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Mothers' experiences of their child's recovery in hospital and at home: a qualitative investigation

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Abstract

Decreasing hospital stays, increasing day surgery and the assumption that parents will manage their child at home necessitate research into children's recovery. Given the scarcity of studies seeking parents' perspectives, this exploratory and interpretive study is timely, presenting a detailed account of mothers' experiences of managing their child's recovery in hospital and at home. The study supports the view that recovery begins not with discharge, but with admission and before, as hospital experiences directly shape the recovery process. Mothers' experiences of hospital's recovery enablers and inhibitors suggest that good recovery practices and policies remain erratic. Following discharge, parents help the child 'back to normal' by 'reading the recovering child' and balancing the child's desire for activity with the need for caution and safety. Developing a deeper understanding of parents' recovery experiences and perceptions would help nurses to form an empathic 'grounding' upon which to base improvements in children's recovery care.

Keywords child • day surgery • mothers' experiences • parents' perspectives • post-operative • recovery

Introduction

The hospitalization of children has changed markedly. For many families, lengthy in-patient stays have been replaced by shorter visits, or even by same-day surgery and discharge. Several forces have driven this change. Clinical and technical advances can mean less invasive surgery or less traumatic treatments. Shorter stays increase 'throughput', reduce direct costs and thus are economically

attractive, while the literature on the potentially damaging effects of hospitalization on children make shorter stays and reduced separation from home and family an attractive option. A critical assumption underpinning these changed patterns is that children can recover as well at home as they would do in hospital; an assumption that would be challenged by those who argue that economic pressures may be causing children to be discharged prematurely – what Duggan (1994: S19) calls the ‘quicker and sicker’ syndrome. Parents could help us to understand more clearly the nature of a child’s recovery, yet their important perspective remains relatively unexplored.

Background

Children’s hospitalization patterns show a clear trend towards shorter in-patient stays. The reasons for such a trend are clear. In the economic argot of the age, increasing patient ‘turnover’ or ‘throughput’ is an urgent consideration for health care providers worldwide in times of financial stringency (Chung, 1995; Rossen and McKeever, 1996; Smith and Daughtrey, 2000; While and Wilcox, 1994). Technological and clinical advances such as laparoscopic ‘keyhole’ surgery have also shortened hospitalization periods (Kotiniemi et al., 1997; MacCallum et al., 2001; Tagge et al., 1999; Yao and Poppas, 2000). Shorter hospital admission periods are also deemed better for both children and their families (Bar-Mor, 1997; Rossen and McKeever, 1996; Schmidt, 1990). While children’s units and hospitals undoubtedly have created a more welcoming and ‘family-friendly’ environment, a hospital is not home (Darbyshire, 1994). Hospitals can be difficult places for parents to be in, both physically and existentially, as they do not speak the language, know the codes or understand the customs and geography, often feeling like ‘pilgrims in an alien land’ (Lander and Warnock, 1999: 32).

There are benefits in the move towards shorter hospital stays but there are also vexing issues to be faced. What are the implications of cost-shifting care from hospitals and professionals to home and family? Are parents prepared for what is involved in caring for a recovering child at home? Do they understand the nature of recovery and convalescence and how to promote these? Do they have the knowledge and support that will give them the confidence to continue their child’s care at home? Do nurses have sufficient understanding of how parents manage their child’s recovery at home? Questions also arise about what constitutes a child’s recovery: is it when they can move around the house, is it when they stop vomiting and begin to eat and drink again, when they go out to play, or return to school? Despite the reduction in hospital length of stay and the associated greater burden of recovery care falling upon parents, there is, as Baker noted, ‘a dearth of research regarding recovery from surgery as a process that extends beyond hospitalization’ (Baker, 1989: 181). Recovery is a term that is taken for granted, so seemingly obvious in its everyday use that its meanings and

implications can be missed. Similarly, 'home' has powerful connotations of comfort, safety, familiarity, privacy and sanctuary (Darbyshire, 1994) that may be altered by the presence of a sick or recovering child. If we limit our understanding of recovery only to physiological and psychological measures we overlook a world of everyday small struggles, defeats and victories that are of such significance for children and their parents.

To provide the most responsive and sensitive recovery service for children and parents, nurses need a clear understanding of how parents actually experience, understand and manage their child's recovery in both hospital and at home. Such understandings remain elusive, as researchers have rarely asked parents to describe directly their experiences of their child's recovery (Bull, 1994; De Jesus et al., 1996; Kankkunen et al., 2002; Lander and Warnock, 1999; Maligalig, 1994; Rossen and McKeever, 1996; Smith and Daughtrey, 2000; Voepel-Lewis et al., 1992). This study contributes to the redressing of this omission.

