CHAPTER 7 EVIDENCE-BASED PRACTICE STATEMENTS

CHILD LIFE COUNCIL EVIDENCE-BASED PRACTICE STATEMENT

SUMMARY

PREPARING CHILDREN AND ADOLESCENTS FOR MEDICAL PROCEDURES

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Rebecca Mador and Wendy Lee, research assistants at the Hospital for Sick Children, are gratefully acknowledged for their contributions in the preparation of this statement.

The purpose of this statement is to outline the key components of effective pediatric psychological preparation. The primary goal of preparation is to reduce the fear and anxiety experienced by a child who is undergoing a medical procedure and to promote his or her long-term coping and adjustment to future health care challenges.[7-10] The long-term implications of negative medical experiences, including ineffective preparation, can be profound; post-traumatic stress, increased fears, and decreased cooperative behavior. [9, 13, 14] Participation in a preparation program has been shown to significantly reduce the negative psychological sequelae experienced by children both immediately before and after the procedure and for up to a month later.[9, 14-16]

Regardless of the medical procedure for which a child is being prepared, the key elements of effective preparation are: (1) the provision of developmentally appropriate information; (2) the encouragement of emotional expression; and, (3) the formation of a trusting relationship with a health care professional.[38, 39] These three components are the essential elements of effective preparation for pediatric patients.

1. PROVISION OF DEVELOPMENTALLY APPROPRIATE INFORMATION

An important feature of sharing developmentally-appropriate information to children consists of providing clear and accurate messages.[14] Information about a medical procedure should be as specific as possible to include both *what* will happen during the upcoming medical procedure as well as *why* it will happen.[41] In addition, explanations should include sensations that the child can expect to experience such as the sights, sounds, smells and feelings.[10, 14]

As part of information sharing, coping techniques aimed at ameliorating fears and anxiety should be offered.[21] Coping techniques introduced to a child should vary depending on the procedure, the child's developmental level and his or her preferred coping style.[2] Effective coping techniques have been found to include visual and auditory distraction, tactile stimulation, counting and singing, and verbal interaction.[2]

2. OPPORTUNITIES FOR EMOTIONAL EXPRESSION

During the course of preparation, it is essential that potential stressors are anticipated and misconceptions and fears are addressed.[3, 42] This requires the health care professionals to pay careful attention to a variety of cues such as facial expressions and other forms of non-verbal communication appropriate to the child's developmental level.

3. ESTABLISHING TRUST WITH THE PEDIATRIC HEALTH CARE TEAM

Preparation programs can provide the context in which children can develop trusting relationships with their health care team.[21] Through the provision of accurate information, the teaching of coping techniques, and the encouragement of emotional expression, the child life specialist is poised to establish a supportive and trusting relationship with the child.[2]

Summary

An extensive review of the literature along with child life clinical experience have validated that most children prepared for medical procedures experience significantly lower levels of fear and anxiety compared to children who are not prepared. Preparation also promotes long-term coping and adjustment to future medical challenges.

For the detailed information and studies reviewed to support this statement, review the complete version of the evidence-based practice statement on preparation, available through the Resource Library section of the CLC Web site (www.childlife.org).

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Preamble

The purpose of this statement is to outline the key components of effective psychological preparation and, by using the best empirical evidence currently available, to validate the methods employed by child life specialists.

This statement is based on an exhaustive search of the literature, which was conducted on i) PsycINFO, which records the literature from psychology and related disciplines such as medicine, psychiatry, nursing, sociology, and education; ii) MEDLINE, which focuses on biomedical literature; and, iii) CINAHL, the Cumulative Index to Nursing & Allied Health Literature, which covers literature relating to nursing and allied health professions. A variety of keywords and combinations such as "preparation"; "fear"; "anxiety", "pain"; "pediatrics" and "medical procedures" were used to conduct the search, which was completed in August 2006 with the assistance of a medical librarian. Searches revealed approximately 350 articles related to pediatric preparation; however, after the results were sorted to exclude repeats and non-empirical based literature, 40 articles remained. These articles were retrieved and evaluated based on the scoring of 2 independent raters using "The Quality of Study Rating Form"[1]. Those articles that received a rating of at least 60 out of 100 points were selected for inclusion in this statement. Any article that scored between 55 and 65 points was re-scored by a second rater to confirm inclusion or exclusion. Finally, 30 articles met the selection criteria. Only 3 of these selected studies specifically evaluated preparation performed by child life specialists[2-4].

