

# THE ROLE OF SPECIALIST NURSES IN IMPROVING TREATMENT ADHERENCE IN CHILDREN WITH A CHRONIC ILLNESS

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## ABSTRACT

Adherence to medical treatment is an ongoing challenge for families and young people with chronic medical conditions. One factor that is likely to influence treatment success is the quality of professional relationships both within the health care team and between the family, child and professionals. This paper explores the topic of professional relationships and adherence and provides an example of how a multidisciplinary team can improve the health and quality of life of paediatric patients. More specifically, the paper argues for the crucial role of the specialist nurse in supporting patients and their relationships with the health care team.

## INTRODUCTION

Adhering to complex medical regimens associated with chronic illness is demanding. Remembering to take several medications several times a day, constantly on the lookout for symptoms associated with acute exacerbations, avoiding activities others 'live for' and eating the right foods rather than what they would like to eat demands a maturity and focus beyond many adults. The addition of developmental constraints and the imperatives of childhood make treatment adherence even more of a challenge for children, and consequently their families and the health professionals caring for them. Establishing the capacity of these children to care for themselves in childhood is important if the poor levels of adherence frequently found in adolescents and adulthood are to be avoided.

The following case study provides an example of the complexities surrounding treatment adherence in children with chronic illness, and the discussion of the role specialist nurses play in improving adherence levels.

### Molly's story

Molly is HIV positive. One year ago Molly's parents died of AIDS related illnesses. Such a huge loss would be difficult for anybody, let alone a nine-year-old child.

Molly is an only child, cared for by her Aunt Judy, who has two other children, aged one and 10 years. Molly has had to cope with a move to a new family, new house, new school and new friends. She is linked in with a counsellor fortnightly to assist in processing these changes.

To support Judy in her new role as carer for Molly, the specialist nurse for paediatric HIV provided ongoing home visits. One focus of the visits was to discuss HIV and the importance of antiretroviral medication and to develop strategies that may assist Judy and Molly to remember to take the medication. However, despite the interventions, Molly's disease was progressing and her condition was deteriorating, with an increase in her HIV viral load and a fall in her T4-lymphocyte (CD4) count. Molly was losing weight and had recurrent oral candidiasis. Both Judy and Molly insisted that her medication was taken without fail, three times daily. However, further questioning more directed to the specific occasions of taking medication revealed that some doses were missed. The reasons given varied from Judy forgetting to give them, to Molly refusing to take them.

Because of the disease progression it was clear that Molly needed a change of antiretroviral medications. However, the paediatric HIV team was reluctant to start a new regimen during the period of instability. The team was concerned the adherence rate, greater than 95% required for the new regimen to be effective against the virus, would be unlikely at this time (Ostrop et al 2000). Missing even a small number of doses, therefore, would cause the virus to become resistant to the medication and render not just the new regimen, but also many other HIV antiretroviral medications useless. If Molly's medication was not changed soon to the new medication her condition would continue to deteriorate. The specialist nurse arranged another home visit to talk with Judy and Molly about the proposed change and explore ways to improve the likelihood that the new medication would be taken by Molly as prescribed.

It was breakfast time when the nurse arrived. Chaos reigned, with Judy feeding her one-year-old and screaming at Molly to take her tablets. The nurse helped Molly get her tablets and stood by as she took them. As soon as they were in her mouth she went running outside to play. The nurse saw her spitting her tablets out onto the grass. When asked why she did not swallow her tablets Molly said she wanted to die so that she could be with her mum and dad. She was so unhappy and cried - one of the few times she had done so since her parents' deaths. When she was asked if she told her counsellor how bad she felt, she said she had not been to see her and she could not talk to Judy either. Judy admitted that it was not always possible to take Molly to her counsellor because she was just too busy and felt too ashamed to tell us.

