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Technology-dependent children and their families: a review

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Background. Advances in medical technology and nursing care have enabled children who rely on long-term medical and technical support to reunite with their families and community. The impact of discharging these children into the community involves a number of unprecedented social implications that warrant policy consideration. To begin with, an effort must be made to understand the phenomenon of caring for technology-dependent children living at home.

Aim. The aim of this paper is to provide a comprehensive literature review on caring for technology-dependent children living at home.

Methods. The review was conducted via keyword searches using various electronic databases. These included CINAHL, MEDLINE, Social Science Index, Sociological Abstracts, Australian Family and Society Abstracts, and the Australian Bureau of Statistics. The articles and books found were examined for commonality and difference, significant themes were extracted, and the strength of the research methods and subsequent evidence were critiqued.

Findings. In this paper, themes relating to home care for technology-dependent children and their families are elucidated and summarized. These are: chronic illness and children; the impact of paediatric home care on children; the uniqueness of technology-dependent children and their families; and parents' experience of paediatric home care.

Discussion. Contentious issues, relevant to the social life of these children and their families, are raised and are discussed with the intention of extending awareness and provoking further debate among key stakeholders. These issues include: the changed meaning of home; family dynamics; social isolation; saving costs for whom?; shifts in responsibility; and parentprofessional relationships.

Conclusion. More research is needed in the arena of paediatric home care, to facilitate relevant policy formation and implementation.

What is already known about this topic

- Advances in medical technology have resulted in increased survival rates for children who are severely ill and, consequently, have elevated the incidence of childhood disability and of children with long-term dependence on medical technology for sustaining basic life functions.
- A cost-effective strategy is to discharge children home to their families so that costs of care can be reduced, and children and their families can enjoy some normalcy.

- The transition from hospital to home is demanding for families and, as a result, the quality of life of technology-dependent children and their families may be impaired.

What this paper adds

- It provides an empirical review of issues associated with technology-dependent children and the experience of their families in caring for them at home.
- It discusses the social implications of introducing medical care and machinery into a home environment, with the aim of providing a more balanced view on medical technology and stimulating critical thinking in this area.
- It establishes a basis and directions for further critical discussions and future research.

Introduction

Advances in medical technology and medical and nursing research have resulted in improved survival rates, and better treatment options and outcomes for children with acute and chronic illness. In Australia, the mortality of children aged under 5 years fell from 2604 per 100 000 in males and from 2214 per 100 000 in females in 1907 to 137 and 111, respectively in 1998 (Stanley 2001). The lives of premature infants have been saved by sophisticated and expensive medical treatments and technology (Donoghue & Cust 1998). However, the impact of medical technology on population data relating to childhood disability is not well documented. Survival rates for infants born prematurely have improved during the past decade, despite minimal advances in optimizing neuro-developmental outcomes (Blair & Shean 1996). Although population data on disability in childhood in Australia are not readily available, changes suggest increases in both the incidence and prevalence of several impairments across the range of severity (Stanley 2001). Increases are clearly related to the survival of high-risk newborns and to children with established disability (Blair & Shean 1996).

The survival rates of children who are medically fragile and technology-dependent have improved and this has placed responsibility on care that relies heavily on hospital resources. Therefore, in order to cut hospital costs and the burden of care for these children, hospitals send them home to their families. Consequently, there is a growing reliance on community-based patient care delivery (Mcfadden 1989).

Paediatric home care has become a significant and necessary component of the health care industry [Office of Technology Assessment (OTA) 1987, Petr et al. 1995, Clemens et al. 1997]. A number of factors have contributed to the growth and development of paediatric home care, including increasing hospital costs for the care of technology-dependent children, the ability to transfer medical technology into homes and consumer preference (Smith et al. 1991, American Health Consultants 1999).

The focus of this paper is to review the literature to gain an understanding of the development of paediatric home care, and its impact on technology-dependent children and their families, and social implications.

Aims

The aim of this paper is to provide an empirical review of current literature on issues and implications associated with the care of long-term technology-dependent children and their families in paediatric home care settings.

