The child’s experience of single room isolation: a literature review

Donna Austin and colleagues find that more information is needed on young patients’ perspectives of isolation in hospital

Abstract
Studies have shown that people who require single room isolation while in hospital often feel lonely, sad, worried, bored and in need of information. A literature review identified only 16 papers reporting on the child’s experience of isolation. Findings indicate that children feel lonely, are scared of the personal protective equipment and feel bored. Patients’ parents feel guilty, worried and under increased pressure to visit their children. It is also suggested that isolation may affect child development.

Keywords
Acute care, child development, child isolation nursing, children’s perspective, infection prevention

INFECTION PREVENTION is an issue of patient safety and therefore central to health care worldwide (Department of Health (DH) 2008). Isolation care is an important element of infection prevention used to segregate patients who are potentially infectious or immunocompromised. When isolation is used for the protection of others, the strategy is referred to as source isolation. When isolation is for the protection of the patient, it is known as protective isolation (Weston 2008).

Children and young people may be placed in isolation units, specialist wards and general children’s wards, for a variety of reasons, according to local and national guidance on infection (Siegel 2002). Source isolation is used to segregate patients with potentially contagious infections, such as respiratory syncytial virus (RSV), rotavirus and meticillin-resistant Staphylococcus aureus (Weston 2008). Protective isolation is used to segregate patients who have immunocompromised conditions and who are vulnerable to acquiring infections from others, such as patients with human immunodeficiency virus (HIV), those who are undergoing chemotherapy or those who have genetic immunosuppression (Posfay-Barbe et al 2008). Children and young people can be in isolation for hours, weeks and, in some cases, months – sometimes alone and in other instances with a parent resident with them in the hospital. Children can also be isolated in their own home, for infectious childhood illnesses or, in some cases, after organ transplantation.

This literature review focuses on children and young people’s experiences of isolation in hospital. There has been little study of their experience, which means that current clinical practice can only be based on limited child-specific research, relevant adult literature and conventional wisdom. Research conducted in adults shows that they may suffer psychologically and socially as a result of being in isolation (Knowles 1993, Gammon 1999). Findings from adult studies cannot, however, be transferred to children’s settings because of the differing levels of psychological and cognitive development, physiological needs and social priorities of children and young people (Kanner et al 2004). This reinforces the importance of child-specific research in this field.

Current practice
Studies have identified a number of infection prevention issues specific to children (Siegel et al 2007). In 2004, the DH recommended that 50 per cent of all paediatric hospital bed spaces in new facilities should be in isolation because of the high number of children requiring isolation (compared with adult facilities).

In England, the DH documents (DH 2007, 2008, 2010) tend to focus on healthcare-associated infections (HCAIs) and adult guidance, and there is
limited guidance specific to child health. The most comprehensive, up-to-date clinical guidelines on isolation precautions are from the US Centers for Disease Control and Prevention (Siegel et al 2007). The guidance is comprehensive and transferable to the UK, and has evolved to help healthcare workers prioritise those who need isolation. However, the child-specific guidance is not comprehensive. These guidelines, together with local policy, are what informs current practice in the UK, so the experience of children in isolation warrants further research.

Search strategy
Literature for this review was found by a combination of electronic database searches, manual searches and incremental searching. An integrative approach allowed the simultaneous inclusion of quantitative and qualitative studies, to understand the phenomenon in full (Whittimore and Knafl 2005). The search terms used included ‘children’, ‘isolation’ and ‘experiences’. The terms were refined using synonyms, were truncated and, where appropriate, were used to distil suitable medical subject headings (MeSH). The electronic databases searched were the Cochrane Library, the Allied and Complementary Medicine Database, Applied Social Sciences Index and Abstracts, Cumulative Index to Nursing and Allied Health Literature, Ovid MEDLINE, PsycINFO and Web of Knowledge. For each database, subject headings associated with the search terms were used, to enable accurate retrieval of papers. Searches were also combined using Boolean Logic to capture all relevant papers and included all literature available from the earliest records on electronic databases up to 2011.

