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Psychoeducational Interventions with Pediatric Cancer Patients: Part II. Effects of Information and Skills Training on Health-Related Outcomes

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In Part I of this paper, we described a model that was used as a framework for reviewing studies of psychoeducational interventions intended to influence illness- and treatment-related behaviors and attitudes in pediatric cancer patients. In Part II, we distinguish between interventions that attempt to influence patients' behaviors just by providing information and interventions that specifically teach skills related to the behaviors they are trying to change. Many types of psychoeducational interventions appear to be effective and those that are training-based generally appear more effective than those that are information-based. Training-based interventions may face a barrier to wide adoption because they are resource-costly, but the development of digital-based training interventions may potentially overcome this barrier.

KEY WORDS: psychoeducational interventions; children; cancer; chronic illness; information; health.

In Part I, we observed that the literature on psychoeducational interventions for pediatric cancer is scattered and lacks an organization model (Bradlyn, Beale, & Kato, 2003). We proposed a heuristic model based on functional concepts taken from the literature on learning and instructional design. We argued that it makes

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sense conceptually to analyze psychoeducational interventions in terms of psychoeducational principles, especially if the purpose is to illuminate the learning processes involved.

In Part I, we reviewed informational interventions to influence patient knowledge. Our analysis of these studies indicated that informational interventions are more likely to increase knowledge if they are interactive or participative in a way that addresses differences in patients' preferences for information and changes in these preferences across time. In Part II, we review studies of the effects of two other categories of intervention, not just on knowledge, but on health-related outcomes. One of these is informational interventions that target health-related outcomes. The other is interventions involving not only information-providing, but also interactive training of specific skills related to health outcomes. The key difference between these two categories is whether they include some active learning paradigm designed to change behavior, as opposed to just presenting information. The lack of studies with pediatric patients was even more apparent in Part II than in Part I, therefore studies of adults are included where they might be indicative of effects with children.

EFFECTS OF INFORMATIONAL INTERVENTIONS ON HEALTH-RELATED OUTCOMES

Distress, Anxiety, and Depression

For many years it was standard practice to withhold information from children with a malignancy, based on the assumption that such a dire diagnosis might result in clinical depression. But, in recent decades, it has become widely accepted that the exact opposite is true; patients who have a developmentally appropriate understanding of their disease have a better psychological outcome than those who do not (Koocher & O'Malley, 1981). For example, a study of survivors of childhood cancer found that early communication of the diagnosis was associated with good psychological and social adjustment as a survivor (Slavin, O'Malley, Koocher, & Foster, 1982).

Controlled studies of adult patients with cancer have shown that informational programs can significantly reduce depression (Pruitt et al., 1992) or both anxiety and depression (Jacobs, Ross, Walker, & Stockdale, 1983). Lack of information may cause increased distress and anxiety, as well as dissatisfaction with care (Fallowfield, Ford, & Lewis, 1995). It has been shown, for radiotherapy patients at least, that there is a strong correlation between patient satisfaction with information provided and low depression and anxiety scores during treatment (Montgomery, Lydon, & Lloyd, 1999). Even minor informational programs can be effective in reducing patients' distress.

Several investigators have examined the impact of an orientation program on reducing psychological distress of adult cancer patients. For example, a brief

orientation program with new patients was effective in reducing self-reported anxiety and mood symptoms, compared to patients in a standard care group (Wells, McQuellon, Hinkle, & Cruz, 1995). Another study examined the effects of a brief orientation at patients' initial clinic visit, including a clinic tour, general clinic operation information, and a question and answer session with an oncology counselor. At follow-up, the orientation group reported lower overall distress and psychological symptoms than a control group that had not received the orientation intervention. The orientation group also demonstrated significantly more knowledge and satisfaction with care (McQuellon et al., 1998). Informing patients by print media has also been shown to be effective in reducing treatment related anxiety (Mohide, Whelan, & Rath, 1996).

A few studies have assessed whether using video to inform patients about their disease and treatment affects psychological states. For example, a study that examined the value of adding a video presentation to handouts of print media found that only the group receiving the video showed significant decreases in psychological distress (Rainey, 1985). In a related study, a take-home video informing patients about chemotherapy and radiation therapy was found to result in reduced anxiety and depression during treatment (Thomas, Daly, Perryman, & Stockton, 2000).