Aims of the study

The aims of this study were to provide a detailed and faithful interpretive account of the experience of a child's recovery from hospitalization and treatment, and to provide a deeper insight into the meaning of recovery from the parents' perspective. Such perspectives are necessary to inform clinical practices and policies that are genuinely responsive to the needs of children and parents.

Method

This study asked the question: 'what is the recovery experience like for the parents of a recently-hospitalized child?' A qualitative research approach, drawing on the tradition of interpretive phenomenology (Benner, 1994a) was chosen, not for ideological reasons, but because it best answered the research question. This approach enabled the ascertaining and interpretation of the ways that parents articulated, and made sense of, these experiences which were related to their child's recovery. Qualitative research data can be obtained in numerous ways, and in this study parents were offered the chance to take part in either an individual or small focus group interview according to their preference. Most parents chose a group interview. Focus group interviews 'are a particularly good choice of method when the purpose of the research is to elicit people's understandings, opinions and views, or to explore how these are advanced, elaborated and negotiated in a social context' (Wilkinson, 1998: 187). The study was carried out at the Women's and Children's Hospital, Adelaide, the major paediatric referral centre for the state of South Australia.

Selecting research participants

Sampling in qualitative research is directed at finding information-rich cases rather than towards randomization and generalization (Kuzel, 1999). Thus parents from various medical and surgical areas of the hospital, who had recent experience of the central study phenomenon of their child's hospitalization and recovery, were invited to participate. Although both 'parents' were invited to take part, all of the study participants were mothers. This does not imply that fathers are uninterested in their child's health or in research, but may reflect currently prevalent patterns of childcare where fathers take a less direct, but still supportive, role (Horner, 1997); also, where mothers remain the predominant carers and being, for example, the parent most likely to stay with the child during hospitalization (Darbyshire, 1994), as well as accompanying them to clinic visits. A clear implication of recruiting only mothers is reflected in this article's title and in the limitations in discussion, where it is emphasized that a study involving only mothers (or indeed fathers) cannot be presented as an account of the experiences of parents in general.

Obtaining and analysing data

Following written institutional ethics approval and discussions with nursing unit heads in each clinical area, parents were contacted and given a jargon-free information sheet explaining the study and inviting them to participate. They were assured of confidentiality and of their right to withdraw from the study at any time without prejudice. Verbal explanation prior to each interview stressed that they could choose to respond, or to decline to respond, to any question. Interviews were conducted in a meeting room at the hospital at a time convenient for the parents, which often coincided with a scheduled clinic or similar visit.

Ten parents, all mothers, were interviewed, eight in three small group interviews and two in individual interviews. Interviews lasted between 30 and 90 minutes. Their children's ages ranged from 6 months to 14 years and all had undergone ear, nose and throat or gastro-intestinal surgery, except for one child who had received a serious burn. Most of the children had undergone day surgery or had spent only a few days in hospital, other than the child who had been burned and who had been in hospital for several weeks. To foster an interpretive openness to the participants' experiences, there was no prescriptive interview schedule. Instead, there were generative or 'trigger' questions based upon the study aims and the existing literature which gave the interviews their focus, for example: 'Can you tell me what life was like for the family when (the child) came home from hospital?' and 'What were the things that made you think that your child was recovering/getting better/making progress?' The interviews were informal conversations that enabled the parents to describe and discuss their experiences and perceptions of their child's recovery. Interviews were tape-

recorded, transcribed verbatim and checked to ensure accuracy and completeness of the interview data. The interview transcripts were organized and coded using N-Vivo qualitative software (QSR International Pty Ltd, 2001) and analytically refined in detail in order to identify and articulate important themes, events, perceptions and understandings illustrating the mothers' experiences of their children's recovery. When reporting participants' quoted comments, the particular mother and interview are cited (e.g. Int#6, M2). This is important to show that, for example, all of the cited data do not come from only one participant or interview. No children's real names are used.

Results

On being the parent of a recovering child

To them it's minor, but to a mum it's big. It's a big thing.

Any discussion of children's hospitalization and recovery should immediately recognize that, for parents, there is no such thing as 'minor' surgery where *their* child is concerned. This is no tired cliché, but a touchstone of an empathetic and sensitive service. Some of the parents in this study had previous experience of bringing their child to doctors, clinics and hospital for treatment, but this does not assuage the anxiety of knowing that your child will be anaesthetized and undergo an operation.

Participants were asked to 'tell the story' of their child's recovery. To do this, they set the context by first describing the child's illness or injury and subsequent hospitalization. This seemed not merely a narrative device, but an important way of showing that the phenomena of recovery cannot be clearly understood as an exclusively post-hospital event. The experience of recovery at home is surely shaped by events and encounters before and during hospitalization, and so this section of the article explores the mothers' experiences of these formative events.

