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Children with a Chronic and Life-Limiting Condition: Teachers' Perceptions and Experiences Regarding Students' School Integration

Danai Papadatou
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The purpose of this study was to explore the perceptions and experiences of Greek teachers regarding the school integration of students with a chronic and life-limiting condition. This national survey comprised a representative sample of 1,792 educators. Of the sample, 19 percent (n = 340) *had at least a child with a serious disease in their classroom throughout their career and were faced with increased academic difficulties and few changes in the child's behavior. Affected by their student's health problem, educators systematically avoided discussing the illness experience with the child and classmates. They tended to become more lenient in their grading, less expectant of high academic performance, and more supportive of the ill child. To facilitate the student's school integration, Greek educators, who felt unprepared to handle such situations, requested training, a closer cooperation with mental health professionals, and ongoing support to effectively handle the experience of a serious illness within their classroom.*

The dramatic medical achievements that occurred during the past few decades have contributed to the cure of several children who were diagnosed with a life-limiting disease. Van Eyes (1976) suggested that these children can be considered as "truly cured" only if biological along with psychosocial standards are taken into account. Like many other clinicians, he encouraged health care professionals to design appropriate interventions that would respond to the complex psychosocial needs of seriously ill children and their family members from the very moment of diagnosis of a chronic and potentially fatal disease. Such interventions aim at helping the family to meet the practical and emotional challenges of the illness and treatment and promote a sense of "normalcy" in the midst of dealing with major life changes.

Normalcy in children's lives can be promoted in different ways. A critical one is regular school attendance and integration into the stream of school life. School attendance serves both educational and psychosocial purposes. It provides the child with education, necessary for self-esteem and hope for the future; enhances the development of social skills with healthy peers; and offers organization in a student's life, thus promoting a sense of control (Eiser and Town 1987; Stevens et al. 1988; Stevenson 1995; Worchel-Prevatt et al. 1998).

Findings of relevant research in various educational settings indicate that school reentry and integration may often become problematic when the child suffers from a serious disease or has been hospitalized for an extended period of time. Potential difficulties in school integration can be grouped in four major interrelated categories:

1. Disease and treatment difficulties: even though repeated hospitalizations or regular visits to the clinic may keep the child away from school, it has been noted that rarely do such medical factors explain the high rate of absenteeism that is common among children with a chronic and life-threatening illness (Henning and Fritz 1983).
2. Child-related difficulties: the most frequently reported difficulties stem from the child's anxiety about being teased and handling questions from peers. In addition, changes in appearance and the inability to keep up with school work due to prolonged absences may increase the youngster's anxiety, who withdraws and becomes isolated from peers (McCormick 1986; Worchel 1992).
3. Parent-related difficulties: parents often deal with their anxiety and guilt over the child's disease by overprotecting him or her. They are reluctant to send him or her to school because they fear infections or peers' remarks and teasing. The possibility that their child may die some day causes them to cling to him or her and consider school as "a waste of time" (Henning and Fritz 1983; Lawson 1977).
4. Teacher-related difficulties: studies exploring teachers' attitudes toward sick children indicate that educators are emotionally affected by the diagnosis of a serious illness in their students and are concerned about the following issues: (1) the lack of knowledge about the disease and the handling of medical emergencies, (2) the uncertainty about student's capabilities that would determine realistic academic expectations, and (3) the inability to handle classmates' reactions (Chekryn, Deegan, and Reid 1987; Davis 1989; Eiser and Town 1987; Stevens et al. 1988).

This study was funded by the European Union and the Ministry of Education of Greece. The study is part of a major project titled *Sensitization and Training of Educators and Health Care Providers in Supporting Seriously Ill and Bereaved Children* (1998-2000) (project leader: D. Papadatou).

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Based on the findings of relevant studies in different educational systems, it has been repeatedly noted that teachers feel unprepared to facilitate the child's school reentry and unable to handle the medical and particularly the emotional difficulties that may arise (Eiser and Town 1987). The need to "educate the educators" has been stressed by Stevens and his colleagues (1988), and attempts have been undertaken to develop educational programs for teachers, publish leaflets with appropriate information, and/or develop a school plan for the integration of the chronically ill child. However, most of the existing school reentry programs are designed for children with cancer (Baskin et al. 1983; Charlton, Pearson, and Jones 1986; Deasy-Spinetta 1981; Katz et al. 1992; Lansky, Cairns, and Zwartjes 1983; McCormick 1986; Ramholt 1999; Ross 1984; Sachs 1980; Spinetta and Spinetta 1980; Stevens et al. 1988). Nevertheless, the proposed principles for an effective integration are applicable to children with other chronic health problems since these children are faced with similar psychosocial challenges (Brown and DuPaul 1999; Wallander et al. 1988). Most of the relevant publications refer to case studies and descriptions of intervention programs that are rarely evaluated. There is further lack of programs with a particular theoretical basis. Of particular value are programs that take into account the complexity and variety of factors contributing to a child's adjustment (Farmer and Peterson 1995; Worchel-Prevatt et al. 1998). Such programs adopt an ecological and/or systems approach, useful in planning individualized interventions, and are aimed to help a child, his or her parents, the teacher, and peers to effectively cope with the challenges of school integration and of living with a chronic disease.

