can be highly relevant to the overall recovery of the patient ” — Court

The programme has been integrated into the broader team from its inception, with funding for the full-time coordinator position provided by the Centre for Adolescent Health. The role of the programme then broadened in the mid-1990s to enhance further integration between services through active contribution to the conceptualisation, development and planning of non-ward based programmes.

“There was a patient group who had ongoing care and it made sense for recreation and socialisation processes to be an important part of their ongoing care, not just their medical stuff” — Bowes

Educationalists on the unit were described as having a complementary relationship with the developing programme at various times. Nursing staff were similarly recognised as strong allies, especially for motivating the young people to attend. Volunteers continue to play a fundamental role in providing the variety of opportunities required at minimal expense and with limited resources.

2. Communication

Many parallels exist between the needs of the adolescent patients and the needs of the team who are providing their care. A safe space is required in order for the adolescent to be supported beyond their medical needs and a range of support must be provided to the programme in order for it to function in this way. Similarly, very good communication is necessary for the programme to function cohesively, both between the patients and the team, but equally within the team itself.

Communication challenges: Addressing the need for communication within the team has at times been challenging. These challenges exist at every level and include responsibility for supervision of the programme, funding and accountability.

“Even though they don’t directly answer to me, we actually have a working relationship to the point that they will always fly things by me before they go ahead and do stuff. So there’s that pseudo reporting mechanism that is about me needing to know what is going on in my unit.” — Shea

It is obviously necessary for the support programme to fit around the medical care needs of the patients throughout their hospital stay. On a daily basis, it is nursing staff who

help establish who might attend the programme, who is enthusiastic and who might require psychosocial support despite their desire to languish in bed.

“When communication levels are low, the default has been to view the programme as baby-sitting, which is not what it is.” — Sawyer

Many of the professionals viewed the attendance of the programme coordinator at multidisciplinary team meetings as essential. Additionally, the coordinator is required to communicate with the ward via the Nursing Unit Manager as well as with the Centre for Adolescent Health via the head of the Adolescent Medical Team. This was considered a valuable mechanism for providing various levels of accountability, feedback, and refinement of the programme. The programme coordinator is also required to develop strong networks within the hospital for them to be able to source additional professional support required for the programme. Finally, they are responsible for recruiting volunteers to be involved in the programme’s daily functioning. It was felt that a sense of programme isolation became apparent when the challenge of these different levels of communication became too great.

Facilitating communication: Despite the many communication challenges, the programme was felt to function effectively by opening up channels of communication between patients and the broader medical team. Conversations that occurred in the safe environment of the programme can be relayed back to the team when appropriate. Mental health is commonly considered taboo by adolescent patients. The programme can often facilitate greater acceptance of these services through the provision of a willing listener.

“Sometimes they really did talk about the tough stuff, and while I was very happy to listen, I couldn’t provide them with the solutions they were probably looking for, so I would always recommend they speak to someone else.” — Tange

Similarly, the psychosocial support team members are able to function as advocates for nursing staff by gently educating patients on why certain procedures are necessary. In this way, they can assist in demystifying some of the young person’s fears about the hospital admission. This is often seen to improve relationships between the adolescent patients and the broader medical team.

3. Identity Formation

With strong supportive and communicative mechanisms in place, the programme was then considered able to address the adolescents’ psychosocial needs. This was the most significant aspect of the programme that was described

consistently throughout its years of operation. Although some patients in the programme are admitted for general medical and surgical procedures of a few days only, others have chronic illnesses such as cystic fibrosis, eating disorders or diabetes that can involve extended hospital admissions with the potential to interrupt schooling and participation in community-based recreation activities. Other young people are hospitalised for psychosomatic illnesses, or may require more frequent admissions because of the interaction of the illness and their home life. It was particularly for these situations that the hospital environment was thought to attend to the developmental tasks that would traditionally be addressed outside of an acute inpatient setting.

According to renowned developmental psychologist Erik Erikson,⁹ the main task of adolescence is the struggle between identity and role confusion. He considers the primary concern of this age group to be the comparison of their own feelings about themselves with “what they appear to be in the eyes of others”.⁹ Erikson states that the achievement of a sense of equilibrium between these two perspectives results in a healthy sense of identity and theoretically, a desire for a particular occupational identity. In contrast, role confusion results from irresolvable differences between sense of self and the perspectives of others. Erikson suggests that adolescents conduct small-scale experiments, or ‘try on’ behaviours and personalities to assist in the formation of their identity. Piaget has reached similar conclusions regarding adolescent’s cognitive abilities and suggests that “having just discovered the capabilities for abstract thought, he then proceeds to exercise them without restraint”.¹⁰ This capacity for flexible and effective thinking is considered to emerge given the appropriately supportive circumstances. In the context of the current investigation, the Adolescent Unit was felt to be responsible for promoting individual patients’ capacity for identity formation for those with particularly frequent or extended stays.

Provision of a dynamic and responsive programme: The first way in which identity formation is promoted was felt to be through the collaborative responsibility that is established between the professionals and patients for the programme.