Hospital experiences

They could kind of explain it more and understand what you are going through.

The hospital experiences of parents of sick children have been well documented (Dampier et al., 2002; Darbyshire, 1994; Garcia de Lima et al., 2001; Hallstrom and Runeson, 2001; Marino and Marino, 2000; Smith, 1989); even a brief stay in hospital with a sick child can be traumatic. As one mother commented:

I stayed the night and that was [laughter] horrific. That was the worst night of my life I think. (Int#6, M1)

While another remarked of her hospitalization experience:

You just can't believe that any normal person could feel so many emotions in one day. (Int#6, M2)

Preparing for hospital

I had no idea what to expect really.

One of the notable features of the mothers' accounts was how variable their knowledge and understanding was about their child's hospitalization. Some parents had been well informed, had their questions answered in a language that they could understand and had seen their child respectfully involved in the process. They were impressed by staff who explained and helped them understand recovery:

She was really good. She was the only nurse up there that took time out to tell us what had actually, like, we knew what had happened to them while they were in surgery but we kept asking them about how long it was going to take them to get better. (Int#1, M1)

This mother gives a linguistic clue as to why participants' experiences may have been so erratic in this respect. If talking to parents, explaining treatment care and recovery, reassuring and generally being with them at a stressful time is still perceived as 'taking time out' (from the 'real work?'), then nurses are conveying an unhelpful message to parents about what is of greater and lesser importance in their child's care and recovery. Mothers valued and appreciated nurses and other staff taking time to talk with them about their concerns. As this mother observed:

You just need that support when you come in. It'd be really nice just to have somebody to sit there and talk to you about that sort of thing. (Int#6, M1)

Parents tried to prepare their child for hospitalization by tailoring information and explanation according to both the child's and their own levels of understanding. This was not an 'either/or' dichotomy between the fully informed and uninformed child. There were things about treatment and hospitalization that parents would tell their children and things that they would not. Explaining to the child was a nuanced judgement that acknowledged the importance of timing as well as the level and content of information given. Parents sought a balance in both content and detail between telling their child enough to let them know what was going to happen, but without overloading them and perhaps causing additional anxiety. As one mother explained:

We didn't talk about it a real lot because I didn't want it to weigh on his mind . . . I basically explained to him what was going to happen so that he would have a clearer picture. (Int#5)

Although one mother was appreciative of a colouring and activity book about hospital and treatment with which her daughter had enjoyed playing with on admission, no participant mentioned any involvement in a 'preparation for hospital' programme of the kind described by, for example, Bar-Mor (1997), Ellerton and Merriam (1994), Lynch (1994) and Murphy-Taylor (1999).

Information and communication

Bugger the bloody pamphlet, tell me what he can bloody eat.

The recovery literature is replete with criticisms of professionals' communication, citing mostly poor quality and quantity of information shared with parents. The drive towards greater 'throughput' is not only linguistically unfortunate but can undermine attempts to provide an individualized and personal service. When such production-line thinking overlooks the uniqueness of parents and children, the dangers of conveyor belt interactions are very real. As one mother commented,

You're standing there thinking, I'm a person. He's a person, not a car getting worked on. I'm not saying everyone's like that, but yeah, it can feel that way. (Int#5)

Mothers had mixed experiences of pre-operative information and discussion. When staff were respectful of not only the parents' but the child's needs and directly involved them in the discussions and explanations in a language that the child could understand, this created confidence. One mother explained:

His surgeon actually explained to him . . . what he was doing, and, and what it would do for him and he had that trust in him. (Int#1, M2)

Another mother was similarly positive, describing how

he knew what was going to happen because his doctor explained it to him very well, so he knew . . . what the procedure was . . . He understood everything. (Int#3, M1)

Conversely, parents were frustrated and uncertain when important explanations seemed unforthcoming. As this mother observed:

I just kind of feel like that they [the specialists] could explain it more and understand what you are going through. It's traumatic going through it all and it's kind of like, this is happening, OK, goodbye. (Int#5)

Equally irritating for parents were the occasions when explanations and information seemed to be more for the benefit of other professionals:

I went in to the specialist, now he had all these student doctors . . . and they were talking this medical lingo that I don't understand at all, I was just sitting there thinking, 'I don't know still what's happening'. (Int#6, M1)

Anesthesia, induction and recovery

When they are going under anaesthetic I don't think anything's minor.

