Continuity of care for children in the 'too hard' basket

A literature review of care needs in the health system

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The following review of literature arose from Project Partnership, an initiative of the Royal Children's Hospital, Melbourne, which was set up to identify systemic and organisational changes which could improve continuity and quality of care for children with long-term and complex health care needs. This article examines research findings and other literature relevant to the experience of families whose children have complex health care needs; the experience of hospital based, health care professionals who care for this group of children; and the complexities of undertaking collaborative research in a large health bureaucracy.

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Project Partnership, a continuity of care initiative of the Royal Children's Hospital, Melbourne, was set up in 1994 following the success of the Home Care Program, which facilitated the move home from hospital of a group of technologically dependent children [Schwarz 1994]. Two project officers were employed to undertake collaborative research with parents and hospital staff to identify systemic and organisational changes which could improve continuity and quality of care for children who are not dependent on technology, but who nevertheless have long-term and complex health care needs.

The main themes and questions for Project Partnership emerging from the relevant literature, as well as the expressed concerns of the project's participants, were:

- Children who require long-term health care (and who often have an associated disability) and their families have special needs for continuity and support. How can the hospital better meet these needs and also involve families in an ongoing consultative process regarding the services provided to them?

- The hospital staff who care for these children face particular challenges – in relation to the long-term aspect of care, the child's disability, the families' needs, and their own training and job satisfaction. How can these staff be supported and empowered to provide continuity of care?

- As an organisation, the hospital also faces several challenges. In an era of financial stringency and new mechanisms for accountability and funding, there is enormous pressure for throughput and an associated tendency to focus on acute services, especially for children who are not chronically ill. How can the hospital ensure that in this current climate it meets the needs of families with whom it has a long-term relationship as well as meeting the needs of the staff who care for these patients?

- For chronically ill children, the hospital is almost always only one of a number of community based service providers. How can the hospital ensure that it makes the best possible contribution to coordination and communication within the wider community network of services?

The following review of literature was prepared for the final Project Partnership report and examines the needs of families with chronically ill or disabled children; the hospital's response to these needs; opportunities and challenges in the current health context; and future possibilities for partnership between parents and health professionals.

SURVIVAL AND DISABILITY

As medical expertise and management progresses, more children of extremely

low birthweight (ELB) are surviving early infancy (Doyle & Kitchen 1993; Tudehope, Burns, Gray, Mohay, O'Callaghan & Rogers 1995). While some Australian research studies on this group of children report that the numbers with long-term disabilities have increased in the same proportion as the overall survival rates (Tudehope et al 1995), other studies report a proportional decrease in disability – that is, that while more ELB children are surviving than previously, proportionately less of them have long-term disabilities (Doyle & Kitchen 1993).

However, regardless of the rate of disability across hospitals, or states, the absolute number of children with chronic long-term conditions inevitably rises with the overall birth rate.

A theoretical understanding of sickness

David Taylor's (1979) work on a theoretical understanding of sickness has led him to propose three components of sickness:

1. The disease, or condition, which has a physical reality;

2. The illness, which is the experience of the disease, and is generally made up of limitations to daily living, as well as pain;

3. The predicament, which is the meaning given to the disease and illness by the individual, family and community.

It is evident that the predicament inherent in long-term, chronic conditions will be influenced by the complexity of the health and welfare system in which the individual and family find themselves; the financial cost of contact with various parts of this system; moral, ethical and political judgements about allocation of resources; and cultural beliefs about disease and illness.

The impact of chronic childhood illness and disability in families

'Our children are so much part of ourselves that when they are seriously ill, or disabled, our own sense of self is vulnerable – our self image is damaged, just as our child is damaged. Many parents, particularly mothers, find that

their self esteem and confidence are seriously undermined' (Tracy 1993, p. 1832).

While the literature which describes the impact of a child's chronic illness on his or her family largely concentrates on family stressors and methods of coping with these, families also report positive attributes of their situation, such as the growth of individual and family values and the strengthening of family cohesion and bonds (Desguin, Holt & McCarthy 1994a; Patterson & Garwick 1994). Looking at a person's 'ability "to grow and change and to strive for mastery both in the external world and in their internal development" allows a more comprehensive picture of both the child and family' (Waters & Lawrence 1993, cited in Desguin et al 1994a, p. 203).

The literature of stress and coping in families with disabled children is reviewed by Tunali and Power (1993), whose research looked at the ways in which mothers adapt psychologically to having a child with autism. More simply, the process of 'coping well' is discussed by Tracy, who talks of the 'emotional roller-coaster' of the 're-adjustment process' (Tracy 1993, p. 1834).