Methods

The review was based on a series of database searches in the domains of nursing, medicine and social science. Databases searched were CINAHL, MEDLINE, Social Science Index, Sociological Abstracts, Australian Family and Society Abstracts, and the Australian Bureau of Statistics.

In these database searches, keywords in the fields of title and abstract were used. Keywords included 'children', 'technology-dependent', 'ventilator-dependent', 'home care', 'respite', 'community nursing', 'paediatric home health care' and 'technology'. Terms were searched for singly and in combination. In addition, reference lists of relevant articles were considered and the publications found were incorporated if useful.

The articles and books obtained were assessed in terms of the rigour of the methodology and methods used during data collection and analysis. This assessment was essential as claims in some qualitative studies may be incongruent with the underpinnings of its methodology (Potter 1996). Questions used in the critique were suggested by Mays and Pope (2000) for scrutinizing the quality of a qualitative study. Six areas were examined, namely worth or relevance, clarity of research question, appropriateness of the design to the question, context, sampling, data collection and analysis, and reflexivity of the account. The purpose was to ensure the reliability and validity of the findings, and to explain any biases in the studies. The themes presented in this paper were derived through exhaustive comparing, identifying, categorizing and critiquing procedures.

Chronic illness and children

Children with chronic illness often express a desire to be 'normal' and be treated as normal (Thompson & Gustafson 1996). The concept of 'normalization' appears regularly in research studies exploring the experience of children with chronic illness (Bird & Podmore 1990, Spitzer 1992, Yoos 1994). For example, in one qualitative study, a child with end-stage renal disease asserted: 'I 'if there's something that I want to do. I go ahead and do it. I don't let my kidney disease stop me' (Snethen et al. 2001, p. 165). 'Living as normally as possible' has been identified as the most common theme in connection with chronic disability (Strauss et al. 1984). Technology-dependent children are not exceptional in needing to establish their independence. For example, a ventilator-dependent, adolescent girl stated:

I look after myself really, I'm not that stupid you know, I'm coming along. (Noyes 2000a, p. 776)

Despite this striving for independence, the care of ventilator-dependent children is frequently based on a 'medical' model of disability (Noyes 2000a, 2000b). Children report feeling 'disabled' by societal perceptions and expectations of people with complex medical needs (Noyes 2000b). There are tensions between institutions and society about the management of people who depend on home technology. On the one hand, health care institutions expect children who are medically stable but require long-term medical and technological support to be discharged home rather than chronically institutionalized in an intensive care unit (Jardin et al. 1999, Noyes 2000a). On the other hand, a fragmented and unsystematic social support infrastructure (Kirk 1999), unreliable statistical data on home mechanical ventilation (Midgren et al. 2000), and under-funded family programmes for the children and their families (Townsend & Robinson 1999, Oslen & Maslin-Prothero 2001), are major obstacles to home care. Obstacles hinder the transition from hospital to home (Capen & Dedlow 1998, Gamblian et al. 1998), restrict return to the community (Fitch & Ross 1998, Cohen 1999) and negatively influence quality of life (Pehrsson et al. 1994, Gelinas et al. 1998). For example, Hochstadt and Yost (1991) argue that 'currently, few programs exist for developing and maintaining this population of children outside of medical institutions. As a result, they may remain hospitalized for months and often years' (p. 191).

Potential risks associated with the management of ventilator-dependent children at home, such as accidental death from unobserved disconnection or malfunction of a ventilator, power failure, falling from a wheelchair or accidental airway obstruction, have been highlighted (Nelson et al. 1996, Chestnut 1998). However, less emphasis has been placed on the emotional and social needs of these children and their families. Thus, there have been calls for more research in this area, to assist formulation of social and public policy (Bond et al. 1994, MacPhee 1995, Noyes 2000a).