Psychological Reactions to Hospitalization and Medical Procedures

The empirical literature on preparation for hospitalization, surgery, or aversive medical procedures provides further evidence about the effectiveness of informational interventions with children. The unfamiliar nature of the hospital can be emotionally stressful for children. However, there is evidence that threatening events that are known and understood are less upsetting than those that are ambiguous and undefined (Vernon, Schulman, & Foley, 1966). It has been reported that a video providing procedural information and a coping model was effective in reducing self-reported anxiety, observed distress, and physiological arousal in a sample of young children hospitalized for an elective surgical procedure, compared to a matched group of children who viewed a control film (Melamed & Siegel, 1975). Notably, children in the treatment group demonstrated a variety of positive changes in physiological measures of recovery also, including earlier first voiding and less use of pain medication. These positive changes in physiological and subjective distress were evident postdischarge.

The effectiveness of this type of intervention has been found to be greater for children who are naïve rather than experienced, for younger children when informed close to the time of hospitalization and for older children when informed several days prior to hospitalization (Melamed, Meyer, Gee, & Soule, 1976). The inclusion of a modeling component along with the information component results in a confounding of the effects of the individual components; the specific effect of the information component is unknown.

Other informational interventions with children are based on the concept that distress is ameliorated when uncertainty about the event is reduced by information about procedures the patient will undergo and sensory experiences that accompany or follow them (Contrada, Leventhal, & Anderson, 1994). A meta-analysis of studies of this type of intervention indicated that procedural information was generally more effective than sensory information for reducing pain and distress (Johnston & Vogele, 1993).

Treatment Adherence

The controversial nature of the concept of treatment adherence is reflected in the lack of a generally accepted definition for the term, as well as the existence of alternative terms that refer to the same concept, including "treatment compliance" and "therapeutic alliance" (Kyngas, Kroll, & Duffy, 2000). A commonly-used definition refers to "the extent to which a person's behavior (in terms of taking medication, following diets, or executing life-style changes) coincides with medical or health advice"(Haynes, 1979, p. x).

Many studies have found nonadherence to be a significant barrier to the successful treatment of children with cancer, especially adolescents. In research on the ability of adolescents to follow oral medication regimes, rates of nonadherence above 50% have been reported (Festa, Tamaroff, Chasalow, & Lanzkowsky, 1992). Nonadherence, especially with chemotherapy and antibiotic regimens, is known to have implications for survival, and there have been attempts both to characterize the barrier to adherence and to design interventions that will improve adherence. Although many demographic, social and individual variables have been found to influence adherence in children with cancer, there have as yet been few attempts to apply this knowledge to the design of effective interventions.

Across the illness literature, associations between knowledge and adherence generally have been found to be small and inconsistent (Eagleton, Walker, & Barber, 1993) and interventions that enhance knowledge do not necessarily improve adherence (George, Waters, & Nicholas, 1983; Haynes et al., 1978). However, such generalities may be misleading, in the sense that findings often are conditional on the type of adherence being studied and the tool being used to measure it (Roter et al., 1998). Some studies of adolescents with cancer have found that level of knowledge is associated with adherence although some types of knowledge are more important than others (Tebbi, 1993; Tebbi et al., 1986). For example, adherence has been found to be correlated with specific knowledge about medication dosage and schedule but not with self-reported understanding of the nature of the illness (Tebbi et al., 1986). Similarly, adherence has been found to be correlated with knowledge of causality and prognosis, but not with knowledge about treatment and disease (Tamaroff, 1992). Also, adolescents are more likely to comply with therapeutic regimens when they believe the treatment will be effective (Kyngas et al., 2000).

The finding that some aspects of knowledge and some measures of adherence are correlated does not mean that interventions targeting knowledge will result in improved adherence. We were unable to find any studies with children that directly tested the effects of informational interventions on adherence. The lack of research on this issue reflects the lack of empirical research generally on treatment adherence in children with cancer. A very recent review located only six studies on adherence with oral medication in children with cancer, and none of these were intervention studies (Partridge, Avorn, Wang, & Winer, 2002).