Although the impact of chronic childhood illness and disability differs between families, at least four major areas of potential stressors have been identified in the literature:

• economic difficulty;

• increased isolation from family and friends;

• personal strain – distress, grief, tiredness, difficulties in travelling to hospital, accessing reliable help, etc;

• illness mastery – intra- and inter-personal coping strategies (Desguin, Holt & McCarthy 1994a; Ellis 1989; Mitchell 1992; Stein & Jessop 1985, cited in Mailick, Holden & Walther 1994; Tunali & Power 1993).

The stress of having a child with disabilities is also influenced by cultural beliefs and values (Ryan & Smith 1989).

In a study which used focus groups to identify the support needs of parents whose children had developmental disabilities, emotional disorders or technology-supported needs, Petr and Barney (1993) report that parents

considered that crises were brought about by:

• the child's behaviour;

• system-induced crises, where a system outside the family either created a crisis or exacerbated a crisis – 'parents become as emotionally exhausted from dealing with the system as they do from caring for their children' (Petr & Barney 1993, p. 253);

• general stress;

• parents' temporary or permanent inability to provide care.

While some studies have found that a family's experience of stress increases significantly with the severity of a child's illness or disability (Williams 1993), 'families whose children with chronic conditions appear normal are just as likely to be stressed as those whose children have visible signs of illness' (Saddler, Hillman & Benjamins 1993, cited in Desguin et al 1994a, p. 202). Research on caretakers' views of coping with chronic childhood asthma found that caretakers' reports of personal strain tended to correlate with reports of economic difficulty and increased isolation (Mailick et al 1994). These writers, along with other researchers, have concluded that practical support is likely to be a very important component of services to families (Desguin et al 1994a; Lee 1994, Mailick et al 1994).

While the provision of State-funded respite is part of a wider debate around economics and the changing philosophies of the public-private continuum of care (Cant & Hand 1994), there are many studies which advocate for the public provision of respite care for children with disabilities (Botuck & Winsberg 1991; Mausner 1995; McKenzie 1994; Mitchell 1992; Stalker & Robinson 1994; Starkey & Sarli 1989).

Family, social and professional support is seen as crucial for families with a chronically ill or disabled member. While Davis and Rushton (1991) found that counselling support was correlated with a greater sense of coping for parents, many other writers discuss the need to actively acknowledge and support the experiences of siblings (Atkins 1989; Desguin et al 1994a; Meyer 1994).

Petr and Barney (1993) found that parents expressed needs for:

- a greater variety of specialised services, particularly respite care;

- integration of the children into everyday community life as far as possible and avoidance of labelling – to 'see the child and not the disability';

- emotional support from family, friends and wider social support systems;

- active advocacy to help deal with unresponsive systems – parents were tired of having to be self-advocates in perceived conflictual and adversarial systems;

- professionals who were respectful, flexible, committed, accountable and willing to learn about the needs of particular children;

- coordinated systems of care;

- financial help.

Chronic illness and hospital care

A number of studies have described the experiences of parents whose children have a disability, and who therefore have long-term relationships with health care providers (Baine, Rosenbaum & King 1995; Calabretto & Johnson 1994; Desguin et al 1994a & 1994b; Horn, Feldman & Ploof 1995; Kristjansdottir 1991; Lee 1994; Lieberman 1989; Moxley, Raider & Cohen 1989; Tracy 1994). These parents value:

- technical expertise;

- easy access to the hospital, with 'reasonable' waiting times[1];

- clear information about the child's illness, the hospital system and other relevant resources;

- acknowledgement of the parents' expertise with their own child and his/her condition;

- partnership between professionals and parents;

- an advocate to coordinate the various parts of the 'system';

- flexible negotiation of roles, especially when the child is an inpatient;

- professional willingness to see the child as a person, not as a disability;

- recognition that the child's illness affects all members of the family;

- time, empathy and attentive listening;

- staff willingness to learn of the child's condition; and

- continuity of care with known, trusted and respected professionals.

Many of these themes have been considered in a South Australian research project based at the Women's and Children's Hospital. The findings of this study indicate that a partnership between parents and hospital staff is seen as achievable and positive (Johnson 1995).

The issue of continuity

It is ironic that at a time when 'technologic(al) improvements increasingly offer substantial benefits ... fragmentation of services, poor communication, and lack of continuity often make them poorly accessible to the children who need them' (Weitzman 1985, cited in Desguin et al 1994a). This situation has seemingly changed very little since the 1970s, when 'basic care (was seen as) either divided or duplicated, but with many of the supportive aspects of care neglected' (Pless, Satterwhite & Van Vechten 1978, p. 9).

Hobbs, Perrin and Iryes (1985, cited in Desguin et al 1994a, p. 207) talk of the 'tangled boundaries of agencies, specialties, and professions' and the fact that even the word 'system seems an overly optimistic label for the capriciousness that exists in the availability of services' for families of chronically ill children.