Impact of paediatric home care on children

The home often provides a developmentally appropriate care environment that is emotionally nurturing and socially stimulating for children (Mack 1991). Abundant evidence demonstrates positive improvements in children's physical, emotional, psychological and social dimensions when a child's illness is managed at home (Bradley et al. 1995, McKenzie 2000). Both the child and their caregiver benefit from a reduced level of anxiety as the focus shifts from illness and helplessness to recovery and function (Kohrman 1991, p. 7, 8). Home care can foster an environment for children to build and develop self-identity by learning and participating in activities that implicitly or explicitly convey family values and beliefs, and create opportunities to acquire social skills. As sociologist Jaber Gubrium notes, home care is 'biographical work' (Arras & Dubler 1995, p. 5) that shapes self-images, defines human relationships and constructs meanings of life.

Uniqueness of the technology-dependent child

Technology-dependent children at home have specific needs that are different from those of children with chronic disability such as muscular atrophy, epilepsy or cerebral palsy. Technology-dependent children are defined by the United States Congress' Office of Technology Assessment as children with 'a medical device to compensate for the loss of a vital bodily function and substantial and ongoing nursing care to avert death or further disability' (OTA 1987, p. 3). Children who are

technology-dependent are diverse and vary in their characteristics of technology dependence. For example, children may require: ongoing or intermittent mechanical ventilation; tracheostomy and oxygen therapy; enteral and parenteral nutrition; intravenous drug therapies; and peritoneal dialysis and haemodialysis. The term 'technology-dependent' children can be used to refer to 'high-tech' dependent children, such as those reliant on a mechanical ventilator, or relatively 'low-tech' dependent children, such as those who have a colostomy (Wagner et al. 1988). The needs of these children may vary from 'continuous assistance of a device and highly trained caretaker to less frequent treatment and intermittent nursing care' (OTA 1987, p. 4). They are often medically stable, have high technical needs, require frequent changes of treatment regimens, experience a prolonged recovery and require skilled nursing (Hochstadt & Yost 1991).

Many technology-dependent children are dependent on more than one treatment device (Beresford 1995). Care of these children relies on substantial and ongoing nursing care provided by either a trained nurse or a trained lay caregiver. Current research strongly indicates that families with technology-dependent children at home confront physical, mental, social and financial stress, particularly when dependent children require an ongoing supply of expensive equipment, continuous nursing care and home help (Leonard et al. 1993, Noyes et al. 1999).

Parents' experiences of home care

Parents with a medically complex child at home report satisfaction in relation to witnessing the emotional and social growth of their child (Diehl et al. 1991, Petit de Mange 1998). Enabling children to participate in education is reported as a vital agenda of parents (Elder 2001, Palmer 2001). Although they struggle with education systems about provision of suitable resources and care, they develop knowledge of, and persistence in, finding ways to meet the needs of their child (Rehm 2002).

Children with disability living at home bring challenges for families (Glass et al. 1999, Scott 2000). Caring for a child who needs life-saving technical support at home can result in adverse health impacts on the primary caregiver(s). Mothers who care for medically fragile children at home are at risk of illness, especially if support and resources are limited or unavailable (MacDonald 1995, Thyen et al. 1999). Social support is the most significant factor in determining the employment status of carers. Unemployed mothers who are from single parent families, or have no social support, are reported to have poorer mental health status and, as a result, are more likely to compromise the quality of care to their children and family (Thyen et al. 1999).

Physical overburden

So far, the physical impact of a technology-dependent child at home on parents has not been researched and is not well documented, despite wide recognition and acknowledgement of the extra physical and emotional burden of caregivers (Wilson et al. 1998, Noyes 1999, Roberts & Lawton 2001). Sleep deprivation, insomnia, high levels of anxiety and depression are experienced by parents of children with severe disabilities at home (MacDonald 1995, Miles et al. 1999). These stress symptoms are no less prominent in parents with a technology-dependent child at home. Reports reveal a number of stress factors encountered by parents, including chronic anxiety about children's unpredictable medical states, high levels of vigilance (especially at

night) and constant beeping and buzzing from machinery alarms (McKeever 1991, Teague et al. 1993).