Since evidence-based practice represents an integration of both clinical experience[1] and the best available research[5, 6], this statement was also reviewed by certified child life specialists across North America in order to ensure clinical applicability. In addition, evidence-based practice acknowledges patient preferences and needs when determining the most appropriate clinical applications for the child and family.

Why Prepare?

The primary goal of preparation is to reduce the fear and anxiety experienced by a child who is undergoing a medical procedure and to promote his or her long-term coping and adjustment to future health care challenges[7-10]. Heightened feelings of stress and anxiety, eating and sleeping disturbances, as well as separation fears are commonly found in children and adolescents undergoing even minor medical procedures[8, 10-12]. The long-term implications of a negative medical experience can be profound; post-traumatic stress, increased fears, and decreased cooperative behavior have been documented among pediatric patients who have not been effectively prepared for a medical experience[9, 13, 14]. Participation in a preparation program has been shown to reduce significantly the negative psychological sequelae experienced by children both immediately before and after the procedure and for up to a month later[9], [14-16]. In this review, 29 of the 30 studies concluded that children who were prepared for surgery experienced fewer negative symptoms than did children in control groups who did not receive preparation[20].

How Studies Evaluate the Effectiveness of Preparation

The majority of research on preparation is quantitative and experimental in design. These studies use anxiety or behavioral manifestation scales to assess the quality and degree of a child's coping. For example, less anxiety and fewer negative behaviors reflect increased coping. Of the 30 studies included in this statement, the most commonly used outcome measures were: a) The Observation Scale of Behavioral Distress revised (OSBD-r)[17], which records behavior over time from the 'anticipation-of-procedure' to the 'post-procedure' phase; b) The Manifest Upset Scale and Cooperation Scale14, which are two five-point scales that rate the child's degree of negative emo-

tional arousal and behavioral upset; c) The Post-Hospital Behavior Questionnaire[18], which asks parents to rank their child's behavior after discharge from the hospital; and d) the State-Trait Anxiety Inventory for Children (STAI-C)[19], which compares the child's dispositional anxiety with the anxiety he or she is currently experiencing.

Approaches to Pediatric Preparation

Although preparation programs are standard practice in many pediatric hospitals[14], the variability in the approaches and outcomes of these programs is substantial. The literature reveals that preparation programs have included role rehearsals with dolls[4, 20, 23-25], puppet shows[15, 23, 26], the teaching of coping and relaxation skills[27, 28], orientation tours of the operating room[20], [24,] as well as educational videos[9, 29], books[16, 30], and pamphlets[25, 31]. Some programs focus exclusively on preparing the child[2, 9, 10, 22, 32-34] while other programs attempt to educate and support the parents[30, 35-37] and siblings as well12. Despite variation in approaches, the literature reveals three common elements that underlie effective preparation and result in improved psychosocial outcomes for children and adolescent patients.

Key Elements of Effective Preparation for Medical Procedures

A child's ability to cope with a medical procedure and the quality and intensity of his or her reaction are influenced by many variables[10, 22]. Such variables include the child's age and developmental level, personality, ability to cope with new situations, prior health care experiences and previous encounters with medical professionals, as well as his or her diagnosis and the complexity/invasiveness of the upcoming procedure[3, 10, 22, 38]. Similarly, family variables such as the family's composition and level of parental anxiety can also influence a child's response[3, 38].