In view of the limited number of research papers relating to the child’s experience of isolation, older papers and the perspectives of researchers, parents and health professionals were included. In incremental searching, references from one document were followed to find other relevant papers (Crookes and Davies 2004).

Manual searches of Nursing Children and Young People (formerly Paediatric Nursing) and the Journal of Infection Prevention were conducted in issues published between 2009 and 2012, to capture recent publications and to ensure that papers that were overlooked by electronic database searching were included in the review.

What is already known
A review of the literature revealed 16 relevant research papers exploring the experience and the effects of isolation on children’s wards between 1970 and 2011. Most of the literature focuses on observations of the child’s behaviour in isolation and the parents’ own perspective, rather than the parents’ perception of how their child experiences isolation or the child’s view of their own experience. Only three studies directly engage with children; this might be because of the ethical challenges related to researching with children (Kirk 2007). Six studies were excluded, either because they were not primary research or because they focused on the efficacy rather than the experience of isolation.

Previous research
The investigations follow differing methodologies, therefore three critical appraisal tools were required. Those selected were Duffy’s quantitative appraisal tool (2005), Atkins and Sampson’s critical appraisal tool for case studies (2002) and Greenhalgh’s qualitative appraisal tool (1997), because of their applicability to the studies reviewed. Each paper was read numerous times, analysed individually and then analysed in the context of the other studies conducted in that decade.

Many of the studies were conducted in the 1970s (Table 1, page 20) and 1980s (Table 2, page 21) and related specifically to protective isolation for severe combined immunodeficiency (SCID) (Simons et al 1973, Drotar et al 1976, Freedman et al 1976, Dalton 1981, Lazar et al 1983, Tamaroff et al 1986). The main findings from these papers were that the processes of cognitive, social, psychological and motor development in the child were altered as a result of isolation. It is important to note that, during this era, there was no preceding research so using single-participant cases was acceptable to establish if this area was worthy of further research. Because of the small sample sizes of these studies, limited credence can be attributed to the findings. Furthermore, many of the children in the SCID studies were subject to long-term isolation (duration of three months to five years) which is not representative of the duration of isolation for any child today (Chan and Puck 2005).

Kutsanellou-Meyer and Christ (1978) studied seven parents of children with SCID and 11 children with aplastic anaemia on one protective isolation unit. The findings from this study are potentially more transferable than from a single case. The suggestion was that children appeared more concerned with the separation from their family and

Children appeared more concerned with the separation from their family than with the possibility of acquiring an infection
Parents and children also felt the need to maintain privacy. Powazek et al. (1978) studied the mothers’ perspectives and the children’s perspectives on protective isolation due to cancer, and concluded through behaviour rating scales that older children scored more highly than younger children in anxiety and depression. The main strength of this study was the large sample size of 123 children, but the scale did not clarify whether anxiety was due to isolation or other factors.

There was only one study during this period with children as the sole focus, to ascertain their perspectives (Broeder 1985). The author used a draw-and-write technique to enable the children and young people with brief non-complicated illness to draw and discuss their isolation room. This method is age-appropriate and can contribute to memory recall (Christensen and Prout 2002). Although this study suggested that children had an understanding of the advantages of isolation, it did not enable a direct comparison with the experiences of children in hospital with more severe chronic conditions.

Table 1: Studies published in the 1970s on isolation of children and young people in hospital