Evidence suggests that the daily routines and continual responsibilities associated with the medical care of a technology-dependent child can result in physical and emotional overburden on the carer (Leonard et al. 1993, Bradley et al. 1995, Thomlinson 2002). Quint et al. (1990) investigated a small group of parents with ventilator-dependent children at home and found that those who had been caring for children for more than 2 years had lower coping scores and were burnt out and exhausted. Jennings (1990) interviewed 10 mothers who cared for children with tracheostomy at home and reported that they found the care-giving experience exhausting and overwhelming. Similarly, mothers with medically fragile children experienced feelings of exhaustion, particularly during the first few weeks after the child was discharged home (Hodgkinson & Lester 2002). These experiences are also reflected in a study by McKeever (1991) who found that parents were constantly on alert for a crisis because of uncertainty about the child's illness and prognosis, and that this could lead to anxiety and depression.

Emotional turmoil

Parents with technology-dependent children at home experience a wide range of emotions such as anxiety, anger, guilt, frustration and sorrow (Smith et al. 1991, Patterson et al. 1994). There is evidence that caregivers of technology-dependent children at home are at risk of depression to an extent that requires medical attention (Thyen et al. 1999, Thomlinson 2002). Research with parents caring for children with chronic illness suggests that the chronicity exerts a constant reminder of their own vulnerability as parents (Bradley et al. 1995, MacDonald 1995).

A person's integrity can be threatened by illness, their world can be disrupted, and they can become vulnerable and frightened in the face of their own mortality (Sabatino 1999). This experience can be intensified for parents with a technology-dependent child at home because of the type and frequency of medical and technical care and frequent encounters with health care workers. For instance, interviews with 16 mothers who cared for ventilator-dependent children at home revealed that seeing medical equipment in the home was a source of chronic sorrow and pain (Wilson et al. 1998). In addition, the mothers explained that the need for nurses in the home was a constant reminder of the reality of the differences between other children/families and their own.

Parents with technology-dependent children at home may experience fear and panic about their child's illness and care (Sudela et al. 1993). For example, parents may fear finding their child dead (Kirk 1998, Wilson et al. 1998, Kohlen et al. 2000). Fear of performing technical procedures on their child and handling medical machinery may also exist (Leonard et al. 1993). Parents often say that they have insufficient knowledge and inadequate preparation to provide technical and medical care (Jennings 1990, Hodgkinson & Lester 2002). Children and adolescents also report distress and insecurity in relation to witnessing the stress on their parents when performing technical care (Noyes 2000b). The treatment regimes of technology-dependent children can be changeable and parents need support.

Some implications of paediatric home care

Changed meaning of 'home'

The introduction of medical technology into a home has social and ethical consequences, as it is often transformed into a miniature intensive care unit (Sudia-Robinson 1998). The traditional meaning of 'home' is altered by the intrusion of medical machinery. Home is usually a place where a person feels most 'at home' and is surrounded by familiar faces, furniture, sounds, smells, tastes and the comforting rituals of everyday life (Mack 1991). It is a place to find comfort and love and be with loved ones, and is supposed to be different to a hospital, which is often associated with efficiency, impersonal relations and death (Westwood 1998).

The development of a high-tech home care industry has resulted in blurring of the boundary between hospital and home (Arras & Dubler 1995). The home environment is rearranged and modified in order to accommodate a respirator, suction equipment, a wheelchair, portable oxygen and other clinical supplies (Bradley et al. 1995). Medical equipment can be noisy and contribute to making a foreign environment (Smith 1991, Sudia-Robinson 1998).