Summary of Effects of Informational Interventions

In general, the evidence indicates that informational interventions can be effective in improving a variety of health-related outcomes, including anxiety, distress, depression. However, studies with children are sparse and mainly confined to interventions targeting distress about painful procedures and hospitalization. It appears that children are responsive even to information interventions in which they have a relatively passive role. The absence of studies of informational interventions on children's adherence is especially regrettable, considering both the need and the evidence of a correlation between knowledge and adherence.

EFFECTS OF SPECIFIC SKILLS TRAINING ON HEALTH RELATED OUTCOMES

The ultimate goal of patient education is not only to increase the patient's knowledge, but also to change health-related outcomes. It has been argued elsewhere that exposing children to information will have little effect on their ability to use that information unless they already have acquired the ability to interpret and use the information (Swanson, 1993). Intended health-related outcomes might not be achieved efficiently unless information is given in a context in which the patient is trained how to use the information appropriately. In studies involving this type of training, the training is given in various skills such as management of pain, anxiety, relaxation, visualization or adherence, with a view to influencing health related behaviors during treatment or even physical treatment outcomes.

Distress, Anxiety, and Depression

The few studies of skills interventions designed to address distress, anxiety or depression in pediatric patients have reported mixed results. One controlled study of adolescent patients undergoing chemotherapy found that teaching strategies for guided imagery, muscle relaxation and self-hypnosis was effective in decreasing pain, anxiety, nausea and vomiting (Zeitzer, LeBaron, & Zeitzer, 1984). A similar

finding of a positive effect was obtained in another study of the use of self-hypnosis by adolescent patients (Cotanch & Hockenberry, 1985). In contrast to these positive findings, a more-recent longitudinal study with adolescent patients found that training on behavioral and coping strategies was not effective in reducing symptom distress, even in the short term (Hinds et al., 2000).

Studies with adults uniformly report positive effects, however, and these are reviewed here as being probably relevant at least to older children. Cognitive-behavioral therapy focused on cancer patients' problem solving has been found in controlled studies to be effective for reducing emotional distress (Worden & Weisman, 1984), anxiety and depression (Greer, Moorey, & Baruch, 1992). In another controlled study, both biofeedback training and cognitive-behavioral therapy were found to be effective in reducing anxiety (Davis, 1986).

Several studies of the use of training involving relaxation combined with guided imagery have found reductions in psychological distress (Baider, Uziely, & De-Nour, 1994; Bridge, Benson, Pietroni, & Priest, 1988), anxiety levels (Gruber et al., 1993), or tension, depression, anger and fatigue (Decker, Cline-Elsen, & Gallagher, 1992). Controlled studies of multicomponent psychoeducational programs, involving information and multiple-skills training, show that improvements in functioning can be produced concomitantly across a range of areas of behavior and affective functioning, including depression, anxiety, and total mood disturbance (Fawzy et al., 1990, 1993).

Training in general stress reduction behaviors can also be effective for reducing affective symptomatology in adult cancer patients. For example, relaxation training has been shown to reduce anxiety and depression (Worden & Weisman, 1984). A meditation-based stress reduction program has also been found to be effective with adult cancer patients with a wide variety of cancer types, stages of illness and ages (Speca, Carison, Goodey, & Angen, 2000). Trained patients' postintervention scores were lower than those of a wait-list control group on measures of depression, anxiety, anger, confusion and somatic and cognitive stress indicators. Substantial changes were found in the trained group between pre- and postintervention scores on these variables

Distress During Aversive Procedures

Psychological interventions within pediatric oncology practice have frequently been used to ameliorate the effects of aversive procedures such as bone marrow aspirations (BMA), lumbar punctures (LP), and the introduction of intravenous needles.

These interventions typically included a training component directed at reducing anxiety and increasing cooperation. BMA and LP provide a unique situation in which to study patients' responses to pain, as acute pain is typical of BMA in

particular and there is no stable pattern of habituation (Harris, Bradlyn, Ritchey, Olsen, & Pisaruk, 1994).

