

PREPARING CLASSROOM TEACHERS FOR THE IMPENDING DEATH OF A STUDENT WITH TERMINAL ILLNESS

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ABSTRACT

The percentage of students with terminal illness in general education settings is increasing, therefore teachers face challenges in dealing with the issue of death and the related consequences following the death of a child. Challenges include their own feelings, the needs of the peers of the ill or deceased student, and the potential needs of the student's family. The importance of understanding children's developmental levels as well as strategies to help teachers integrate the concept of death into the classroom are included.

Violence in our society, specifically within our schools, has focused much attention on both death and the untimely death of students. Additionally, the inclusion of students with life threatening or terminal health-related conditions has increased the direct experience of students and teachers with death. The need for teachers who are cognizant of the needs of their students, the challenges presented by the topic, and their roles and responsibilities as professionals, seems paramount given the emergence of death as a timely topic. There is one main distinction however, that separates death as it relates to a terminally ill student from other causes of death (i.e., sudden death from accidents or trauma) that might arise during a school year. This distinction is the element of time. The impending death of a classmate with a terminal illness gives teachers time to help their students perceive and

respond to the death in a healthy manner. Twenty percent of all deaths of children aged five to fourteen are caused by malignant neoplasms, congenital anomalies, and human immuno-deficiency virus infection, whereas 11% of all deaths for these ages are due to homicide and suicide (Corr, 1996). Preparation for the predictive death of a student, however, necessitates a professional response. This work focuses specifically on the preparation necessary when the death is anticipated during the academic year.

Students with disabilities have and continue to receive special education services in a variety of settings ranging from general education classrooms to separate schools. The Individuals with Disabilities Education Act requires that students with disabilities receive their specialized services in the least restrictive environment which is determined by each student's Individualized Education Plan (IEP). For most students, the least restrictive environment is the general education classroom with special education services. According to recent statistics, students receiving special education services in the categories of multiple disabilities, orthopedic impairments, and other health impairments have been increasingly receiving their education in the general education class, resource room, or separate class in their neighborhood school (U.S. Department of Education, 2000).

Court decisions have helped to define what the least restrictive environment is for students in these categories. In the *Oberti v Board of Education of Clementon, New Jersey*, the court determined the least restrictive environment for the student with multiple disabilities was the general education classroom (Boundy, 1996). In a recent U.S. Supreme Court decision, *Cedar Rapids Community School District v. Garret F.*, the court required the school district to pay for nursing services for the student in the local school (Katsiyannis & Yell, 2000). These decisions make it apparent that students with multiple and health related disabilities will be included in general education settings in increasing numbers.

Some students receiving special education services under these disability categories have terminal conditions that will result in the death of the student during the school year (Chomicki, Sobsey, Sauvageot & Wilgosh, 1995). Other students may die due to accidental or other causes and these tragic deaths may not be the result of a disabling condition. The numbers of students both with and without identified disabilities are not easily distinguished in national statistics reporting the number of deaths by age and type (e.g., terminal illness or accident). A brief examination of the statistics related to the increased inclusion of students in the categories multiple disabilities, orthopedic disabilities, and other health impairments indicates the growing impact of this population on the schools.

Students served under the disability category "multiple disabilities," some with terminal illness, are increasingly being educated in their neighborhood schools. Specifically between the years 1987 and 1997 the percentage of students in this category being served within the regular school setting, such as general education classrooms and resource rooms, increased almost 5% (U.S. Department of Education, 2000).

Similarly the number of students eligible to receive special education services under the disability category "orthopedic impairments" has increased over the past fifteen years. The percentage of students in this category receiving educational services within a general, resource, or separate class has increased to 15%. Almost 14% of these were students who receive their services in the general classroom. This increase may be, in part, due to the percentages of students who previously received services in a public separate facility or in a home/hospital environment since the percentage of students in these two respective placements dropped from 27% in 1987 to 6% in 1997 (U.S. Department of Education, 2000).