Regardless of the medical procedure for which a child is being prepared, the key elements of effective preparation are: (1) the provision of developmentally appropriate information; (2) the encouragement of emotional expression; and, (3) the formation of a trusting relationship with a health care professional[39, 40]. These three elements were proposed previously by Vernon et al. in 1965 following a review of the literature at the time[40]. Three decades later, in a review of 400 studies and a meta-analysis of a final sample of 22, O'Connor-Von[39] substantiated these three components as the essential elements of effective preparation for pediatric patients. These three elements were also evident in the articles reviewed here.

1. Provision of Information

Of the 30 articles reviewed in this statement, all described information dissemination as an integral part of the preparation program. Providing accurate medical information to children lessens negative behavior and promotes faster recovery post-operatively[9, 16, 21, 34] while also attenuating fear and anxiety[7-9, 26]. Although there are a variety of ways in which child life specialists can provide developmentally appropriate information to children; the emphasis should be on providing clear and accurate messages[14]. In addition, information about a medical procedure should be as specific as possible as this can lead to a greater reduction in anxiety than when children receive only standard or more generalized forms of information[7,14, 28].

While it is evident that information is a necessary and important component of preparation, the methods should vary with the child's age and developmental level[10]. Information should include both what will happen during the upcoming medical procedure as well as why it will happen[41]. For example, Campbell et al.[41] found that providing children with the reasons for the medical procedure as well as the sequence of events significantly reduced their anxiety when compared with control groups who did not receive this information. In addition, explanations should include sensations that the child can expect to experience such as the sights, sounds, smells and feelings[10, 14]. Of the published studies that specifically reported providing procedural and sensory information to children in the experimental group, all reported that these children demonstrated less emotional distress than children in control groups[10, 14, 16].

As part of information sharing, coping techniques aimed at ameliorating fears and anxiety should be offered[21]. For example, Campbell et al.[41] found that when a preparation program included information regarding coping techniques, behavioral outcomes were more positive for children undergoing surgery. In another study, Peterson and Shigetomi[35] compared the effectiveness of providing children ages 2 to 10 years old with information only, coping techniques, filmed modeling or coping plus filmed modeling. Children who were provided with coping plus modeling techniques were more calm and cooperative than children in the other groups. In addition, coping techniques introduced to a child should vary depending on the procedure, the child's developmental level and his or her preferred coping style[2]. Effective coping techniques have been found to include visual and auditory distraction, tactile stimulation, counting and singing, and verbal interaction[2]. Six of the 30 studies were found to include information regarding coping

as part of their preparation programs and all reported significant positive outcomes[2, 27, 28, 35, 37, 41].

2. Opportunities for Emotional Expression

During the course of preparation, it is essential that potential stressors are anticipated and misconceptions and fears are addressed[3, 42]. This requires the child life specialist to pay careful attention to a variety of cues such as facial expressions and other forms of non-verbal communication. Fegley[33] compared two groups of children, one that received standard information about a radiological procedure and another in which children were encouraged to ask questions and express feelings about the procedure. Findings indicated that children who asked questions and expressed concerns were less distressed and spent significantly less time seeking information during the procedure.

3. Establishing Trust with Members of the Pediatric Health Care Team

Preparation programs can provide the context in which children can develop trusting relationships with their health care team[21]. Through the provision of accurate information, the teaching of coping techniques, and the encouragement of emotional expression, the child life specialist is poised to establish a supportive and trusting relationship with the child[2]. In an evaluation of child life intervention in the emergency department, Stevenson et al.[2] noted that the child life specialist played an integral role in establishment of trust with the child. Key strategies for building rapport included asking the child questions about topics such as age, grade in school, pets, or the number of siblings. In another study, Wolfer and Visintainer[14] randomly assigned children to one of five experimental groups or a control group. The experimental groups consisted of combinations of home preparation with different types of in-hospital preparation which included supportive care. Supportive care was defined as the nurse making a special effort to establish a trusting and supportive relationship with the child and parent. Children and families who received any form of preparation and supportive care expressed significantly greater satisfaction with their hospital experience when compared with children and families in other groups.