Several studies have investigated the effectiveness of cognitive-behavioral interventions for young children experiencing BMAs or LPs. The interventions consisted of several different methods hypothesized to decrease distress and increase cooperation. Components included a video showing a model successfully coping with each of the procedures, behavioral rehearsal, emotive imagery, and positive reinforcement. The video included an information component in which sensations and the procedures were explained and illustrated (Jay, Elliott, Ozolins, Olson, & Pruitt, 1985; Jay, Elliott, Woody, & Siegel, 1991). These interventions have been shown to be effective for reducing self-reported, observed, and physiological arousal in a significant number of children. Modeling interventions may be consistent with social learning theory (Bandura, 1977; Bandura, 2000), in which modeling is regarded as a means of obtaining vicarious experience that can improve the patient's perceived self-efficacy to cope well in the modeled situation. Such self-efficacy is highly correlated with the successful enactment of the targeted behavior.

A review of benavioral and cognitive interventions for helping children cope with pain associated with treatments, including treatments for cancer, concluded that while many interventions have been shown to be efficacious, there are issues that must be addressed before these interventions will be widely adopted (Chen, Joseph, & Zeitzer, 2000). Issues referred to were the matching of the intervention type to the child's preferences, and reduction of the cost of interventions in terms of the requirement for expert supervision. This raises the issue of children's coping styles, that is, whether they prefer to attend to information about a procedure or avoid that information. These styles have most commonly been labeled monitoring versus blunting (Miller, 1987), avoidance versus nonavoidance (Suls & Fletcher, 1985), sensitization versus repression (Field, Alpert, Vega-Lahr, Goldstein, & Perry, 1988), or rumination versus distraction (Nolen-Hoeksema, 1987).

The congruency hypothesis is that an individual's preferred method of coping is potentially important, in that interventions which match an individual's coping style are more likely than those that are incongruent to decrease distress and increase adaptive coping (Auerbach, Kendall, Cuttler, & Levitt, 1976). Research with adults generally supports the congruency hypothesis (Auerbach, Martelli, & Mercuri, 1987) and there is also support found in the child literature (Christiano & Russ, 1988; Fanurik, Zeitzer, Roberts, & Blount, 1993).

If some coping strategies are more consistent than others with beneficial treatment attitudes and behaviors, it is valuable to know not just how a patient's existing coping strategies may affect information seeking and other treatment related behavior but, more importantly, whether inappropriate coping strategies are modifiable by training. The studies showing that modeling interventions can change the way children deal with painful procedures may be interpreted as showing that

interventions can succeed by changing coping strategies. In keeping with this view, it has been suggested that interventions may be unsuccessful if they are not consistent with patients' coping strategies, and also do not change these strategies (Hinds et al., 2000).

Treatment Adherence

In a previous section on informational interventions we reviewed evidence regarding the importance of adherence in children with cancer, and pointed out the lack of relevant intervention studies with an informational focus. The situation with regard to behavioral skills interventions is only a little better, but provides at least some evidence that interventions that include a behavioral training component can improve adherence both in children and adults. Moreover, it appears that such interventions may lead to prolongation of survival (Richardson et al., 1987; Richardson, Shelton, Krailo, & Levine, 1990). This single relevant intervention study included 94 newly diagnosed patients, about 25% of whom were in the age-group 17–24 years. Since the results were not affected by the variable of age, it seems reasonable to generalize the results of this study at least to older adolescents. Patients were randomly assigned either to one of three educational interventions or to a control condition in which they received the standard information and instructions. The three educational interventions all included a slide-tape presentation combined with either: (1) a home visit; (2) in-hospital pill-taking training; or (3) home visit plus pill-taking training. All three intervention groups were found to be more adherent than controls with medication, based on blood tests for metabolites. This result is consistent with findings from studies of other chronic diseases, that educational programs are more likely to improve adherence if they combine information with training delivered interactively at the individual level (Olson, Kaufman, Ware, & Chaney, 1986; Roter et al., 1998).

A less encouraging result was found in a study of a behavioral intervention of childhood cancer survivors, in which no improvement was found in targeted health behaviors (Hudson et al., 2002). However, these survivors were arguably unsuitable for testing an intervention, in that they were an average of ten years postdiagnosis.