<table>
<thead>
<tr>
<th>Reference</th>
<th>Sample</th>
<th>Condition</th>
<th>Study design</th>
<th>Findings/perspectives</th>
<th>Limitations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Drotar et al. 1976</td>
<td>One boy Duration of isolation: one year, US</td>
<td>Severe combined immunodeficiency (SCID)</td>
<td>Case study of a boy for first 14 months of his life</td>
<td><strong>Observer:</strong> bonding between mother and child impaired. Social development of child improved after discharge</td>
<td>Single case Dated study No observational measurement tool used Specific condition</td>
</tr>
<tr>
<td>Freedman et al. 1976</td>
<td>One boy Duration of isolation: 52 months, US</td>
<td>SCID</td>
<td>Case study of one boy through first 52 months of his life in protective isolation</td>
<td><strong>Observer:</strong> his motor skills were more advanced than normal. The boy demonstrated less social interactivity. His language development was delayed</td>
<td>Single case Dated study No observational measurement tool used Specific condition</td>
</tr>
<tr>
<td>Kutsanellou-Meyer and Christ 1978</td>
<td>Eleven patients with aplastic anaemia Parents of seven infants with SCID Duration of isolation: 3-20 months, US</td>
<td>SCID Aplastic anaemia</td>
<td>Case study of a unit of adolescents with aplastic anaemia and infants with SCID</td>
<td><strong>Child by proxy of an observer:</strong> adolescents appeared to be more distressed by separation from people, activities and objects than the possibility of death. Adolescents attempted to maintain privacy</td>
<td>Dated study Only one setting Single observer</td>
</tr>
<tr>
<td>Powazek et al. 1978</td>
<td>123 children and their mothers Duration of isolation: not specified, US</td>
<td>Cancer</td>
<td>Quantitative: Trait Anxiety Inventory, Patient Behaviour Rating Checklist and Maternal Depression Scale</td>
<td><strong>Child by proxy of an observer:</strong> older children in isolation (&gt;12 years) were more anxious than younger children. <strong>Parents:</strong> positive opinions of the infection prevention measures and the convenience of long visiting hours</td>
<td>Dated study No description of sample size calculation No baseline data for behaviour presented Mainly parental data</td>
</tr>
<tr>
<td>Simons et al. 1973</td>
<td>Non-identical twins with lymphopaenic hypogammaglobulinaemia Duration of isolation: 2.5 years, Germany</td>
<td>SCID</td>
<td>Case study of twins using development scales every three months and observation by the researcher</td>
<td><strong>Observer:</strong> separation anxiety, intellectual capacity below average</td>
<td>Only two cases Dated study Very specific condition Type of isolation – no longer common practice</td>
</tr>
</tbody>
</table>
of why they were in isolation, it also found that they were scared of the personal protective equipment. However, the small sample of six children and limited description of the methods of analysis require that the findings are viewed judiciously.

The data from the 1970s (Table 2) and 1980s (Table 3) are largely case studies, and for the most part sample only one condition, in particular SCID, which is rare (Chan and Puck 2005). These limitations significantly reduce the transferability of the findings to contemporary children’s wards. There is also limited exploration of what the children think about isolation; most of the research is observational or from the perspective of the parents. However, with the inclusion of Broeder (1985), the research was moving towards the incorporation of children’s perspectives and child-appropriate methods. Despite this, during the 1990s this line of research was not continued.

There was a paucity of studies in the 1990s related to isolation, with only one study identified. This explored the experience of 24 mothers caring for a child undergoing bone marrow transplantation in isolation (Kronenberger et al 1998). Mothers described isolation as a stressor for themselves, but no comment was made on the child’s experience. However, theories of emotional contagion suggest that children may unconsciously mirror parental...
behaviours (Davis and Siegel 2000, Hatfield et al 2009). The lack of research in this decade could be because of the ethical obstacles to researching with children (Kirk 2007). Although society had become less paternalistic, and the Children Act of 1989 advocated including children in research, the important ethical considerations of researching with children followed closely (Kirk 2007).

In the 2000s (Table 4) there was an increase in the number of studies in this field and growing interest in children’s perspectives, driven by documents such as Every Child Matters (Department for Education and Skills 2003) and the National Service Framework for Children (DH 2004). These suggest that children have valuable perspectives that should be incorporated into practice, but only two (Koller et al 2006, Russo et al 2006) of six studies produced in the 2000s consider children’s experience.

Interest in the impact of source isolation is likely to have been generated from epidemics, such as severe acute respiratory syndrome (SARS) and influenza A H1N1, but the more common indications for source isolation in child health, such as RSV and rotavirus, continued to receive limited research. This is possibly because the impact of shorter isolation may not be thought as severe. However, it is clear from the experiential data from adults in isolation, that there can be psychosocial effects of being in isolation after as little as 24 hours (Knowles 1993).