One of the most difficult times for parents was when their child was anaesthetized. Even when they were offered the opportunity to accompany their child and to help 'put them to sleep' (surely one of hospitalization's most unfortunate euphemisms), this was a distressing time. As one mother noted:

I went up with him while they put the gas in and put him to sleep and that was pretty horrifying. (Int#6, M1)

Horror is a well-chosen term here, for what lies unspoken at the heart of a child's anaesthesia and surgery is the possibility, at once both remote and omnipresent, of the child's death. If induction of the anesthetic was difficult for parents, this was often surpassed by the wait for the child's safe return from theatre and by the post-operative appearance and behaviour of the child. Participants described the various explanations that they had received concerning the child's return from theatre, but few felt that this had best prepared them for what to expect. Nor did they describe being adequately prepared to manage their child's continuing recovery at home. There seems a world of difference between hearing that your child will return from theatre with an intravenous infusion, bandaging or drainage tubes and then actually seeing the child with all of the paraphernalia of serious illness in place. This mother's reaction was common:

He came back [from theatre] and the nurse read out to go home today, and I just burst into tears! 'I can't take him home' because he's got a drip, 'I can't take that with me, what am I going to do?' (Int#5)

Even for one participant who was a health care professional, this was the moment when her carefully-constructed composure broke down and

the wheels fell off . . . I was still being 'it's going to be OK'. Like you know, that [health professional] side I think comes out automatically . . . But the wheels fell off I think when I walked into recovery and saw him. (Int#6, M2).

What nurses may see as 'basic equipment', but what Place (2000: 175) calls 'technodressing', such as IV infusions, electronic monitors or drainage tubes are often perceived by patients and parents as emblems of emergency and as touchstones of serious illness. When people hush their voices to describe a friend or relative in hospital who is 'on a drip', this is cultural shorthand for how seriously ill they are. Small wonder perhaps that parents can be so distressed when they see such familiar indications of seriousness attached to their child.

Other parents described more difficult hospital recoveries that were often characterized by unanticipated pain, confusion about what was happening with their child and feelings of helplessness that they were unable to 'make things better' for their child. As this mother recounted:

He looked really pale . . . and he told me . . . it was like knives going through his stomach and he wanted to die. I mean that was pretty. . . that started me off . . . when you've got a little eight year-old telling you [that]. I wasn't ready for that. (Int#5)

The mothers described feeling limited in their ability to help with their child's immediate recovery, especially if the child was in pain or discomfort. They spoke of having a limited understanding of what to expect in relation to their child's post-operative condition and especially in relation to possible post-operative pain. As this mother commented:

Now I didn't know how long he was going to be in this pain. I thought, I don't know if it's going to be days, I don't know if it's going to be a whole week. I mean, I didn't know and I'm thinking, so I was really stressed that: Oh, he's going to have to go home and is he still going to be in this pain. (Int#3, M1)

Most of the mothers described how 'all they could do was' to comfort and calm the child, cuddling and holding them, trying to get them to sleep or distracting and amusing them.

Discharge

He can go home when he's had a drink.

Participants had mixed responses to the timing and circumstances of their child's discharge. Where the child was clearly pain-free, keen to be home and where parents were confident in their abilities to continue care, discharge was welcomed. As this mother of a child with asthma noted:

Yeah, he takes his mask good. I think he's more relaxed at home and he's just happy to be home with his brothers, and sisters. (Int#2)

However, where a mother deemed her child's condition to be more serious and his care more demanding, early discharge was almost dreaded:

What about when I go home? What, how do I look after him? I'm not a nurse. I don't understand. . . (Int#6, M1)

Flexibility of discharge timing, and being able to stay in longer if the child wished, was appreciated:

I said to the nurse, 'What happens now?' And she said, well you know, 'she could stay if she wants', and when I finally woke her, I said, 'Do you want to stay here the night and go home tomorrow?' There's no pressure to go home or anything, and then she said, 'I want to go home'. (Int#1, M3)

Parents often welcomed the reassurance of staying in hospital overnight, feeling 'more relaxed, so that if anything happened I was already in here' (Int#1,

M2); and 'believing that when you are in there [hospital], you're going to be OK because you're getting the best treatment' (Int#5).