In Greece, to date, psychosocial support for chronically and/or seriously ill children is usually limited to the services offered within the hospital by members of interdisciplinary teams. The only comprehensive community service offered to seriously ill and bereaved children is the counseling center, developed recently by Merimna, a nonprofit society for children facing illness and death. Experts from this society conducted a major project during the period from 1998 to 2000 at the School of Nursing of the University of Athens. This project, which was funded by the European Union and the Ministry of Education of Greece, was titled *Sensitization and Training of Educators and Health Care Providers in Supporting Seriously Ill and Bereaved Children* (Project Final Report 2000). The two main goals of the project were (1) to sensitize professionals to the short- and long-term effects that a serious illness and/or death has on a child's life and development and (2) to offer a training program to a limited number of educators and health care professionals on how to effectively support seriously ill and bereaved children and facilitate their social integration. The first step toward the achievement of these goals was to conduct a national survey to identify for the first time the existing perceptions and experiences of Greek educators regarding seriously ill and/or bereaved children and subsequently develop (1) a training program to meet their specific needs and (2) intervention programs for children. The present article explores the perceptions of Greek educators toward seriously ill children and the experiences of those who had in their classroom a student who suffered from a chronic and life-limiting condition. The study of educators' perceptions of bereaved children's adjustment and experiences regarding student support is the topic of another article.

METHOD

Participants. A representative sample of the total number of Greek schools was identified, according to data obtained by the Ministry of Education, National Statistical Service (1998-1999). This sample included educators who worked in 480 schools (300 elementary schools, 97 junior high schools, and 83 high schools). The identified schools were randomly selected according to the following four criteria: educational level (elementary vs. junior high vs. high school), type of school (public vs. private), geographic regions (fifty-two Greek counties), and population size in each county (five categories). The selected schools were located in Athens (17 percent); in cities with more than 50,000 inhabitants (22 percent); in towns with 10,000 to 49,999 inhabitants (25 percent); in small towns with 2,000 to 9,999 inhabitants (22 percent); and in villages with less than 2,000 inhabitants (14 percent).

Of 3,500 questionnaires distributed, 1,810 were completed and returned (response rate 52 percent). A total of 1,792 fully completed questionnaires was included in the final analysis of the data. Out of the 1,792 respondents, 1,705 (95 percent) worked in public schools and 87 (5 percent) worked in private schools, while 64 percent ($n = 1{,}141$) taught in elementary school and 36 percent ($n = 650$) in junior high and/or high school. The sample was composed of 58 percent female and 42 percent male teachers. The smaller percentage of males is not surprising, given the higher overall ratio of female to male educators in Greece. The age of educators ranged as follows: thirty to forty years (52 percent), forty-one to fifty years (35 percent), and older than fifty-one years of age (11 percent). The sample was classified in three categories based on their teaching experience: (1) less than one to eight years (24 percent), (2) nine to eighteen years of experience (42 percent), and (3) more than nineteen years (34 percent).

Measures. An extensive questionnaire was designed that was composed of the following two sections:

- Section 1: teachers' perceptions about the impact that illness and death have upon a student's life, behavior, and school performance and
- Section 2: teachers' experiences and responses (1) to a student who suffered from a chronic and life-limiting health condition, (2) to the death of a student, (3) to a student who grieved over the death of a loved one, and (4) to the death of a colleague. The questionnaire also included personal and demographic information and a pilot study was conducted with twenty educators.

In the present study, results from Section 1 (only in relation to the chronically ill child) and Section 2 (only in relation to the student who suffered a chronic and a life-limiting health condition) are presented. Section 1 and Section 2 included closed- and open-ended questions.