The problems identified were discussed with the paediatric HIV team and a case management meeting was called. A key representative from each service was invited

to participate and roles and responsibilities in the planning sessions were identified. The specialist nurse was appointed as the case manager and coordinator of Molly's care. From this point on, all services were processed through the specialist nurse. The group identified gaps in Molly's care and the following strategies were put in place:

- Weekly visits were arranged with her counsellor - with transport to these appointments and then on to school.
- An easier medication regimen was started, twice daily - at breakfast and at night.
- Judy was asked to watch Molly and ensure she swallowed her new medication.
- Arrangements were made for respite care for Molly. This involved spending every other weekend with a couple who offered to provide her with additional attention and support. This arrangement was formalised through community services and provided Judy with a rest from her very demanding duties as carer of Molly.
- Judy was offered regular counselling and support by the HIV social worker.
- Ongoing education and discussion of issues continued with the specialist nurse.

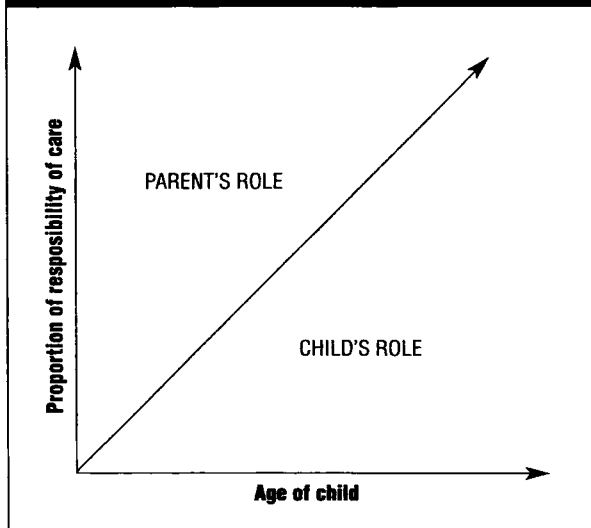
### **Factors affecting adherence in children and adolescents**

The term compliance, defined as 'the extent to which a person's behaviour coincides with medical care and advice' (Sackett 1976) implies obedience to treatment orders or recommendations, without in-depth discussion or negotiation. 'Compliance' has been widely criticised for focussing on the physician's role and emphasising the subservience of the patient and their families (Karoly 1993). Compliance research has been criticised as one-dimensional, practitioner centred, reductionist, consistency oriented and amotivational (Karoly 1993). The term 'adherence' is intended to be less judgemental, emphasising the relationship between the patient and provider (Kyngas, Kroll and Duffy 2000).

More recently, the multiple social, psychological and situational factors affecting adherence have been increasingly recognised and researched. The feelings, motivations and capabilities of children with chronic illness and their families, which are liable to change over time, are also increasingly being considered when discussing issues of adherence. The challenge of adherence for the health care professional is in assisting and supporting children, adolescents and their families through their difficulties. However, adherence in adolescents is often complicated by conflicting perceptions from parental and health care professionals of what is important in their lives (Kyngas et al 2000).

In the paediatric setting, decisions on health care and adherence issues involve a number of participants - the parent, other family members, and health professionals - rarely the child. Decisions are made with the child's perceived 'best interests' at heart (Bricher 2000). However, while collaboration may be an ideal in paediatrics, factors such as laws governing the age of consent, cognitive and functional ability and emotional maturity necessitate adult supervision of medical regimens in most young children. Ideally, as the child develops, management of treatment regimens are modified, leading to shared management of their health (Kieckhefer and Trahms 2000).

Figure 1: Graphical depiction of the transition to self-care as the child matures



The health care professional can facilitate ongoing relationships with children of different ages by assisting them in negotiating the changing nature of the interactions with their parents as they seek greater independence. When a child reaches adolescence and decides that they are ready to assume control over their life, the presence of a chronic illness has the potential to increase reliance on parents and other adults, creating resentment and a sense of a loss of control (Kyngas and Hentinen 1995). The connection between feeling out of control and poor mental and physical health have been explored in the psychological literature and some evidence exists that this relationship is true for adolescents with a chronic illness (Kuttner et al 1990). Family support at this time needs to take into account the increasing maturity and independence of needs of the child. Encouragement and acceptance of independence by parents have been found to be associated with good compliance; and, a lack of trust and an authoritarian approach, with poor compliance (Kyngas et al 1998).