Case management, or care management[2], is seen as one of the key elements of coordination and continuity of care (Cleak 1995), whether this is undertaken by family members[3]; a key person or team of professionals within the hospital (Simmons 1994); a paediatrician based in the community; or an agency external to the hospital (Desguin et al 1994a; Luntz 1994). For a care manager external to the family, two issues which need to be considered are whether the care manager should act as a counsellor and to what extent it is possible to advocate or manage the services of autonomous agencies, which have no direct accountability to the care manager (Austin 1993; Desguin et al 1994b; Hatfield 1993).

The Office of the Public Advocate (1992) outlines four core aspects which are seen as essential to a case management framework:-

- a consumer focus (rather than a service oriented focus);

- consumer empowerment;

- coordination of services;

- single point accountability

Mechanisms which enhance these principles include the use of patient held records; case conferences; referral to other service providers; the creation and maintenance of organisational links between different levels of health care and community support systems; identifying gaps in service systems; and discharge planning which is anticipatory, supportive to both consumers and professionals, and monitored (Cleak 1995; Desguin et al 1994b; James 1987; Metropolitan Hospitals Planning Board 1995).

Positive and clear communication is seen as another key element of continuity. Klerman comments that, while medical professionals 'function as a well-organized unit' in episodes of acute crisis, 'interprofessional problems' tend to arise 'when the condition is chronic' (Klerman 1985, cited in Desguin et al 1994a, p. 211).

Good communication includes the need to establish structures and routines which promote clarity, efficiency and coordination in the care of these children, such as special designations on files and computer databases, computer alerts to notify other relevant specialists in particular circumstances and care plans containing medical, psychosocial and educational information held by the family and all involved professionals (Desguin et al 1994b; Horn, Feldman & Ploof 1995; Vaz 1995).

Caring for children with disabilities in hospital

The nursing experience of caring for children with disabilities is described in Robinson et al's (1993) participatory action research study centred on the 3 West Orthopaedic Unit of the Royal Children's Hospital, Melbourne. The authors state that those nurses who have had more experience nursing children with disabilities are more likely, than nurses with less experience, to compile a detailed listing of the child's needs during an inpatient stay (Robinson et al 1993, p. 34). Even so, this study suggests that 'at best the care provided by nurses,

to families of children with disabilities, is of an inconsistent quality' (p. 50), one of the reasons for this being that the nursing focus tends to be on medical and technical concerns, rather than on 'the child's disability and the maintenance and restoration of pre-existing abilities, following surgery' (p. 25). Draper (1993, p. 26) makes a similar point when she states that 'medicine has tended to focus on acute conditions ... at the expense of ... chronic illnesses'.

Although overseas research studies have found that health professionals' attitudes to people with disabilities are often negative and unaccepting (Gething 1992, p. 25), an Australian study has found that nursing students and experienced nursing professionals display 'more positive attitudes towards people with disabilities than members of the general population' (Gething 1992, p. 29).

However, the experiences of families whose disabled children were frequent patients at the Royal Children's Hospital and who were interviewed for a student research project in 1992 were mixed (Mitchell 1992). Parents' views are illustrated by positive and negative comments such as:

- 'There were some excellent caring staff';

- 'The Gastrology Department is great, the dietician rings and the stomal therapist rings. They give lots of follow-up and support';

- 'The staff don't understand the stress. It's not just the illness, it's all the time';

- 'If you don't talk, walk, sit, stand, roll over or anything, you're just neglected there';

- 'The staff would rather pick up "normal" children';

- 'I have come in and seen his drinks and meals left on the bedside table. He can't even reach them'.

The work context in hospitals

The findings of research undertaken in the field of disability by Hatton and Emerson (1993) demonstrate the importance within the work context of supervisory support, organisational democracy, training and development, adequate income and ensuring goodness of fit between staff and organisational aims.

This view is amplified in research on the organisational context of empowerment practice, undertaken by Gutierrez, GlenMaye and De Lois (1995). These researchers discuss the concept of a parallel process in which organisation-staff relationships are likely to mirror staff-consumer relationships. Organisational practices which supported empowerment of consumers were identified as generous staff development and training opportunities; collaborative service design and management; and administrative leadership and support for empowering practice.

These findings may also be viewed within a feminist paradigm. Female nurses and other professionals in hospitals may be seen as working in a hierarchical context, which is dominated by (largely male) medical professionals and management (Street, 1992). Robinson et al (1993) and Webb (1989) argue that this has the effect of disempowering nurses from seeking to make significant changes to their practice.