However, the potential benefits of shorter hospitalizations could be illusory for parents if they were apprehensive about their child's condition and their ability to care for the child at home. A child's early discharge could place parents in the difficult position of openly disagreeing with professionals and of 'confessing' that they may not be confident or competent enough to care for the child at home, especially if this care is framed by professionals as being 'easy'. As this mother observed:

I knew I should have said, 'No. I want him to stay in', but it's, you know, the doctor comes in and says he can go home: 'It was minor surgery, he's fine. He'll be like a piece of cake in the morning, won't even know he's same child.' Oh yeah? (Int#6, M1)

For this mother, discharge seemed less of a planned process and more akin to being simply left to her own devices:

The doctor came and visited about 8 o'clock in the morning and he said, 'oh, he can go home when he's had a drink'. I mean the surgeon wasn't all that terrific I suppose, not very talkative. I was like, what do I do with him? You know, I don't know, he's only six months-old, he's not really eating food. Am I supposed to feed him? (Int#6, M1)

Mothers were asked about any post-discharge follow-up but only one mother from a rural area had received home visits from specialist nurses. No participant mentioned any kind of written information or advice which was related to their child's recovery, save for one mother's disparaging reference to the 'bloody pamphlet'. Only one mother recalled the promise of a follow-up phone call at home:

I asked about a follow-up, do we get a follow-up, and she just, the nurse said, 'yeah, they'll ring you'. So, I thought, 'OK'. (Int#5)

However, the call was not received.

Reading the recovering child

She looked fine in herself.

Most mothers in this study agreed that their child was keen to be discharged home from hospital sooner rather than later, but also understood that even caring for child undergoing a 'normal recovery' could be challenging.

Appreciating how parents understand their child's illness and promote their recovery following discharge requires recognition of the situated meaning of these two fundamental concepts of 'recovery' and 'home'. I use 'situation' here in

the sense described by Heidegger and developed by Benner and other researchers in the interpretive tradition (Benner, 1994b). For Heidegger, a situation was never simply a place and time or a straightforward 'state-of-affairs', for a situation encompassed a greater totality of meaning. As Guignon notes: 'To be in a situation, then, is to be part of an unfolding story with a distinctive temporal structure' (Guignon, 2000: 85). Heidegger's particular explication of the nature of a situation also stressed its potentially life-changing nature as a 'unique conjuncture of a person's unfolding life story' (Guignon, 1992: 139). Surely these mothers would share this understanding of being at a crucial existential juncture where decisions, actions and judgements must be made and whose implications for both child and parents may be profound. One mother articulated this sense of situation perfectly:

If he's going to be cured OK, that's fine but what's his life going to be. You know, what's he going to have to do? Is he going to have to miss out on things because he's . . . because of the surgery or . . . what's going to happen 20 years down the track, and they can't tell you that. And that's really hard when you've got to make a decision for you child. (Int#6, M1)

Recovery can be no more a purely physiological or psychological process than home can be merely a physical location. Recovery at home takes place, or does not, within a matrix of places, meanings, interpretations, connotations, expectations, people, concerns and practices. In recalling and recounting the stories of their child's recovery, the mothers articulated a wide range of such concerns.

Recognising recovery

Can you tell me what he's going to be like? That's what I really worried about.

Parents had generally vague expectations regarding both their child's recovery and how they could best promote and manage this. Some of the mothers were uncertain as to which aspects of their child's behaviour and reactions were significant and meaningful for their recovery. It seemed difficult for them to know exactly which signs or indicators were 'important enough' to be reported, which ones they could deal with themselves and which could be safely ignored. What seemed easier for them was determining that their child was keen to go home. They noticed when their child was becoming more active, restless, playful, hungry and harder to keep occupied, as this mother noted:

When she starts to get better and wants to play and do things like that and she's sort of more bright and alert then you know . . . she's obviously wants to get home, so we try and get her home as quick as possible. (Int#3, M3)

Pain and significant symptoms

How much longer am I going to have to put up with him crying?

No parent can comfortably watch their child being in pain and so it was no surprise that the mothers had a clear focus on their child's levels of pain or discomfort as central indicators of recovery. While parents might expect their child to be, for example 'groggy and irritable' (Int#1, M3) immediately post-operatively, the expectation was that they would not be experiencing worrying levels of pain and discomfort following their discharge home.

One mother's extensive account of her baby's problematic recovery period at home was significant here in showing the perceptual mismatches that can occur between professional and parental understandings around the most seemingly simple of concepts/words – 'uncomfortable':

Can you tell me what he's going to be like? That's what I really worried about, what he would be like when he comes home. I mean I didn't expect him to be . . . like perfect. I expected him to be in some sort of discomfort and, everyone I spoke to said, 'Oh, he'll be uncomfortable'. OK. 'Well what's uncomfortable? Is uncomfortable [that] he can't bear to be touched on his stomach? Should I be holding him up? Where should I be holding him?' You know he can't, he can sit up but he's, like, wobbly. If he falls over is it going to hurt? Is, you know, should I sit him up, should I put him in a chair, restrain him? Should . . . what should I do with him? (Int#6, M1)

Telling parents that their child may be 'uncomfortable' for a few days after returning home may work in a majority of cases where recovery is relatively unproblematic and where the child is older and can readily express discomfort. However, such shorthand will not help parents whose child's condition is more serious, whose home care needs are more specific and who may be too young to have developed a language of distress and comfort that the parents readily understand.