Procedure. Permission was granted by the Greek Ministry of Education. The director of each selected school was contacted by phone and was informed about the goals of the study. The questionnaires were sent by air courier to be distributed to all educators in their schools. Each educator received an envelope with instructions and a questionnaire. He or she was asked to anonymously complete it, put it in an enclosed envelope, and return it to the school director, who then forwarded all the material to the researchers. The educators' participation was voluntary.

Findings were qualitatively and quantitatively analyzed. Descriptive statistics were used to calculate educators' distribution in relation to various demographic variables (gender, age, teaching experience, basic education, postgraduate training, type of school, educational status). The data of the study were evaluated using the Statistical Package for the Social Sciences.

Multiple two-way chi-square analyses were done to assess differences between certain demographic and personal variables (gender, age, marital status, educational status, teaching experience) and the educators' specific perceptions toward issues related to seriously ill students and their peers. Significant differences are only reported. Data obtained from open-ended questions were analyzed using content analysis.

RESULTS

Results are presented in two sections. The first section addresses the educators' general perceptions toward seriously and chronically ill students, while the second section addresses the experiences only of those educators who reported to have had a student with a chronic and life-limiting health condition.

SECTION 1: TEACHERS' PERCEPTIONS TOWARD CHILDREN WITH A CHRONIC AND LIFE-LIMITING CONDITION ($N = 1{,}792$)

Section 1 included closed- and open-ended questions that are presented in three thematic parts. Educators were asked to assess on a five-point Likert-type scale (1 = *very little,* 5 = *very much*) the degree to which they believed that children who suffer from a chronic and life-limiting condition are affected in their academic performance and school behavior. They were also asked their opinion regarding open discussions about illness. Finally, a question addressed whether educators had sufficient knowledge to cope with chronically ill students, and an open-ended question invited them to describe the role of the school in such situations.

Effects of Illness on Students' Academic Performance and Behavior

The large majority (81 percent) of teachers recognized that these children are likely to be much and very much affected in their learning performance. Only gender and marital status were found to differentiate marginally educators' responses. Female ($\chi^2 = 9.4$, $df = 4$, $p < .051$) and married educators ($\chi^2 = 21.58$, $df = 12$, $p < .042$) were more likely to acknowledge the major effects of a chronic illness on students' academic performance.

Seventy-five percent of teachers believed that children's behavior was affected to a high degree (much or very much). Interestingly, those who worked in elementary school in comparison to those who worked in junior and high school ($\chi^2 = 31.58$, $df = 8$, $p < .000$) as well as educators who had more than nineteen years of teaching experience ($\chi^2 = 36.98$, $df = 16$, $p < .002$) were more likely to report major changes in students' school behavior.

Open Discussion about the Illness

Almost half of the teachers (48 percent) believed that discussions between teacher and student about the chronic or serious illness should take place. Twenty-five percent suggested that such discussions should be avoided, and 27 percent argued that an open discussion depends on several factors. However, gender, age, and prior teaching experience seemed to significantly differentiate their responses. More women than men ($\chi^2 = 8.5$, $df = 2$, $p < .014$) and those aged thirty to thirty-five ($\chi^2 = 50.4$, $df = 14$, $p < .00$) believed that such discussions depend on the following factors: (1) the developmental stage of the student, (2) the student's personality, (3) the nature and seriousness of the disease, and (4) the educator's sensitivity and ability to cope with such students. A significant relationship was found between teaching experience and discussion of student's illness ($\chi^2 = 31.95$, $df = 8$, $p < .000$). Educators who had more than nineteen years of teaching experience did not believe that discussions should take place.

Educators' Knowledge about Handling Seriously and Chronically Ill Students and the Role of the School

Eighty percent of the teachers reported to feel inadequately trained to handle such situations. They suggested four different ways that would help them prepare and effectively support these students: (1) information from specialists (psychologists, doctors), (2) increased training in child psychology, (3) training in death education, and (4) the existence of a school psychologist who would work in close cooperation with educators.

They identified as key providers for students' support the school psychologist (78 percent), the child's teacher (66 percent), the educational consultant (14 percent), and the school administrator (13 percent).

SECTION 2: TEACHERS' EXPERIENCES REGARDING CHILDREN WITH A CHRONIC AND LIFE-LIMITING CONDITION

From the 1,792 respondents, 340 educators (19 percent) reported to have had a student with a chronic and life-limiting condition in their classroom. These educators completed Section 2 of the questionnaire, which aimed to identify their experiences toward these children, the most frequently reported health conditions that educators were faced with, and observed changes in ill students' academic performance and behavior as well as ways that facilitated school reintegration. Out of the 340 educators, 325 (95 percent) worked in public schools and 17 (5 percent) in private schools, while 136 (40 percent) taught in elementary school and 204 (60 percent) taught in junior high and/or high school. This subsample was composed of 61 percent female and 39 percent male teachers. Data from Section 2 are presented in the following six thematic parts.