The family-hospital relationship

Any relationship between a family with a sick child and a health care provider is likely to be complex, with issues of anxiety, control, anger and helplessness in evidence. If the child has a chronic condition, these issues are likely to be exacerbated and may lead to considerable conflict between family members and staff (Darbyshire 1994; Gans 1983; Horn, Feldman and Ploof 1995; McLaughlin & Carey 1993; Shaw & McMahon 1990).

Health professionals hope that children will get better and therefore may find it difficult to acknowledge that a cure is not possible and that all they can offer is comfort, kindness and dignity. Furthermore, professionals may expect that parents will be grateful for their efforts regardless of the outcome. When there is neither a cure nor gratitude, professionals may paradoxically feel upset and angry with the parents (Nunn 1994), who in turn feel upset and angry with the difficulties in dealing with 'the system' as well as with the outcome itself (Petr & Barney 1993).

However, if this conflict is viewed as simply 'one of the stages of development of consumer empowerment' (Tower

1994, p. 195) and not a stalemate, it may be seen as an intrinsic part of the continuum of a working relationship, which can, over time, move towards partnership (Desguin et al 1994a).

Nunn (1994) argues that the issue of consent needs to be negotiated continuously in any true partnership between parents and health professionals. He writes 'The essence of care is a clearly agreed contract and the essence of contract is consent. If something is going wrong in the communications between professional carer and those cared for, the first place to look is to the issue of consent' (p. 3).

The consumer movement

The consumer rights movement, allied as it is to the concepts of self-help, de-medicalisation, independent living and de-institutionalisation, is based on a recognition that individuals with a particular life experience are more expert about their own needs than are professionals (Tower 1994) and, furthermore, that they have a right to significant and ongoing input into the design and operation of the services which assist them.

While case-mix funding requires greater emphasis on length of stay and discharge planning (Cleak, 1995), increasing attention is also being paid to consumer satisfaction (Nagel 1991; TQA Research 1994) and the balance between cost and quality (Zander 1992).

Clinical pathways, critical paths and care map systems[4] all provide a data base for continuous quality improvement and research, case management through collaborative care and a degree of patient centredness, especially if patients and their families take part in the development of these systems (Zander 1991). In addition, the rationale for the introduction of these systems increasingly includes consumer satisfaction criteria such as decreasing fragmentation of services, increasing patient/family access to services and participation, leading to improvement of patient and family satisfaction (Zander 1993).

Beyond the hospital

The current policy emphasis on continuity and coordination of care

(Metropolitan Hospitals Planning Board 1995) is an exciting development in the provision of care for consumers with complex health needs, even in the context of fiscal constraints. Of particular significance is the widespread acknowledgement of the need to look beyond medically oriented hospital treatment to the development of networks of care in which hospitals are only one (albeit important) part. Concepts such as 'hospital in the home' and 'the boundaryless hospital' (Vining, Braithwaite & Lazarus 1994), with their emphasis on providing hospital type acute care in non-hospital settings, have set the scene for further debate.

The challenge for hospitals therefore seems to us to be twofold. Internally, a care management *system* needs to permeate the hospital's fundamental vision and therefore its organisational thinking, management and structures. This would involve a fundamental re-negotiation of the relationship between clinical and administrative structures in the hospital to emphasise patients' needs rather than professional and departmental boundaries. The task is clearly developmental and requires changes in attitudes and 'culture' as well as new procedures and systems, some of which will utilise emerging information technology.

The second challenge for the hospital relates to its interface with the larger network of consumers, community support, health and respite services. Although children with chronic health care needs will undoubtedly benefit from technological advances and new medical treatments, their quality of life will also continue to depend on the partnerships which the hospital creates with other care providers. ✪

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[1] Professionals are also increasingly paying attention to waiting times and repetitive recording of information, as part of overall quality improvement (Baine, S., Rosenbaum, P. & King, S. 1995; Berwick 1994; Brown, Sheehan, Sawyer, Raftos & Smyth 1995).

[2] The terminology in this area tends to be confusing, eg, in contrast to care management, the term 'managed care' is seen within the US context as 'a strategy developed by the health care industry as a means to control profitability in the disbursement of health care resources' (Cornelius 1994, p. 47). In Project Partnership, the term *care management* was used, rather than the more commonly used *case management*, as we felt it more adequately reflected a commitment to sensitive collaboration with patients around their care needs, compared with the more administrative meaning of the word 'case'. 'Care management' is nevertheless concerned with coordination and administrative efficiency.

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[3] Whoever undertakes care management, the family is seen by many writers as the primary source of continuity for the child and his or her care (Desguin et al 1994b).

[4] In distinguishing these terms, Zander (1992) describes critical paths as 'cost descriptors' and care maps as placing cost and quality in balance.