“I had to talk to them about it, which is probably the most crucial part of the programme, talking to the kids and finding out what they need. I think what the programme really strove to do was give them ownership over it...they came up with the ideas. There were also times when they felt terrible and they couldn’t do that, but at the same time, encouraging them and giving them the options to make those decisions was important.” — Tange

The professionals involved in the programme commented that it is important to listen to the needs of the patients. The “horses for courses” (Sawyer) approach has been adopted as the most effective way of providing a dynamic and responsive programme. Using this approach, the actual content of the program is individualised and activities may exist anywhere on the spectrum between recreation and creative expression. This has been exemplified by the diverse range of approaches used by various programme coordinators over the course of the programme development. Despite distinctly differing foci in terms of activities over the years, the goals of the programme appear to have remained remarkably constant over time.

A more recent development is the range of activities provided by the body of highly skilled volunteers. This has greatly diversified programme content. However, as ever, various components of the programme are juggled to meet the presenting needs of the patients each day, as well as integrating different patient groups.

“So I think it’s a shuffle between having a programme that caters to the kids who have a history and a repeated history and those that are just here for a couple of days and then move on. So I have to plan and create a structure that will cater to these kids simultaneously in one group setting.” — Quiah

Providing opportunities for participation: In order to provide responsive programming, it is felt necessary to focus on offering opportunities for adolescents to work through what is going on in their lives. The emphasis on offering opportunities is closely linked to the concept of identity formation. The adolescent is treated with respect and provided with opportunities, however the responsibility for utilising them rests with the young person.

“That was one of the biggest things I learned about young people, is that everyone boxes them into being difficult, but if you give a kid the chance to make a decision, or the opportunity to be involved in something, then you open a whole new set of doors for kids.” — Tange

Once again, the ability to make opportunities available relied on various levels of support both inside and outside the hospital, as developed by the programme coordinator. This requires resources being on hand. The team of skilled volunteers was felt to be particularly useful in this regard.

“It’s about providing an opportunity for respite from medical procedures and providing it within the kind of atmosphere or providing mediums that are encouraging people to look at exploring ways of self expression, particularly creatively self-expressing. This might be

about the illness that they’re grappling with or perhaps their personal life-space.” — Quiah

The formation of durable relationships: However, adolescents often appeared disinterested in opportunities they were offered, either because they did not want to take the risk of something new or because they were ‘desperately trying to be cool’. It was this feature that was to make the relationship between the programme coordinator and the patient so important. Once engaged in durable relationships, adolescents were felt to be considerate, even loyal. The paradoxes of engaging young people in this stage of life are well expressed by Anna Freud.¹¹

Adolescents are excessively egoistic, regarding themselves as the centre of the universe and the sole object of interest, and yet at no time in later life are they capable of so much self-sacrifice and devotion. On the one hand, they throw themselves enthusiastically into the life of the community, and on the other, they have an overpowering longing for solitude. They oscillate between blind submission to some self-chosen leader and defiant rebellion against any and every authority. They are selfish and materially minded and at the same time full of lofty idealism. At times their behaviour to other people is rough and inconsiderate, yet they themselves are extremely touchy. Their moods veer between light-hearted optimism and the blackest pessimism. Sometimes they will work with indefatigable enthusiasm and at other times they are sluggish and apathetic.¹¹

Focussing on strengths and abilities: Many adolescents with a chronic illness spend, by necessity, large amounts of time focused on their disease and the limitations it causes. However, the psychosocial support programme was felt to provide a safe environment with opportunities and relationships that allowed young person to explore other aspects of themselves.

“It was about always being really positive with whatever we were doing with them, to give them an outcome where they could get a sense of themselves and a sense of achievement and feel good about themselves. That was all it had to be really. These kids were always the kids that were never there at school and that failed. So you had to really look at their strengths and focus on that to pull them out of it.” — Jensen

The programme was felt to encourage young people to focus on strengths relevant to life in the community, as well as addressing areas of need during their hospital stay. Young people were encouraged to get in touch with themselves as whole people, not just diseases. In addition to providing opportunities for self-expression, the incorporation of success-oriented experiences was felt to

be an important element of how the programme is effective.

This could be defined in many ways, but one of the ways was that teenagers are going to survive better is if they feel good about themselves, if they don't give way to despair ... and you can do that with the assistance and support of other teenagers. — Court

Conclusion

Utilising a discovery-oriented approach, this small-scale qualitative investigation reveals that identity formation has consistently been the primary focus of the psychosocial support programme on the adolescent unit at the RCH programme. This is despite the many different activities that have variously formed the focus of the programme over time. The additional findings regarding the importance of support and communication are essential knowledge for those considering the implementation of such a programme and provide guidance for developing a management infrastructure and appropriate levels of funding.

In this era of evidence-based practice, programmes that aim to reduce the impact of disease and disability by promoting opportunities for youth development can be difficult to justify. Having identified that these multidisciplinary youth professionals consider this programme functions through the promotion of identity formation, an important challenge is how this somewhat elusive outcome can be measured.

This study suggests that the psychosocial support programme at the RCH has experienced many successes. The participants in this study have provided opportunities for many disadvantaged young people to sing, swim, climb, and create. In doing so, they have shared the delight that these young people have expressed in participating in new experiences. They have learned that adolescents gain much from the support they provide to one another and have learned ways of facilitating this support. The psychosocial support programme was felt to provide a way for young people's psychological and emotional health to improve, despite their need for hospitalisation.

"The programme is really the physical element that helps remind us that what we are trying to achieve in

hospital is much more than simply the medical management of an individual with a disease or disability, but that we are also here to explore with young people the ways in which they can enjoy life and develop more fully, despite their illness or disability. It is a tangible way in which we try to look after the whole person." — Sawyer

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