Educators' Experiences with Students Suffering from a Chronic and/or Serious Illness

The five most frequently reported health conditions that educators were faced with were (1) blood diseases, such as thalassemia anemia, sickle cell anemia, and hemophilia (32 percent); (2) cancer (29 percent); (3) diseases of the central nervous system, such as epilepsy, paralysis, and myasthenia (22 percent); (4) genetic disorders, such as diabetes (22 percent); and (5) heart diseases (14 percent). Few mentioned having children with asthma, renal failure, and meningitis in their classrooms. Educators were asked to describe what affected them most in dealing with their students' illnesses. Their responses fell in three categories: (1) their inability to handle a medical crisis, (2) the child's physical changes, and (3) the child's coping with illness.

More specifically, several educators were affected by a medical crisis. They felt unprepared or incompetent to handle the crisis because they were often unaware of the student's health problem. "One of my students went into coma," wrote a teacher, "and we could not bring him around, until his mother instructed us by phone to offer him some water with sugar that helped him recover." Another one reported, "I was not informed by parents that he suffered from epilepsy. When he had a crisis in class, I was shocked!" But even when educators were informed by parents that the child suffered from a chronic illness, they often felt unprepared and insecure to deal with an eventual crisis.

Other educators were mostly affected by the child's physical changes and stigma associated with the illness, as reported in the following example: "I was mostly affected when she received radiation therapy, because she was bold and wore a wig."

Finally, a group of educators was affected by the student's coping strategies and particularly the child's determination to overcome difficulties and fight for life, as reported in the following accounts: "She coped very effectively," and "When she was at school, she tried very hard to cover her lost lessons and to excel."

Observed Changes in Ill Students' Academic Performance and Behavior

Most teachers (61 percent) identified changes in the students' academic performance due to the increased number of absences or to the nature of the treatment that affected the children's ability to carry on with the learning process. By contrast, changes in the students' behavior were reported with less frequency.

Few sensitive educators reported behavioral changes that facilitated or hindered the child's integration in the classroom. These changes involved (1) the development of a more trustful and close relation with the teacher and/or peers, (2) the child's introversion and tendency to withdraw from peers, and finally (3) the child's increased aggressive behavior toward classmates. It became apparent that children displayed more difficulties in their relations with peers than with their teachers. Following are examples of educators' written comments: "He felt closer and more comfortable with me, yet more withdrawn with others and his performance decreased," and "He was more friendly to me but aggressive with peers."

Descriptions of the child's withdrawal from peers were usually associated with an observed sadness and melancholy, while descriptions of aggressive behaviors toward peers were often accompanied by a broader sense of irritability: "He looked more calm and mature, maybe also melancholic. Sometimes he knew his lessons and sometimes not. He didn't become involved in mischief anymore," and "He became irritable and often cried, he protested against his classmates' behavior and neglected his homework."

Peers' Attitude and Behavior Toward the Ill Child

When educators were asked whether they observed changes in peers' behavior toward the ill child, half of them (51 percent) did identify changes that were described as positive in their majority (80 percent). More precisely, they referred to the peers' expressed love, acceptance, understanding, and friendliness or sympathy.

Few educators described specific acts by which classmates helped the sick child, such as "his peers helped him with his classwork, with moving around, because he was paralyzed," and "her classmates offered genuine support by visiting her in the hospital and at home and by showing their love and affection." Only a minority of educators reported teasing, aggressive, or harsh behaviors addressed to the sick child, usually because of apparent physical changes (e.g., baldness).

Educators' Attitude and Behavior Toward the Ill Child

A significant number of educators (60 percent) recognized changes in their attitude and behavior toward the seriously or chronically ill child. According to the qualitative analysis of their accounts, the nature of these changes was related either to their own expectations of the child's academic performance or to the development of a closer relationship that aimed to support the sick child.

In relation to the first category of responses, they reported to become "more lenient" in their grading and "less expectant" of high academic performance. They avoided exercising pressure on these children. In relation to the second category, educators reported an increased attention and conscious attempt to understand and emotionally support the chronically ill child, as shown in the following account: "I became nicer towards him, I avoided criticism in order not to upset him or bring him in a difficult position. This was done discretely in order to avoid any display of pity."