Under the disability category "other health impairments," the trend continues. About 93 % of these identified students are now educated in their neighborhood school, which is an increase of 21% over a ten year period. Inclusion of students from this category represent the largest increases for any disability category in two education environments, the general education classroom and the resource room (U.S. Department of Education, 2000). The inclusion of students identified under these disability categories has placed the issue of impending death firmly within neighborhood schools (Peckham, 1993).

Teachers who have students identified as having a terminal condition that affects their academic performance will be in contact with, or a member of, a multidisciplinary team which will develop the student's IEP. These plans address student's educational needs. In compliance with the Individuals with Disabilities Education Act, members of the multidisciplinary team must include the student's parents, a special education teacher, a general education teacher, an administrator, and may include others such as the student, counselor, and/or medical personnel. Each of these members has specific roles in creating the educational plan. The team meets to address changes in the student's health status as these changes impact the student's education. A less obvious function of the team is to provide a structure of communication and support for everyone working with the student who is terminally ill.

Through the team meeting and/or through other conferences (Moller, 1967), the educational staff can determine the parent's feelings about their child's impending death (Gyulay, 1978; Kubler-Ross, 1993), pertinent cul-

tural perspectives (Grollman, 1995b), how they have approached the topic of death with their child (Romain & Verdick, 1999), and how they feel about the preparation of the child's peers for his/her death (Dobihal & Stewart, 1984). In addition to having input regarding any of these issues, the parents may also need support and suggestions (Chomicki et al., 1995). Teachers and/or school counselors can provide both, if they are comfortable doing so, and can also direct parents to other resources that might be helpful. The support provided to parents on the team is also essential for the other team members. Certainly teachers, administrators, counselors, and other school personnel may experience stress related to the death of a child within their respective classes and/or school (Moller, 1967). The necessity of establishing support groups (see Appendix A), whose focus is not strictly on the educational ramifications of the child's terminal conditions, seems appropriate (Small, 1991).

These support groups may continue to meet even after the student dies (Schnieders & Ludy, 1996). When a student or group of students die due to an accident or traumatic event, schools and communities typically respond by offering grief counseling at the schools (Thompson, 1995). In some cases counselors are assigned to each classroom in the building. Since many adults acknowledge their difficulty when confronted with death, it should be of no surprise that children are challenged cognitively and emotionally by this major event. While their difficulty is compounded by a number of factors, the ability to conceptualize the event is directly linked to both age and cognitive development (see Table 1).

For example, the egocentricity of children between the ages of three and six may evidence itself in feelings of guilt following the death. Children functioning at this level may believe they are personally responsible because they thought or said something like "Drop dead" or "Go away."

Around these ages children do not conceptualize the finality of death (Grollman, 1995a). Their belief that the deceased person is still alive in the coffin may lead to concerns about the person closed up in "that box" as well as the belief that the person might be able to venture out at will, perhaps at night.

Around the age of six until about ten children personify death as some dark character (perhaps a skeleton or ghost) who appears at night. Since death, so conceptualized, becomes tangible, children at this level of development believe that they and others can escape or hide from it (Grollman, 1967). Children at this stage are curious about death, ask direct questions, and are open to receiving honest, direct answers (Garanzini, 1987). Toward the end of this stage, typically beginning around age twelve and extending

TABLE I
Children's Conceptualization when Discussing Death

Ages	
3-5	<ul style="list-style-type: none"> • Feelings of guilt and grieving are normal. • It is natural for all living things to die. • Figurative language confuses student's understanding of death. • Terms such as "final" or "forever" are meaningless.
6-8	<ul style="list-style-type: none"> • Death is caused by physical reasons, not by being "taken away." • Death is often symbolized with ideas of ghosts or haunting images.
9-10	<ul style="list-style-type: none"> • Students believe that death can be avoided. • Direct questions about the person's body are asked. • Students are open to direct honest answers.
11+	<ul style="list-style-type: none"> • Death is irreversible. • Feelings about death may be expressed through artistic outlets. • Students begin to understand how organ donation may help others.

Note: This information synthesizes text from Garanzini (1987) and Molnar (1983).

into adulthood, children enter into a stage in which they are cognitively able to conceptualize death as irreversible and inevitable. At this stage they can also think abstractly about the concept of afterlife and fully understand what "death" means (Garanzini, 1987; Molnar, 1983).