The research carried out during this era explored parents’ own perspectives and recorded their feelings of guilt and fear when leaving their children in isolation (McKeever et al 2002, Wu et al 2005, Koller et al 2006, Chan et al 2007). Parents also described the need for information and pressure to spend time at the hospital to relieve their child’s boredom and loneliness (Russo et al 2006, Rotegard and Sykepleievitsenkap 2007).

The two studies that addressed the child’s perspective were specific to SARS (Koller et al 2006) and cystic fibrosis (Russo et al 2006). Koller and colleagues found that children in isolation experienced distress, sadness, loneliness, fear and worry. Only five children were interviewed, but as the total population with SARS is likely to have been small, a sample of five may be representative. Strict isolation policies were implemented and these included parents being separated from their children, which clearly affects transferability of the findings.

Russo and colleagues found that children with cystic fibrosis resented being separated from their peers who also had the condition and were in hospital. They expressed the need for increased use of technology, such as the internet, to communicate with others to alleviate boredom and social isolation. The study explored children’s experiences of isolation using questionnaires (with limited explanation as to format) distributed to 101 children. There was only a 23 per cent response rate and this tended to be from the older children, which significantly affects the validity of the conclusions.

During the 2000s (Table 4), research involved more varied methodology, encompassing parents’ and children’s perspectives and a wider variety of conditions. However, the use of child-appropriate strategies is scarce, which limits the amount the child may feel able to disclose. Because of the lack of child perspectives, child-friendly methods, larger sample sizes and variety of conditions, no studies can be entirely transferable to contemporary practice.

**Adult experiences of isolation**

Research among adults in isolation has long had a much stronger evidence base (Knowles 1993, Gammon 1999, Rees et al 2000). Findings suggest loneliness, depression, stigma, a greater need for information, lack of social contact, less contact with healthcare professionals than the patients on the main open ward and perceptions that the physical environment was restrictive (Gaskill et al 1997, Kennedy and Hamilton 1997, Campbell 1999).

However, some adults did appreciate the privacy (Campbell 1999). Although these findings are not transferable to children and young people, they have suggested additional avenues for enquiry.

**Discussion**

It is important to recognise that many of the findings are comparable with the wider literature from up to 50 years ago, pertaining to children’s experiences of hospital admission in general (Gofman et al 1957, Perrin and Gerrity 1981, Forsner et al 2009). The additional stressors resulting from isolation include: less space; increased use of personal protective equipment; limited interaction with other children; fewer sources of stimuli – such as access to communal spaces – and the physical and psychological barriers created by isolation.

As indicated by the National Service Framework for Children (DH 2004), children require access to play, education and social facilities, and it is important to find ways of providing these. With the literature published so far, it is impossible to see if these child-specific needs are being met for children isolated in hospital now.

From this literature review it is evident that source and protective isolation affect the child’s
experience of being in hospital. Most of the studies identified by this review are dated, have small sample sizes, are not representative of the child-health population and use samples specific to one condition. Only four of the investigations found actually asked children what they thought about being in isolation, and only one study was conducted in the UK.

Thus, when reviewing the data on children’s experience of isolation as a whole, it becomes clear that there is a considerable need for further research, with robust clinical studies that specifically explore the child’s perspective on being in isolation. Until further research has been conducted, the evidence available thus far can be transferred only very cautiously to practice in other settings, although a few suggestions for practice enhancements can be made.

**Conclusion**

Isolation has been shown to affect adults on a psychosocial level. There is a paucity of robust
child-specific studies pertaining to children’s experience of isolation. Therefore, firm conclusions about how children experience isolation cannot be drawn.

This article aims to address the lack of literature on studies that follow child-appropriate methods. Until further research is conducted, children’s nurses are required to work with a limited appreciation of the experience of isolation from the child’s perspective. Further robust research is required to better capture the child’s experience of being in isolation.

**Points for practice**

Children’s nurses have a pivotal role in caring for children in isolation by:

- Keeping families well informed.
- Ensuring isolation policies are adhered to.
- Spotting behavioural and emotional cues.
- Ensuring adequate input from play specialists and education.
- Using technology to relieve boredom for young people.

**References**


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