Families describe the presence of nurses as both supportive and disruptive (Patterson et al. 1994, Coffman 1995). In one study, a father of a ventilator-dependent child requiring 24-hour nursing care said

Lack of privacy mean[s] we have people coming and going all hours of the day and night and [they are] mostly female nurses, so I've got to be dressed appropriately when I'm walking around the house. (Coffman 1995, p. 139)

Thus, the meaning of 'home' as a place of security, privacy, and comfort is challenged or even lost for families with technology-dependent children at home. (Coffman 1995, Ruddick 1995)

Notwithstanding, high-tech home care can provide undisputed benefits for patients and families. Many parents welcome the discharge of their child to the home. They are no longer in a distant hospital or in an intensive care unit where life and death is the centre of everyday activity.

The introduction of high-tech home care results in challenging moral, social and policy considerations (Arras 1995). For example, Illich (1976) warns of the danger and prevalence of 'social iatrogenesis' (p. 40), in which people are unable to cope with their surroundings when they are penetrated and controlled by medicalization. Oldman and Beresford (2000) examined the impact of British housing conditions on people with disability, to illustrate the inadequacy of the medical model of disability in addressing the needs of people.

It can be argued that a social model of disability is appropriate because 'problems' do not originate from the functionality and impairment of people with disability, but stem from society itself. In other words, disability is not caused by the person being unable to participate in society but by society, which disables the person and prevents participation. A social model of disability highlights the responsibilities of society to meet the needs of people with disability. Kirk (1999) stresses the importance of health care professionals, political and social decision-makers, interest groups,

merchandisers and community support networks in adequately addressing the needs of children and families. Social policy should not be developed by categorizing medical devices (technocratic rationality) and calculating economic efficiency (economic rationalism). It must embrace values and ethics that are essential to sustain the dignity of human beings (value rationality).

Family dynamics

Parents with a technology-dependent child at home experience role conflict and ambiguity (Carnevale 1990, Murphy 1991, Wilson et al. 1998). For example, parenting can become confusing because of the nature of medical procedures that parents have to perform and the resulting discomfort and pain to their child.

Family relationships in the home of a technology-dependent child can be challenging due to the context of care at home (Patterson et al. 1992, Leonard et al. 1993, Teague et al. 1993). Behavioural changes in siblings (Smith 1991) and negative sibling relations, such as jealousy, resentment and rivalry, may occur (Quint et al. 1990, Petr et al. 1995). In addition, marital problems can occur (Teague et al. 1993). Marital discord relating to issues such as unevenly divided home duties (Petr et al. 1995), physical and emotional burnout (Miles et al. 1999), loss of privacy (Coffman 1995), and financial burden (Fleming et al. 1994, House 1995) can result in deteriorating marital relationships, family dysfunction and exacerbation of depression. Moreover, stressful family dynamics can be aggravated if families are socially isolated (Bradley et al. 1995).

Social isolation

Families with technology-dependent children at home are prone to social isolation (Kirk 1999). Evidence demonstrates that families of children with complex medical needs have difficulty in finding appropriate community support networks and services (Wheeler & Lewis 1993). It is reported that families with technology-dependent children at home engage in long battles for limited resources and the right to appropriate services, which can be time-consuming and stressful (McKeever 1991, Petr et al. 1995). Studies report that parents are dissatisfied with paediatric home care services because they are fragmented and poorly coordinated (Wheeler & Lewis 1993, Thorne et al. 1997, Kirk 1999). As a result, parents may be left on their own to coordinate health services to meet their child's needs.

Freedman and Clarke state that:

Unfortunately, systems for providing families of medically complex children with financial assistance for needed services are very fragmented and largely inadequate consequently, assessment of current and alternative systems for the funding of care of medically complex children is an important step in the development of adequate systems of care. (Freedman & Clarke 1991, p. 259)

Studies of medically complex children have demonstrated that the financial burden associated with home care is a significant source of stress (Wilson et al. 1998). Families with technology-dependent children at home, particularly single-parent and low-income families, are highly vulnerable to financial burden (Aday et al. 1988). House (1995) studied 98 informal caregivers of ventilator-dependent children at home and found that single-parent households had a fivefold likelihood of loss of income.

Financially difficult situations are likely to be even more pervasive and persistent if there are no national or local financial reimbursement schemes to cover loss of employment hours and the cost of supportive services such as paediatric home nursing and home help (Kirk 1999).