Educators who reported no changes in their attitude or behavior justified their responses by stressing the importance of not differentiating the ill child from his or her peers. One teacher wrote, "My behavior did not change, at least obviously, I tried not to make him feel different from his classmates," and another one commented, "I did not change, because I did not want my behavior to make him feel uncomfortable or think I was pitying him."

Even though not all educators acknowledged changes in their behavior, they reported a wide range of feelings toward the ill student. These involved caring, affection, and love, often coupled with admiration for the way the child was coping with the challenges of the illness. Some educators experienced mixed feelings of sadness, pity, and fear, as described in the following example: "I was feeling sad and fearful at the same time, I found myself in tears when I looked at him. I don't want this to happen to any child." Other educators referred to feelings of anger triggered by their need to make sense and justify "why" children had to bear and cope with such experiences. In addition, feelings of helplessness and awkwardness were common due to their difficulty to approach their students.

Overall, few teachers reported difficulties (22 percent) in their relations with the ill child, and these were usually related to problems with school performance, changes in behavior, and lack of cooperation with teacher. Children were then described as "irritable," "extremely sensitive to remarks," and either "totally withdrawn" or very "aggressive" toward peers. The latter was evident in the following account of a teacher who wrote, "Every time he returned at school after a blood transfusion, he screamed and beat up other children and became very restless." Some teachers reported difficulty in mediating the conflicts among peers: "It was hard to mediate his relationships with other students, especially when they complained to me about his behavior."

Educators were asked to describe how they had handled the reported problems. Learning difficulties were dealt with understanding and patience and by setting lower academic expectations. Behavioral difficulties were handled primarily by discussion and recommendations, such as "I encouraged him to play with his friends." Only one teacher consulted a psychologist to more effectively handle the difficulties that occurred in his classroom between the sick child and his peers.

Discussing the Child's Illness

It is impressive that only 23 percent of 340 educators discussed the illness or therapy directly with the sick child, and 17 percent of them took the initiative to openly address the issue with peers. A small percentage (10 percent) approached the topic only after peers voiced questions or made remarks. By contrast, in most cases (72 percent), teachers discussed the illness and treatment with parents.

The reasons for avoiding an open discussion were usually attributed to the sick child, to the parents who requested avoidance of any disease-related discussion, or to the teachers' personal difficulty. More in particular, educators avoided talking with children who were very young (e.g., "His age did not allow it") and who did not know the diagnosis of their disease (e.g., "She was not aware of the seriousness of her health condition and considered herself normal"). They also expressed reservations about causing distress or uneasiness in ill children by bringing up the topic of their disease.

The small percentage of educators (23 percent) who reported to engage in an open communication initiated a discussion with the occasion of the child's repeated school absences, prolonged hospitalization, a trip abroad for medical purposes, or even a medical crisis occurring within the class setting. Other opportunities for such discussions included the child's symptoms or obvious physical changes. The content of discussions addressed topics related to the diagnosis, the symptomatology, the treatment, and the way the disease affected the child's daily life: "Our discussion was more focused on medical tests and encouraging results." Often, through discussions, teachers attempted to boost the child's moral or help him or her deal with practical concerns related to schoolwork.

Communication was also critical with classmates who often raised questions in their attempt to understand why a child was not playing, why he or she was frequently absent, or why he or she had physical changes. Whenever the teacher honestly responded to such questions, peers had the opportunity to clarify further concerns about the child's illness, its seriousness, and its treatment. Sometimes, their concerns were focused on their own behavior and their willingness to support the sick child. Whenever the teacher maintained an open approach, effects were positive for everyone involved, as reported in the following accounts: "She felt encouraged and began to try more in her homework. She felt loved and cared by her classmates"; "We all bonded, knowing that we all needed each other"; and "His confidence in me and in his classmates increased because everyone treated him as if he was normal."

Our findings suggest that even though most educators avoid discussing with the child or classmates the disease, they have no reservations to addressing the topic with parents. Usually, parents initiate such conversations to excuse the child's long absences from school or a decrease in his or her academic performance.

School Interventions and Educators' Further Suggestions for Interventions

Educators were asked whether their school applied any interventions that facilitated the child reintegration and adjustment to the illness. Only 33 percent described various forms of intervention that were classified in four categories: (1) informing educators of a child's health condition and treatment; (2) providing financial aid to the family to cover expenses due to the child's medical needs; (3) emotional and practical support of the ill student by being lenient in grading, by accepting and justifying the increased number of school absences, and by maintaining contact during the child's hospitalization; and (4) guidance and family referral to medical experts, to specialized centers abroad, or to mental health centers for psychological support.