Physiological Endpoints and Survival

Although there are no studies of the effects of skills training interventions with children, there are several adult studies that included physiological measures related to biological stress responses and immune-system function. A study using biofeedback or cognitive therapy found significant changes in urinary cortisol consistent with the observed reduction in anxiety (Davis, 1986). A study using relaxation, guided imagery and biofeedback training found changes in immune

system markers correlated with reduction in anxiety (Gruber et al., 1993). In their longitudinal studies of psychoeducational interventions, Fawzy and colleagues found changes in natural killer cell indices consistent with increased immune function up to one year following treatment (Fawzy et al., 1990; Fawzy, Fawzy, & Canada, 2001).

A few longitudinal studies have reported differential survival rates for patients receiving psychoeducational interventions and appropriate control groups. For example, lower rates of recurrence and deaths at a six-year follow-up have been reported (Fawzy et al., 1993). In the previously-mentioned study of the effects of various educational programs on adherence, it was also found that the multicomponent education programs significantly enhanced survival (Richardson et al., 1990). Importantly, the size of this effect in the multiple-regression analysis was similar to that of a blood assay measure of adherence. That study, which included adolescents over 16 years of age, is indicative of the potential for psychoeducational interventions to influence the most important outcomes in cancer treatment.

Summary of the Effects of Skills-Training Interventions

Our review of skills-training interventions highlights the neglect of research with pediatric cancer patients. The exception to this is the body of work on interventions to help children deal with aversive medical procedures and hospitalization. Those studies are uniformly positive in showing that interventions that include even minimal skills training can nevertheless be effective for reducing distress and increasing cooperation.

Treatment adherence, in older children at least, appears to be responsive to educational interventions with at least one interactive training component focused on adherence behaviors. Most studies indicating that psychoeducational training can enhance survival and other physical outcome measures have been conducted with adults. However, the single study that included older children and young adults indicates that training interventions can improve survival in this group also.

GENERAL CONCLUSIONS AND FUTURE DIRECTIONS

The model for psychoeducational interventions we have advanced provides a useful framework for organizing and analyzing the research on psychoeducational interventions for childhood cancer. The model makes a distinction between interventions that essentially don't involve formal training based on an accepted learning paradigm and those that do. After reviewing the evidence, however, in those areas where there is sufficient research with children, it seems that positive results can be obtained from interventions in both categories. Comparison of

relative effectiveness is made difficult both by the lack of studies and the related fact that there are almost no studies that allow a direct comparison of the two types of interventions on the same outcome variables. The sole exception, an evaluation of multicomponent learning-based interventions that used standard information as a control showed clear superiority of the learning-based interventions in improving adherence and survival outcomes (Richardson et al., 1990). An important limitation in the generality of this finding to pediatric cancer patients is that the youngest participant was 17 years old.

It is lamentable that there is so little research on interventions to improve adherence in children and adolescents. Given the acknowledged importance of this issue, the substantial research on causes of adolescent nonadherence, and the evidence that nonadherence is related to specific illness-related knowledge, there is every reason to focus resources on the development of effective interventions. On the current, albeit limited, evidence that learning-based interventions involving interactive training on specific skills are the most efficacious approach to improving treatment adherence and survival in young people, it would seem important to study the relative efficacy of alternative interventions of this type.

It is a reasonable assumption that the characteristics of skills training interventions that makes them successful in producing desirable outcomes for patients are that typically they are individualized (patient-centered), interactive, run by expert trainers, multimodal, and directly train the behaviors they target for change. An obvious barrier to the widespread use of such interventions is the high cost per patient to deliver the intervention. Possibly, the recent development of interactive health games for children with cancer represents an attempt to capture these characteristics as an expert system within interactive digital technology. This type of development represents a logical response to the need for an accessible, cost effective psychoeducational intervention. As would be expected of so recent a development, there is little research on the effectiveness of such digital games. The one relevant published study of a game for children with leukemia provided evidence only that the game increased the children's perceived sense of control over their illness (Dragone, Bush, Jones, Bearison, & Kamani, 2002). While this may be encouraging, there is clearly a need for more extensive research covering a wider range of outcome measures.

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