Furthermore, caregivers who report loss of income are more likely to have low insurance cover and restricted physical activity (House 1995). Therefore, employment may be able to buffer the negative effects of care at home on maternal mental health, provided there is sufficient and appropriate support to meet the needs of the child at home or in school. Based on this hypothesis, health policies should address the issue of financial burden and encourage labour force participation by caregivers (Thyen et al. 1999).

Kirk (1999, 2001) has called for formal education programmes to train nursing specialists to support families of technology-dependent children at home, because shortage of appropriate community nursing support may cause delays in hospital discharge and social isolation of families. Lack of appropriately skilled community nurses can also exacerbate difficulty in gaining access to short-term or respite care (Petr et al. 1995, Wilson et al. 1998, Noyes 1999).

Community-based professionals, including trained paediatric nurses, can be unfamiliar with the specialized needs of technology-dependent children (Wheeler & Lewis 1993, Kirk 1999). In addition, fear of litigation and legal implications can make community nurses reluctant to provide home care for technology-dependent children (Townsend & Robinson 1999, Kirk 2001). Indeed, paediatric home care nurses have highlighted the lack of formal guidelines and policy to facilitate their work with families (Scannell et al. 1993). As a result, community health services are often cautious about educating and training lay caregivers to perform medical tasks and provide short-term respite care (Kirk 1999).

Although respite care is vital, as it means that parents can recharge physical and emotional reserves and participate in household duties, and family and social activities, there are few research studies on the existence of community respite services and their contribution to meeting the needs of these families (Kirk 1999, Glendinning et al. 2001). Without effective respite services, families are likely to experience social isolation (Noyes et al. 1999).

Saving costs for whom?

The OTA (1987) asserts that 'the care of many technology-dependent children is likely to be least costly to society and to public or private insurers when it is provided at home' (p. 6). However, a close examination of cost indicators reveals a bias towards hospital-incurred expenses and less consideration for the social and financial situations of families (Jacobs & McDermott 1989, Bakewell-Sachs & Porth 1995). Costs are reduced because of the change of labour force from professionals to parents and the decreased number of laboratory investigations when children are cared for at home (Aday et al. 1988).

The actual cost for families who care for technology-dependent children at home has not yet been established and concerns have been raised about methodological flaws in some cost evaluation studies (OTA 1987, House 1995). Research investigating the

labour costs of caring for technology-dependent children often considers only indicators related to economic production and overlooks the non-monetary labour contribution of carers at home. Care-giving activities and responsibilities at home are hidden and ignored (Jaudes 1991, Bakewell-Sachs & Porth 1995). For example, insurance cover, and equipment, pharmaceutical, electricity, telephone and transport expenses are potential financial burdens that are hidden within families. To this end, Jacobs and McDermott (1989, p. 158) assert that 'although hidden costs are costly to assess, they are real nonetheless and from a public welfare standpoint they deserve full recognition'.

Shift of responsibility

The move toward paediatric home care has meant that medical and technical work, once provided in hospitals by trained health care professionals, is now provided by family members at home. The impact of this health care reform on families in the community is significant. Schachter and Holland (1995) stress that the shift of responsibility for patient care from institutions to family members at home has produced a spectrum of issues that demand psychological, social, ethical, financial and policy solutions.

Mothers are often the only family members who are taught technical procedures (Jennings 1990). In one case, a mother was shown how to change a tracheostomy tube on the day of discharge (Jennings 1990). Hospital staff tend to assume that families are prepared both to take their children home and cope with technical care (Scannell et al. 1993, Spiers 2002). There is a lack of congruence between the expectations of parents and those of professionals that warrants attention (Glendinning & Kirk 2000).