When educators were invited to offer further suggestions about school interventions, they reported the following:

- the psychological support of educators who had a sick child in class by their colleagues or a psychologist—this was the most frequently reported suggestion;
- information about the child's illness and his or her medical and psychological needs;
- discussion about the handling of difficulties that may arise in the child's integration in school and the peers' acceptance of their ill classmate;
- close collaboration with parents and ongoing exchange of information about the child's health condition and adjustment to the chronic illness;
- collaboration with various experts or social services—educators suggested that the school should hire a school counselor or psychologist, or a nurse and physician, who would be available to the child, family, as well as to the educators;
- availability of home or hospital visits to help the student with class work;
- fund-raising to support the family with the medical expenses; and
- building arrangements for handicapped children.

DISCUSSION

The objectives of this study were twofold: to explore Greek teachers' perceptions as well as teachers' experiences regarding chronically ill students' school integration. In regard to the overall perceptions that teachers (N = 1,792) have about these children, findings suggest that most educators recognize that ill students are likely to be affected in their learning performance and school behavior. Female and married educators acknowledge with greater frequency the possible effects of a serious illness on children's academic performance. This may be due to an unconscious identification with a maternal role in their relations with their students. In addition, those teaching in elementary school recognize with greater frequency that changes are also expected to occur in school behavior. This finding may be explained by the fact that Greek educators in secondary schools usually teach one or two subjects in each class and are expected to follow a very structured curriculum having, thus, little opportunity to observe changes in students' behavior.

In regard to educators who had a personal experience with a student with a chronic and life-limiting condition (n = 340), it became obvious that educators were sensitive to observed changes in students' academic performance but reported with less frequency changes in behavior. Similar findings are reported in other studies (Henning and Fritz 1983; Spinetta and Spinetta 1980). This may be due either to the child's need to avoid being singled out from peers or to the educator's tendency to underestimate behavioral changes and to perceive the sick child as "normal."

Half of this sample described an overall positive attitude from peers toward the ill child, displayed through expressions of love, acceptance, understanding, friendliness, or sympathy. Very few teachers reported teasing or aggressive behavior, as well as difficulties in handling conflicts among classmates. This encouraging finding illustrates the importance of peers' support network. Young people trust each other, and in many cases, the classmates are the first ones to provide help and to support each other (Stevenson 1994).

Educators recognize changes in their attitude and behavior toward the ill child. Similar to other studies (Chekryn, Deegan, and Reid 1987; Davis 1989), they report difficulties in setting realistic academic expectations, as a result of which they tend to become more lenient in their grading. Moreover, they actively attempt to develop a closer relationship to support the sick child and stress the importance of not differentiating him or her from peers.

Even though teachers had no prior education on the process of facilitating students' reintegration, they nevertheless appeared to instinctively respond quite appropriately. The experience of a child's illness affected them in many different ways. Their accounts focused primarily on their own helplessness and ignorance of handling a medical crisis and of dealing with the child's physical changes. It becomes apparent that it was not the seriousness of the child's condition that affected teachers most frequently but rather the practical aspects of coping with a medical crisis along with the fact that they were often not informed by parents about the child's health condition.

Only 23 percent of these educators reported having discussed the illness or the therapy directly with the sick child, and occasionally with peers. Teachers' reluctance to openly discuss the illness was reported in few other studies. Eiser and Town (1987) have found that the majority of

educators believed that the sick child's integration in the classroom was not likely to have any beneficial effects on the other students and therefore avoided discussions with healthy peers. By contrast, even though half of the overall sample of Greek teachers supported the need for an open discussion, the reluctance and avoidance of those who had experiences with ill children stemmed from their lack of knowledge, skills, uneasiness, and fears, as well as from the prevailing attitude of Greek families to hide the diagnosis of a serious illness from children (Papadatou 1995, 1997, 2001).

These teachers requested medical information and more training in child psychology and in death- and dying-related issues. Finally, they highlight the importance of hiring a school psychologist who—in cooperation with them—will facilitate the child's school integration.

Implications of this national study are important on several factors:

At a prevention level, teachers highlight the need for specialized training programs addressing the ways by which to facilitate school integration of ill students. Moreover, findings suggest that educators lack the necessary communication skills to initiate and handle "sensitive" or "difficult" topics with students and their peers.