Medical treatment can isolate adolescents - both physically and psychologically - from their peers and may even stigmatise them. For example, one recent study found that 58% of students without asthma and 42% of teachers believed that fellow students with asthma could become addicted to their medication (Gibson et al 1995).

On the other hand, peer acceptance of medical regimens, whether by active support or by modification of lifestyle can assist compliance (Kyngas et al 1998).

Other factors complicating the issue of treatment adherence in children include family functioning (Hanson et al 1992), parenting style (Kyngas et al 1998), parental self-esteem (Gavin et al 1999), relationships with peers (Kyngas et al 1998) and parental worry about the condition (Hazzard et al 1990).

Parents, who mediate the relationship between the health care practitioner and the child by reporting and interpreting the child's symptoms and emotions, are often influenced by their preconceptions and personal circumstances (Sartain et al 2000).

It is important for health care professionals and parents working with children with chronic illness to implement anticipatory guidance to facilitate self-care, rather than relying on crisis management when problems arise. One model of shared management (Kieckhefer et al 2000) suggests introducing simple concepts from around the age of two years, with a gradual progression to self-management and transition to adult care by 18 years. More research, however, is needed into the specific difficulties that may be faced and how to overcome adherence problems when the responsibility for care switches from the parent to the child.

### The role of health care professionals in treatment adherence

Central to adherence is communication and rapport between the patient and in the case of children, the child, family and health care professional. Research has shown that up to 50% of all adult patients do not remember physician advice immediately after the consultation (DiMatteo 1994). Given that communication is frequently with parents, it is likely that this statistic has relevance for adherence in the paediatric setting.

Why don't people remember what they are told by their physicians? It is likely that a range of factors are involved. Apathy during the appointment is an unlikely cause as research has also indicated that 90% of patients want to work in partnership with physicians and obtain as much information as possible. When more active involvement in care is promoted, patients are more satisfied with their care, experience greater symptom alleviation, a higher level of overall improvement, less distress and greater perceived control (DiMatteo 1994). Given that patients want information, but frequently appear not to be receiving this information in an effective manner, it is worth examining what variables impair communication and what facilitates good rapport between patients and health care professionals.

Relationships with health care professionals would ideally continue over long periods of time. However, for an ongoing relationship to be successful, parents, children and adolescents must be able to trust the medical

knowledge of health care professionals as well as confide any doubts they might have of treatment efficacy and side effects. In many cases, non-adherence is not so much a case of failure to comply, but a search for alternatives. If a patient or parent does not believe in the benefits of the treatment, they may refuse it or look for alternatives (Saunders and Lawton 1993). Likewise, patients must have faith in the knowledge and good will of nurses caring for them when their illness cycles through greater wellness and sickness, as so often occurs, or when treatment may become unpleasant and difficult.

Physical symptoms are more easily measured and detected than psychosocial problems, however the impact of psychosocial factors is often neglected, despite the potential impact on adherence (Newell et al 1998). It is important to be able to interpret the patient's mood as these factors are known to positively and negatively impact on the self-perception of symptom severity and medication adherence (Schanberg et al 2000).

Prejudice can also damage health care professional-patient relationships. For instance, when dealing with people who are 'different' there may be a tendency to attribute negative behaviours to personal characteristics rather than circumstances in their environment or those relatively outside of their control (Pettigrew 2001). Translating this tendency to health care, it must be acknowledged that the potential for discrimination can play a huge part in communication with patients. Race has been found to influence physician perceptions of adherence, intelligence and likelihood of risky behaviour (van Ryn and Burke 2000). Racial group membership can also influence the perception of risk for particular illnesses (Sadler et al 2000). Countering these problems begins with health care professionals developing self-awareness and monitoring their own behaviours. It also demands that any interventions that are tailored to specific communities are collaborative and avoid the pitfalls of patronisation or stigmatisation (Sadler et al 2000).