Since children conceptualize death differently depending on their developmental level, it is important that teachers are knowledgeable regarding the stages and the coinciding conceptualizations. Consequently they will be able to not only understand children's questions, comments and concerns but will also be able to focus answers and discussions toward the appropriate level (Grollman, 1967; Moller, 1967).

While it is important that the classroom teachers know how their students understand death, it is also important for teachers to explore their own feelings about the topic (Gyulay, 1978). While there are many ways to do this, talking to colleagues, friends, counselors, religious leaders or others, regarding the topic may be helpful. Certainly it is important that teachers are comfortable talking about death before they open discussion with either individual children or groups of children (Romain & Verdick, 1999).

Whether a child is diagnosed with a terminal illness or condition during the school year or he/she enters the school previously diagnosed, one person in the school should be designated as the contact person. For example, at the elementary grade level, the primary contact person may be either the classroom or special education teacher. At a middle or high school, the contact person may be a guidance counselor or other school administrator. Certainly the school nurse will be a key person and may be the school contact (Gyulay, 1978; Stevenson, 1995).

It is important to determine if the school personnel will speak directly to the parents or health care provider. This may depend on the culture of the family. In keeping with the Buckley Amendment, the representative of the school must have parental permission before contacting or sharing any information with health care providers. Another important consideration is how much the parents wish to share with the school.

Children reportedly are witness to many deaths prior to reaching adulthood (Sedney, 1999) presumably through numerous arenas (e.g., home, school, neighborhood, community), involving various levels of emotional attachment (ranging from parents and/or close relatives to small creatures), and through a variety of ways (e.g., personal involvement, media, hearsay). The necessity of educating children regarding death by accident and illness is apparent. The increased inclusion of students with terminal illness further strengthens the need for death education (Thornton & Krajewski, 1993).

Before proceeding with discussion of various strategies for death education lessons, several notes of caution are necessary. First, teachers must examine their own feelings about death (Gyulay, 1978; Moller, 1967; Thornton & Krajewski, 1993) and be confident, comfortable and able to discuss the topic of death. If a teacher is not, his or her own reluctance and reticence in answering the inevitable questions and discussing the topic openly will not only further confuse children but also may introduce apprehension and increase fears. Second, sensitivity to a wide range of perspectives about death must be respected within today's increasingly diverse classrooms. The teacher must educate themselves about the possible religious, ethnic, and cultural ideologies present within the classroom and how those variables impact discussions about death (Grollman, 1995b). Work with parents, other teachers, social workers, counselors, and members of the community can help increase the teacher's perspectives on possible issues that might arise as this challenging topic is placed in the classroom curriculum (Toray & Oltjenbruns, 1996).

The use of children's literature has been one way that numerous sensitive topics have been introduced, intentionally or non-intentionally, into classrooms (Corr, 1995; Romain & Verdick, 1999; Ross, 1967; Thornton, 2001).

The topic of death is introduced and even explored in numerous children's books that are available through current web sites (see Appendix B). The teacher is cautioned to read the book, consider the age of the children for whom it is intended, and the purpose for the selection of the piece.

One starting place is to re-examine stories already used in classrooms. One example is *Charlotte's Web* by E. B. White. In this story, frequently read in elementary classrooms, Charlotte, the spider, can save Wilbur, the pig, but she acknowledges the inevitability of her death. Few teachers have conceptualized this story as a way to carefully integrate the concept of death into their classrooms in which a student with a life threatening disability or condition is present. This theme could be carefully integrated into a classroom discussion on the inevitability, how Wilbur deals with the knowledge of this, and further into the concept of what will happen after her death, how Wilbur will go on, etc. While the in-depth examination of specific examples of children's literature is not the focus of this work, this example demonstrates how the integration of the topic into the classroom is actually already in place. The necessity of making teachers aware, willing, and comfortable in developing and exploring the theme is essential.