Following the results of this national study, the School of Nursing at the University of Athens offered a training program (100 hours) on how to support seriously ill and bereaved children, addressed to three different groups of professionals: (1) a group of educators, (2) a group of health professionals, and (3) a group of psychologists and social workers. Toward the end of the training, participants formed interdisciplinary teams and began to implement their knowledge and skills in various school and hospital settings, sensitizing their colleagues to the needs of seriously ill and bereaved children. This sensitization process continues to grow, while guidelines are being developed to help schools promote the reintegration of children with special needs (Nielsen and Papadatou 1999).

At an intervention level, the study suggests the adoption of a team approach among family and members of the school and local community (e.g., medical, nursing, and mental health professionals) to secure ongoing information and to offer support according to children's individualized needs. In that respect, the counseling center of Merimna (the nonprofit Society for the Care of Children and Families Facing Illness and Death) has offered specialized services that benefited a significant number of school communities, facilitating their adjustment to the serious illness or the death of a child. This, however, does not substitute for the imperative need to increase positions for school psychologists who will work closely with children, parents, educators, and health care professionals.

A data-based model of alternative school psychological services has been developed recently with the aim of promoting children's well-being by filling the void of psychological services within the school system. Intervention programs for various groups of students with different needs have been designed and occasionally implemented in schools and children's institutions, emphasizing the necessity for a multilevel partnership-based framework (Hatzichristou 1998; Hatzichristou et al. 2000).

At a postvention level, schools should organize an ongoing system of evaluation to determine how the child's academic and psychosocial needs are met and the formal support systems available to educators who need consultation and support in handling eventual difficulties.

Regardless of whether a child with a chronic or a serious illness will be cured or die, our responsibility is to promote his or her development, enhance his or her self-esteem, and contribute to the quality of his or her life. By facilitating school reintegration, we offer to healthy children a unique opportunity to learn how to be sensitive to the needs of others, how to provide care and support, and how to mature through life's adversities. The school has a critical role to play in this process, and educators have the right to receive all the necessary knowledge, skills, and support that would help them be effective in their work and interventions.

REFERENCES

Baskin, C. H., C. F. Saylor, W. M. Furey, A. J. Finch, and D. J. Carek. 1983. Helping teachers help children with cancer: A workshop for school personnel. *Children's Health Care* 12:78-83.

Brown, R. T., and G. J. DuPaul. 1999. Introduction to the mini-series: Promoting school success in children with chronic medical conditions. *School Psychology Review* 28 (2): 175-81.

Charlton, A., D. Pearson, and P.H.M. Jones. 1986. Children's return to school after treatment for solid tumours. *Social Science and Medicine* 22:1337-46.

Chekryn, J., M. Deegan, and J. Reid. 1987. Impact on teachers when a child with cancer returns to school. *Children's Health Care* 12:234-45.

Davis, K. G. 1989. Educational needs of the terminally ill student. *Issues in Comprehensive Pediatric Nursing* 12:234-45.

Deasy-Spinetta, P. M. 1981. The school and the child with cancer. In *Living with childhood cancer*, edited by J. J. Spinetta and P. Deasy-Spinetta, 153-68. St. Louis, MO: C. V. Mosby.

Eiser, C., and C. Town. 1987. Teachers' concerns about chronically sick children: Implications for pediatricians. *Developmental Medicine and Child Neurology* 21 (1): 56-63.

Farmer, J. E., and L. Peterson. 1995. Pediatric traumatic brain injury: Promoting successful school reentry. *School Psychology Review* 24:230-43.

Hatzichristou, C. 1998. Alternative school psychological services: Development of a data-based model in the Greek schools. *School Psychology Review* 27 (2): 246-59.

Hatzichristou, C., A. Vaitsi, P. Dimitropoulou, and B. Falki. 2000. Center for school and family consultation and research: A partnership-based framework for the development of alternative school psychological services in the Greek schools. In *Education, communication and counselling*, edited by L. Malikiosi, 217-33. Athens, Greece: Ellinika Grammata.

Henning, J., and G. K. Fritz. 1983. School reentry in childhood cancer. *Psychosomatics* 24:261-69.

Katz, E. R., J. W. Varni, G. L. Rubenstein, A. Blew, and N. Hubert. 1992. Teacher, parent, and child evaluative ratings of a school reintegration intervention for children diagnosed with cancer. *Children's Health Care* 21:69-75.

Lansky, S. B., N. U. Cairns, and W. Zwartjes. 1983. School attendance among children with cancer: A report from two centers. *Journal of Psychosocial Oncology* 1:75-82.

Lawson, B. 1977. Chronic illness in the school-aged child: Effects on the total family. *Maternal Child Nursing* January/February: 50-56.