For long-term care to have a positive impact, a non-hierarchical collaboration within the medical team and between the patient and health care professionals should be established (AEIOP 2000). Critical attributes of successful collaborations within the medical care team include good communication, a shared philosophy on issues relevant to care, mutual trust and respect and the ability to evolve (Lockhart-Wood 2000). Failure to communicate between the physician and the patient and the physician and the nurse can result in poor-quality patient care (Larson 1999).

### **The role of the specialist nurse in adherence**

Adherence to treatment can be improved by the involvement of a multidisciplinary team including a specialist nurse. The increasing independence of the nursing profession in Australia after the commencement of tertiary training (Appel et al 1996), and the development of specialist nurse positions over the last 20

years, has contributed to an increasing recognition of the unique role that nurses play in the care of long-term patients.

Specialist nurses' provide expert nursing care which has been found to improve communication and increase access to services (Mills et al 1999). Because of a greater depth of interaction with the patient, the specialist nurse is in a position to understand the complexity of the contextual issues affecting a patient's adherence to their treatment. Nurses, who typically spend more time with patients than physicians, can develop informal lines of communication that are supportive rather than directive (Fenwick et al 2001). Specialist nurses' have also been described as having the experience and intuition required to interpret complex situations, advocate for patients and determine an effective course of action (Adams et al 1997).

Specialist nurses are also skilled in communication, consultation, role modelling and patient education (Appel et al 1996; Kyngas et al 1998). Supportive communication and availability allow nurses to work with patients from the 'inside out', rather than the 'outside in' that typifies many physicians' visits (Reutter and Ford 1996). These factors enhance the ability of specialist nurses to deal with complex and multi-faceted issues such as adherence. They also allow specialist nurses to develop trusting relationships with patients and, where necessary, mediate relationships between patients and other team members.

### **The role of the specialist nurse in case management**

The medical treatment of children and adolescents requires ongoing support from multiple sources - parents, friends, school, community and health care workers - if the children are to successfully care for themselves. Parents are expected to perform a number of specialist tasks associated with the care of their children: assess symptom severity, administer medication, conduct day to day care including exercise and diet, advocate for their child, take them to multiple appointments, liaise with schools and continue to be cognisant of the needs of the rest of the family.

How can parents be reasonably expected to accomplish all of these tasks without a mechanism that supports the family outside the visit to the doctor? How can a paediatrician working alone effectively address the complexities of adherence during a consultation every two to three months with the time constraints inherent in a busy practice? A coordinated team approach is necessary.

To facilitate the team approach, there needs to be equality among members as each team member looks at adherence from a differing perspective. This requires a fluid approach to care, with each person's contribution respected and valued as a key piece of information. The team approach also requires case management to coordinate services provided to the family reducing not adding to the level of confusion often experienced by

families with a child with a chronic illness. It is important that the message given is consistent. It is also important that the services support not substitute for family functioning. Nurses can play a pivotal role in case management by ensuring continuity of care and communication among the health care team (Wolfe 1997) by virtue of the greater amount of time they have available to spend with each family.

Recognition of multidisciplinary teams as the preferred model in treating chronic illness has increased over the past 20 years, with this model of care now receiving worldwide recognition. A team approach has been identified as increasing survival, improving clinical status and satisfaction with care in cystic fibrosis (Madge and Khair 2000).

A specialist nurse is ideally placed to provide the vital link between the family and the health care team. While research has demonstrated that a specialist nurse can view the professional boundaries in multidisciplinary teams as blurred, clarification of team roles and the maintenance of a disciplinary focus can allow nurses to work flexibly with other professionals (Wales 2002; Ryan and Hassell 2001). Working flexibly allows for a maximal utilisation of skills and enables members of different professional groups to respect and complement each other.

In summary, Molly started on her new treatment regimen and her condition improved. Her HIV viral load has fallen to undetectable levels and her T4-lymphocyte count has increased. With regular visits to her counsellor she was able to talk openly about her parents. She became a happier child and loved her special time away with her respite carers. The difficulties Judy faced in providing optimal care were uncovered because of the ability of the specialist nurse to spend time in the home environment. No one person could have provided the type of support Molly needed at this stage of her life. A coordinated team effort stabilised Molly's health and improved her quality of life.

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