Parent professional relationships

Professionals' inherent power can devalue parents' position when comes to decision-making. The tension between professional expectations and parental role can complicate the process of role negotiation (Kirk 2001). For example, parents with technology-dependent children may experience contradictory expectations (McKeever 1991) because they are asked to become sophisticated health care experts and be responsible for their child's care at home but, at the same time, are expected to defer to, and comply with, advice from professionals. There are concerns about parental responsibility and the degree of choice parents can exercise in the face of professional power (Kirk 2001). Some studies have emphasized that relationships between parents and health care professionals can be problematic, and that attention to issues of control, trust and competence is warranted (Scannell et al. 1993, Coffman 1995).

Changes in the balance of power do not necessarily lead to the development of parentprofessional relationships that are characterized by partnership (Kirk 2001). Sensitivity and a reciprocal style of communication in negotiating and developing positive parentprofessional relationships should be encouraged in both clinical and home contexts (Seid et al. 2001). In order to achieve this goal, it is also important to understand home care professionals' perceptions of paediatric home care; at present, little is known about this topic (Scannell et al. 1993).

Limitations of the review

A lack of research-based literature in this area generated difficulty in gaining insights into the issues and experiences of children with long-term technology dependence at

home, and their families. There are hardly any relevant quantitative research studies, which is predictable given the difficulty of accessing this group of children and their families in the community. Notwithstanding, it is crucial for academics and practitioners to initiate quantitative research to develop, validate, implement and evaluate clinical and fiscal indicators of coping in technology-dependent children at home, and specific members of their families.

Qualitative research studies in the area are equally important. Although scarce, increasing numbers of qualitative studies are emerging and have provided important and relevant understandings for future research and policy formation. However, there are shortcomings in the research methodology and methods of these studies that may compromise rigour.

Existing studies described as qualitative lack clear and detailed description and explanation of their qualitative methodology and interviewing methods (Scannell et al. 1993, Noyes et al. 1999, Oslen & Maslin-Prothero 2001). The analytic methods used incline to content analysis, in lieu of in-depth description, interpretation and identification of contextual relationships within and between themes. Lack of clear description of the analytic process and rigour is also seen in Wilson et al.'s (1998) study, in which grounded theory was used to investigate basic social processes in coping by 16 mothers of ventilator-dependent children. In contrast, Coffman (1995) studied nine parents' experiences with paediatric nurses in the home, using hermeneutic phenomenology. In this study, the methodological framework, and methods used in data collection and analysis were clearly detailed, and rigour and study limitations were discussed.

Another limitation of the review relates to the disproportionate amount of literature focusing on administrative and operational measures involved in assisting the transition of this group of children and their families from hospital to home. There is little scholarly work that debates and discusses the potential physical, emotional, social and political implications of discharge for the children, their families and society as whole. Current trends indicate that hospitals may be ready to discharge these children (Pilmer 1994) but it is often debatable whether the community is ready to accept them, in terms of sufficient and appropriate support infrastructure to help them to cope and maintain a good quality of life (Kirk 1999, Glendinning & Kirk 2000). Medical technology can work wonders on human physiology and survival but its impact on the way we live and survive in society has yet to be questioned and explored.

Conclusions

This paper has explored the unique needs of technology-dependent children who are cared for at home. Issues relating to the concept of 'home', the scope of responsibility of professionals and parents, and altered relationships between the child, parents, siblings, professionals and society have been examined.

Despite paediatric home care being encouraged, particularly in the health care systems of the United States of America (USA) (OTA 1987), United Kingdom (UK) (Glendinning et al. 2001) and Australia (Cooper 1999), current knowledge about the impact of medical technology on children at home, families and society is minimal. Lack of research in the area has meant that many major issues have not been

adequately investigated and evaluated. Lack of evidence can also result in difficulties in establishing efficient and effective social, legal, clinical and fiscal policies to help technology-dependent children to return to the community, and to improve and sustain quality of life for them and their families.

Therefore, the appropriateness of current social and public policies in home health care for technology-dependent children and their families should be re-examined and re-evaluated, based on the findings of sound research studies. This is to recognize and acknowledge that the needs of these children and their families warrant urgent research attention and consideration from policy makers, professionals and society.

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