For the mothers whose children experienced less traumatic recoveries, managing pain and discomfort was often more easily achieved by observing the child and using comfort measures and distractions such as videos and mild analgesics. This was the common 'Panadol and Playstation' strategy described by this mother:

So they played video game things and he came home from that and he was just totally exhausted, his stomach started to hurt and he wasn't well at all, so I had to give him Panadol [paracetamol/acetaminophen] and put him to bed. (Int#5)

Balancing activity and safety

It's a really big adjustment to not be doing something all the time.

In reading their child's recovery, parents balanced their attempts to help their child back into their normal activities or routine with simultaneously protecting

them from any possible complications and setbacks caused by 'overdoing it', such as increased pain or opened suture lines. It is common to consider a child's recovery in terms of encouraging and enabling them to return to their pre-treatment activity levels. However, many parents described the converse challenge of preventing them from rushing too quickly back to their usual sports and pastimes. As this mother noted:

He's one of those really active kids and all of a sudden he had to just sit there and he'd play a lot of cards with me and stuff. (Int#5)

She also explained how she judged his recovery progress by watching his reaction to resuming activities:

So I figured that, if you've just gone to a friend's for an afternoon and you're like that [tired] and you're still sleeping until 10.30 in the morning when you're usually up at 6.30 to 7, you obviously still need that extra . . . Your body's still healing. (Int#5)

This balance between normal activity and safety was difficult to achieve, especially where the child felt bored and restricted and desperately wanted to return to their 'normal stuff':

Mine wanted to go outside and play basketball and I said, 'Forget about it!' [Laughter] So the boy's fourteen you know so he loves his sport and I said, 'No, you've just got to sit at home and you've got to you know, just relax'. So, it was just basically videos all the time or the computer or whatever. So by the first couple of days he was totally bored and I said, 'No, you've just got to take it easy for the first week'. (Int#3, M1)

Parents considered a range of indicators as they determined whether, and how, their child was recovering. They observed, for example, their child's eating, sleeping, activity, mood, readiness for school or playgroup and general behaviour. They monitored the child's symptoms such as pain and vomiting, and noted their need for, and reactions to, medications. They also acted on the reports of others such as family friends, relatives and teachers, who would 'report back' on how the child was when the parent was not present.

Discussion

It is predictable, given the worldwide political and economic climate and the emerging evidence of safety, cost-effectiveness and satisfaction (Letts et al., 2001; MacCallum et al., 2001; Ramanujam et al., 1998; Sprunger et al., 2001; Tagge et al., 1999) that children will experience shorter hospital stays, day-surgery services will increase and parents will be expected to take a greater role in caring for their discharged child. Therefore, this article is timely in exploring how parents under-

stand and manage the recovery aspects of their child's hospitalization, discharge and eventual return to health.

At the existential core of children's hospitalization and treatment is the fearful possibility or actuality that for parents, their child will be vulnerable, afraid, alone, in pain, anaesthetized, unconscious and beyond their care for some time. In a deeper and darker place lies the most unthinkable of possibilities – that somehow, something may go wrong and their child may die. Such parental fears cannot easily be dispelled, even by well-meaning attempts to minimize the experience as 'minor surgery' or by appeals to reason, statistics or risk ratios. These fears operate in a different realm of knowing. 'Knowing' that the chances of an adverse effect are one in a million does not prevent a parent from worrying that her child may just be that one. In the context of cancer risk, Gifford usefully distinguishes between objective risk and 'lived risk' (Gifford, 1986: 220). This may account for why the parents' stories of their child's recovery focused in such detail on the period surrounding their anaesthesia and immediate post-operative recovery.

The mothers were clear that recovery was not merely a post-hospital phenomenon. All aspects of the child's illness or injury – their admission, hospitalization and discharge – had an impact on how the parents described and managed the child's recovery at home. Previous studies (Bragadottir, 1999; Bull, 1994; De Jesus et al., 1996; Lander and Warnock, 1999; Smith and Daughtrey, 2000; Snowdon and Kane, 1995) have been critical, or indeed scathing (While and Wilcox, 1994), of the poor quality of information given to parents whose child was undergoing day surgery. In this study parents again described the vital importance of being informed and knowledgeable about both their child's current condition and prospective care at home. Their experiences of receiving information and explanations that were vague or jargonistic rather than timely, comprehensible and specific, mirrored many of the information shortcomings identified in earlier studies. However, parents were very impressed and appreciative when staff made a clear attempt to involve the child directly in information and explanation and to do this in such a way (and such language) that the child could understand. These mothers were in no doubt that this purposeful informing and involvement of the child paid dividends later in the recovery process.