McCormick, D. 1986. School reentry program for oncology patients. *Journal of the Association of Pediatric Oncology Nurses* 3:13-25.

Nielsen, M., and D. Papadatou, eds. 1999. *When serious illness and death affect school life* (in Greek). Symposium proceedings. Athens, Greece: Merimna.

Papadatou, D. 1995. The child with a chronic and serious disease and the family (in Greek). In *Health psychology*, edited by D. Papadatou and F. Anagnostopoulos, 215-41. Athens, Greece: Ellinika Grammata.

———. 1997. Training of health professionals in caring for dying children and grieving families. *Death Studies* 21 (6): 575-600.

———. 2001. The evolution of palliative care for children in Greece. *European Journal of Palliative Care* 8 (1): 35-38.

Project Final Report. 2000. *Sensitization and training of educators and health care providers in supporting seriously ill and bereaved children* (in Greek). Athens, Greece: Ministry of National Education.

Ramholt, B. 1999. Making school a success for children with cancer and for their siblings (in Greek). In *Proceedings of the symposium "When illness and death affect school life,"* edited by M. Nielsen and D. Papadatou, 51-73. Athens, Greece: Merimna.

Ross, J. W. 1984. Resolving nonmedical obstacles to successful school reentry for children with cancer. *Journal of School Health* 54:84-86.

Sachs, M. B. 1980. Helping the child with cancer go back to school. *Journal of School Health* 50:328-31.

Spinetta, P. D., and J. J. Spinetta. 1980. Teacher's appraisal: The child with cancer in school. *American Journal of Pediatric Hematology and Oncology* 2:89-94.

Stevens, M.C.G., J. I. Kaye, C. F. Kenwood, and R. J. Mann. 1988. Facts for teachers of children with cancer. *Archives of Disease in Childhood* 63:456-58.

Stevenson, R. G. 1994. Helping peers to help themselves: The role of peer support in times of crisis. In *What will we do? Preparing a school community to cope with* *crises*, Death, Value and Meaning Series, edited by R. G. Stevenson, 175-81. Amityville, NY: Baywood.

———. 1995. The role of the school: Bereaved students and students facing life-threatening illness. In *Children mourning, mourning children*, edited by K. J. Doka, 97-111. Washington, DC: Hospice Foundation of America.

Van Eyes, J. 1976. What do we mean by the "truly cured child"? In *The cured child*, edited by J. Van Eyes, 81-97. Baltimore: University Park Press.

Wallander, J. L., J. W. Varni, L. Babani, H. T. Banis, and K. Wilcox. 1988. Children with chronic physical disorders: Maternal reports of their psychological adjustment. *Journal of Pediatric Psychology* 13 (2): 197-212.

Worchel, F. F. 1992. Adjusting to childhood cancer: A model for psychosocial care. In *Teaching more than medicine: Psychosocial consideration in pediatric oncology*, edited by J. Van Eyes, D. R. Copeland, and E. R. Davidson, 135-51. Houston: University of Texas M. D. Anderson Cancer Center.

Worchel-Prevatt, F. F., R. W. Heffer, B. C. Prevatt, J. Miner, T. Young-Saleme, D. Horgan, and M. A. Lopez. 1998. A school reentry program for chronically ill children. *Journal of School Psychology* 36 (3): 261-79.

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When a Child Dies: Money Matters

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The financial implications of a death are rarely discussed—indeed, in the case of a child's death, almost never. This article describes an exploratory study conducted in the United Kingdom in response to the belief of staff in a children's hospice that for many bereaved parents, the nature and extent of their financial problems were obstructing the effectiveness of support and help available to deal with emotional aspects of grief and loss. Findings from depth interviews with bereaved parents and staff in health and care services, and a questionnaire sent to all U.K. children's hospices, throw light on the reasons for and the impact of financial problems. Findings provide a number of pointers to ways of improving support for parents whose child dies. At the same time, findings provide strong arguments for including money in debate about dealing with death in contemporary society.

The financial impact of death is a topic apparently rarely visited in the literature and research about dying and death. Yet financial issues—access to and levels of income and financial support and management of resources—play a key part in all aspects of our lives and many of the major decisions we make. Much is known about the financial impact of caregiving, during the period that may precede death, but little about the financial impact of death for bereaved people.

This article draws on exploratory research from the United Kingdom in this area. Our aim is to help to put money into the debate about death and dying, to show that it is possible to talk to recently bereaved parents about the financial impact of their child's death and that this is an area of

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