Another way the concept of an impending death can be integrated into the classroom also involves little modification of the typical classroom structure. The teacher must be willing to see the potential in the 'teachable moments' ever present in a classroom and then connect them to the concept of death (Thornton, 2001; Thornton & Krajewski, 1993). While these examples may be seen as very simple and perhaps as stretching the concept, the opportunity to make connections between the abstract concept of death and the reality of the actual event is essential for younger elementary age children. The death of classroom pets, insects, even flowers and plants can present valuable teachable moments for an aware and sensitive educator (Dobihal & Stewart, 1984). Further connecting these moments to children's literature (e.g., Buscaglia's *The Fall of Freddy the Leaf*) helps children experience the topic in a more integrated fashion. This integration can form a thread throughout the daily life of the classroom, rather than the placement of 'death education' on a schedule of events or topics to be covered during a set time frame.

While the use of children's films to help children conceptualize and prepare for an impending death can be seen as a valuable addition to the death education curriculum, recent work by Sedney (1999) implies some cautions relative to the selection of those films. Her analysis of *Snow White*, *Bambi*, *The Land Before Time*, and *The Lion King*, reaffirms the value of not only death education, but grief education as well. She acknowledges that children

“absorb information and even potential coping skills for handling grief while they are watching films that include death” (p. 322). Her in depth analysis of these four films however, implies a note of caution for teachers. She suggests that teachers utilizing these films and others not included in her analysis, would be well advised to follow the viewing with discussions designed to elicit questions and ‘fill in the gaps’ that might arise.

The focus of this work has been on death and the challenges, it presents to teachers working within today’s inclusive settings, specifically students who have terminal health-related conditions. These concepts apply to the broader topic of death and how it might be addressed within the schools. Teachers, administrators, students, and their parents unfortunately are presented with the untimely death of school aged children as the result of accidents or suicide. The death of these students are usually followed immediately by grief counseling provided to all associated with the student who died. Students who die as a result of a terminal illness will also be grieved by their teachers, administrators, peers, and family members; however, due to the nature of their illness, the impact this type of death has on others can be lessened.

APPENDIX A
Support Groups

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| <p>Association for Death Education and Counseling
342 North Main Street
West Hartford, CT 06117-2507
(860) 586-7503 Fax: (860) 586-7550</p> | <p>This association offers resources, an annual conference, a human resource network, and a newsletter to its members.</p> |
| <p>Center for Grief
1133 Grand Avenue, St. Paul, MN 55105
Phone: 651-641-0177 Fax: 651-641-8635</p> | <p>“A non profit organization dedicated to offering help and hope for the difficult times in our lives”</p> |
| <p>The Compassionate Friends, Inc.
P. O. Box 3696
Oak Brook IL 60522-3696
FAX: 630-990-0246
877-969-0010</p> | <p>Provides education and support for individuals who work with the grieving child. Included are clergy, teachers and counselors. Information also provided on support groups in 600 locations</p> |
| <p>Rainbows
2100 Golf Road #370
Rolling Meadows, IL 60008
Phone: (800) 266-3206
Fax: (847) 952-1770</p> | <p>Provides curriculum and training for establishing peer support groups for children, adolescents, and adults who are grieving a death, divorce, or other painful transition in their family. Trains counselors.</p> |
| <p>The Dougy Center for Grieving Children
3903 S.E. 52nd Avenue,
P.O. Box 86582 Portland, OR 97286
Phone: (503) 775-5683</p> | <p>Provides loving support in a safe place where children grieving a death can share their experience as they move through the healing process. The Dougy Center extends supportive services to the family, caregivers, schools, and the community.</p> |
| <p>Bereaved Parents of the USA
P.O. Box 95
Park Forest, IL 60466
(708) 748-7672</p> | <p>Designed to aid and support bereaved parents and their families following the death of a child. Information and referrals, newsletter, phone support, conferences, support group meetings.</p> |

APPENDIX B

Web Sites Listing Children's Books

<http://www.death-dying.com/channels/topic.php/topic/26>

<http://www.alivehospice.org/about/publications.html>

<http://www.therapeuticresources.com/grief.html>

<http://www.barrharris.org/>

<http://growthhouse.org/books/books.htm>

<http://www.chw.edu.au/parents/books/books-08.htm>

<http://www.booktrusted.com/booklists/deathindex.html>

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