I contend that leaflets, videos, information sheets and other technologies of telling will, on their own, be of limited value if there is not a fundamental culture of respect for parents' and children's perceptions, understandings and experiences. For parents, this is not ultimately about whether they were given 'enough' information, it is about whether staff really cared about them and their child. Following MacLeod's (1996) exemplary work on 'Noticing, Understanding and Acting', this is about whether nurses noticed that the parents seemed anxious or confused or uncertain, whether they understood what the parents were 'going through' and what they did at that moment to help them to reach a clearer or different understanding, or to another important question. Appreciating that

parents will have different needs for information and advice and that they will require different approaches, perhaps even on different days or even within a day, is part of the complex mosaic of skilled clinical judgement, or to paraphrase Lindeman (1989: 195) slightly, the artistry of recovery nursing.

The mothers in this study shared the parental concerns about post-operative pain which are repeatedly expressed in the emerging literature on children's recovery (Finley et al., 1996; Jolliffe, 1997; Kankkunen et al., 2002; Kotiniemi et al., 1997; Sikich et al., 1997). Finley et al. found that in supposedly 'minor' surgery such as tonsillectomy, circumcision and strabismus repair, almost half of the children that were studied experienced 'clinically significant pain' (1996: 83). Similarly, in this study several mothers were distressed by the extent of their child's pain and felt helpless and unable to provide either comfort or pain relief. As the mother of a baby who had undergone abdominal surgery remarked in some exasperation, 'I wasn't told he would be screaming like this!' (Int#6, M1). In reading their child's recovery, parents had a clear focus on their child's pain and discomfort/comfort levels. Reid et al. (1995) asked parents to diarize the 'clues' that their child was experiencing post-operative pain. They found the pain 'cues' that parents used included verbal reports, observations, appetite, sleep quality, visual and aural discomfort signs and physiological observations. This study strongly supports these earlier findings as these mothers used similar cues in monitoring and managing their child's return to normal functioning. What is of continuing concern is that some children still experience levels of immediate and post-discharge post-operative pain that are distressing for parents, and for which occasional paracetamol seems the analgesia of choice.

Caring for their recovering child at home was an almost exclusively personal responsibility for the mothers in this study. While they may have received some informal help from partners, spouses, relatives and friends, as with other families reported in recent studies (Lander and Warnock, 1999; Smith and Daughtrey, 2000) they were expected to manage essentially on their own, without professional support. Given the volumes of research in children's nursing devoted to partnerships in care, and the proclamations made in almost every hospital's vision and mission statements about meeting and exceeding their 'customers' expectations, it is paradoxical that such devotion to partnerships with parents often seems to end at the hospital's exit. MacCallum et al.'s conclusion regarding children undergoing ambulatory adenotonsillectomy seems apposite for all children:

A well-informed, reliable caretaker and support from the day-surgery staff is essential in early discharge of young patients. (2001: 75)

Several aspects of these mothers' experiences resonate directly with the substantial work of Mishel and others on uncertainty in illness (Mishel, 1988; Penrod, 2001) and especially in childhood illness (Dodgson et al., 2000; Horner, 1997; Stewart and Mishel, 2000). The study also helps to redress the gap identi-

fied by Penrod, who noted that 'we know little of the phenomenological experience of states of uncertainty' (2001: 243). Mishel (1988) defined uncertainty as 'the inability to determine the meaning of illness-related events', and further identified that 'uncertainty is a virtually universal experience for families facing serious childhood illness' (Stewart and Mishel, 2000: 313). This study suggests that these dimensions of uncertainty may also apply to parents whose children have experienced 'minor illness'.

While early conceptualizations of uncertainty tended to emphasize its cognitive characteristics (McCormick, 2002) more recent work has posited a more existential or phenomenological dimension. For example, Penrod (2001: 241) proposes that uncertainty is not primarily 'a set of possibilities, but a state of being'. She also links uncertainty to distress, enduring and suffering – aspects of uncertainty that the participants in this study would surely recognize. Mothers in this study described difficult experiences of uncertainty related to gaining knowledge and information about their child's condition and treatment, recognizing and understanding their child's 'recovery cues', appreciating the severity or otherwise of symptoms and generally relating to, and working with, the health care system.

However, it would be both a conceptual and clinical mistake to assume that uncertainty can be eliminated and substituted by a supposedly preferable, if illusory, state of 'certainty'. Very few aspects of parenthood or child and family health are 'certain' and most parents would accept this. The mothers' accounts in this study suggest that what is being asked of health professionals and hospitals is not that they 'produce certainty', but that they communicate and practice openly, respectfully and collaboratively with parents in such a way that parents develop or regain the confidence in their own expertise that allows them to better understand the meanings associated with their child's illness and recovery, and so respond appropriately at each stage of their child's recovery.