Research Gaps and Confounding Issues

Over the past 30 years, our knowledge of the substantive issues associated with effective preparation has improved. However, this review reveals several existing gaps and confounding issues. For example, critical questions remain regarding how best to prepare children of different developmental levels[39, 40]. Much of the literature focuses on the psychological preparation of preschool and early school age children. This is most likely because this group is more at risk for misunderstanding medical explanations. As such, less is known about the effectiveness of preparation with toddlers and adolescents.

A related developmental issue concerns the notion of timing. In only one study, the timing of the preparation program relative to the day of surgery was identified as a significant variable in that preparation was not uniformly effective for all children[20]. For example, only children who were 6 years or older and who received the preparation at least five days prior to surgery benefited from the intervention[20]. Preparation had a negative effect on young children with a history of previous hospitalization, suggesting that these children require specialized methods for preparation and alternate timing [21, 22].

Given that many pediatric facilities offer group preparation with two or more children at the same time, it is essential that this approach be properly evaluated. Only one study in this review addressed group preparation[43]. McGrath prepared children 3-12 years old for surgery in small groups and found that children who were prepared in groups experienced significantly less anxiety and more satisfaction with their surgical experience than children who were prepared individually. Currently, limited research on group preparation inhibits the development of evidence-based practice in this area.

Some studies offer poor descriptions of the programs under evaluation and do not adequately control for key variables such as age, gender, prior hospital experience, and personality variables such as anxiety proneness[39]. As clinical experiences have shown, standard preparation programs are not beneficial for all children[21] particularly in the case of children who exhibit heightened levels of anxiety during and after preparation for medical procedures. Unfortunately, minimal research has investigated the impact of personality traits and associated coping styles on the effectiveness of preparation. Future research should begin to ascertain which children and adolescents are least likely to benefit from standard forms of preparation. These types of research initiatives can begin to address alternate forms of psychosocial support for this population leading to enhanced levels of evidence-based practice.

A myriad of approaches to preparation exist and are used by a variety of health care professionals across pediatric settings. In some settings, children are prepared by child life specialists, while in others, nurses may be involved. For this reason, meth-

ods of preparation can vary tremendously depending on the experience, philosophy and educational training of the professional. Since there are only a few studies that directly address preparation by child life specialists, it is imperative that research evolves to include impartial evaluations of various approaches across disciplines.

Finally, current research methods in this area are predominantly quantitative and few studies include participants from various cultural backgrounds. The processes involved in preparation are complex; consisting of several known and possibly unknown variables. Additional research from within a qualitative paradigm can more adequately explore complex processes associated with pediatric preparation. Accessing the views and perspectives of children, adolescents, and their parents could assist in supporting a family-centered care model which can better acknowledge cultural differences.

Summary

An extensive review of the literature revealed that most children prepared for medical procedures experience significantly lower levels of fear and anxiety as compared to children who are not prepared. Preparation also promotes long term coping and adjustment to future medical challenges. Key elements of effective preparation include the provision of clear and accurate information about the medical procedure and potential coping strategies, the encouragement of emotional expression and the establishment of trust with a health care professional. Despite a greater understanding of how to prepare children for medical procedures, research gaps and confounding issues exist. In particular, studies must begin to address which methods of preparation are most effective for specific developmental levels, personality traits and cultural backgrounds. Studies should also explore how best to encourage emotional expression from children during the course of preparation. Since a variety of approaches are being used by different disciplines, research on pediatric preparation must evaluate which forms constitute the best outcomes for children and families. These studies should include both quantitative and qualitative methodologies in order to provide a comprehensive examination of current practices which can inform child life clinical practice and policy development across pediatric health care settings.

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TABLE 1. FINAL SELECTION OF STUDIES INCLUDED IN THIS REVIEW	
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