Limitations of the study

This was a small scale, exploratory, qualitative study conducted in one children's hospital. Thus it would be foolish to over-generalize from this study to the entire population of parents whose child has recovered from hospitalization and treatment. The single interview, which is something of a staple of qualitative research, has many limitations, not least the inability to seek further clarification, ask additional probe questions and track experiences over time. Despite such limitations, much can be learned from a rich and detailed account of the experiences of even small numbers of mothers in such a context. This study has highlighted the broad commonalities of mothers' experiences of their children's recovery that deserve the attention of children's nurses, and that contribute to the emerging research literature which explores the experiential and existential elements of

recovery. 'What can we learn from only a small scale study?' is a criticism frequently levelled at qualitative research. As Harry Walcott explained recently, the answer is simply, 'As much as we can'.

Recommendations

Researchers who have no direct responsibility for patient care services should be cautious in concluding their work and, critics may add, discharging their responsibility, with lists of prescriptive changes to practice that 'nurses must' make. A more modest proposal here are some observations and suggestions that may help clinicians to consider how to develop a deeper appreciation of parents' experiences of recovery, which would form a firm grounding for subsequent improvements in recovery care.

- If we are to take 'parent participation' seriously, is there a need for a forum or mechanism in day surgery and similar areas where parents (and perhaps older children) can have a genuinely advisory voice in how the service is operated? If so, how can staff create and sustain this?
- Information, explanation, knowledge and advice are still contentious issues for parents and practitioners. What would be the effect if practitioners viewed these primarily as human relationships or professional caring issues, rather than as pamphlet availability or 'telling parents' ones?
- Parents value flexibility in 'the system' and being able to make informed and supported choices and decisions about their child. Could such flexibility be built into more aspects of the child's treatment, discharge and recovery? Rather than having an overly-determined 'pathway', how would parents respond to a system which asked them 'how they would like to play it' in relation to their child's stay and recovery?
- Parents would appreciate a follow-up phone call from the hospital inquiring as to how the child is doing. This is both a valued caring gesture and an opportunity for them to ask any questions about the child's recovery at home. In a busy unit, can this be operationalized as a priority on a par with say, identification bands, pre-meds and post-operative observations?
- Parents need to have a contact phone number for someone who can give them knowledgeable help and advice about their child, at any time of day or night, should they have a concern or problem following discharge. Why this seems difficult to achieve is unclear.
- Sensitive and responsive services for parents and children must surely be based on a deep appreciation of their situation – the 'what this is like' – for the families concerned. A useful focus here for clinical development work would be to draw on parents' altruism by exploring ways of enabling parents and

children to participate in fora and mechanisms that are welcoming. Here, they could share their experiences of hospitalization and recovery with staff in order to improve mutual understandings. Colleagues interested in areas such as parental participation, consumer involvement, children's rights and quality assurance may also be keen to collaborate in developing such initiatives.

Conclusion

Increases in day surgery and generally shorter hospital stays have a crucial impact on the nature of children's recovery and the role that parents play in this process. Seeing these changing patterns of treatment provision as something that nurses should be 'for' or 'against' seems to be pointless dichotomizing. In a service that is sensitive and receptive to parents' and children's preferences, there will be both choices available for families and also nurses providing care who are committed to helping and supporting the child and parents through their experience of hospitalization and recovery. Mothers' experiences in this study highlighted the need for staff to appreciate that this was not 'minor surgery', but a difficult, uncertain and often traumatic time. Parents who are involved, informed, communicated with, advised specifically and who feel cared for, and cared about, will be more confident and capable of being 'partners in care' and helping their child through the hospitalization and recovery process.

Shorter in-patient stays radically alter our previous understandings of the nurse-patient and nurse-parent relationship. What kind of 'partnership' or relationship can be expected between nurses and parents who see each other for less than eight hours? One of paediatric nursing's pressing challenges is to develop creative and effective ways of responding to these changes. An essential part of this process will be to foster a research-based appreciation of parents' understandings and experiences of what it means to be the parent of a recovering child. Something written in the wider context of working with parents seems especially relevant to developing the policies and practices in recovery care that will rise to these challenges:

We need the humility to listen to parents before we plan services for them. We need to learn from them before we presume to teach them. For only from a basis of such shared understandings can a system of genuinely shared and humane care evolve. (Darbyshire, 1994: 185)

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Note

- 1 Harry Walcott made this observation during his Keynote Address at the Qualitative Health Research Conference, Bournemouth, UK, September 2002.

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