

TEACHERS' KNOWLEDGE AND SUPPORT SYSTEMS REGARDING STUDENTS WITH TERMINAL ILLNESS

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ABSTRACT

This study examined teachers' knowledge and support when working with students with terminal illness or having experienced a student death. One hundred and ninety teachers of students with physical or multiple disabilities responded to a 40 item questionnaire that was distributed nationally. Results indicated that teachers have greater knowledge and support in this area than 21 years ago, although there continues to be deficits. For teachers receiving support, the school nurse was identified as their primary source of support, as well as the primary source to answer questions, and discuss the teachers' role. School counselors were identified as the primary support for classmates (in addition to receiving support from their teacher). Teachers identified several areas in which they wanted assistance and support which have implications for future research and training.

Death is an inevitable and universal experience for all living things. However, death and dying remains a topic that is regarded by many as uncomfortable and even inappropriate for public discussion (Harrawood, Doughty, & Wilde, 2011; Horridge, 2011; Mak, 2011). It is especially difficult to contemplate the death of a child. Although approximately 2.5 million people die in the United States every year, slightly over 50,000 of these are infants or children (Heron, Sutton, Xu, Ventura, Strobino, & Guyer, 2010). Evaluation of these statistics suggests that experiencing the death of a school-age child is not a highly probable event for teachers. However, with the increasing inclusion of children and adolescents with terminal illnesses or special health care needs into public schools, coupled with advances in medical technology that allow children with vulnerable health to live longer, the likelihood that teachers will encounter student death increases. It also magnifies the need for teachers who can sensitively and effectively meet these student's health and emotional challenges, as well as support classmates, parents and themselves when faced with students who are dying. Unfortunately, teachers typically do not receive formal training on how to support a student who is dying, nor how to support classmates, parents, or themselves (Lazenby, 2006). This deficiency, added to factors such as anxiety and personal fear of death, complicate the dynamic and may reduce the ability of teachers to effectively and compassionately support students, their families, and themselves.

Historically, family members were integrally involved in many aspects of the death process. Currently, physical caregiving, preparation of the body after death, and internment, previously provided by family members, have been supplanted by professionals who assume these roles and responsibilities. Children, who might have witnessed many of these activities at younger ages,

may not experience them until they are much older (if at all). Added to the physical distance placed between the living and the dead in contemporary Western society are views that children must be “sheltered” from the emotional impact of death and a belief that children cannot comprehend the meaning of death, which may lead parents to discourage discussion about illness, dying, and death (Holland, 2008). These prohibitions create additional barriers to communication and understanding. At a time when we have more students in the school with severe medical conditions and terminal illness who will die before they graduate, the need for informed professional support is essential.

The development of concepts about death and reactions to death are highly influenced by variables such as age, intellectual function, culture, media, religion/spirituality, communication opportunities, and personal experience (Clute, 2010; Cox, Garrett, & Graham, 2005; Hunter & Smith, 2008; Mak, 2011; Niemiec & Schulenberg, 2011; Smith, Alberto, Briggs, & Heller, 1991). Speece and Brent (1984; 1992) note that a mature concept of death is attained by most children by the time they are 9 or 10 years old, although children approach their understanding of death at different rates. Eventually, most children will understand the five major concepts of death: 1) inevitability (everything dies), 2) universality (nothing is exempt), 3) irreversibility or finality (not coming back), 4) cessation or nonfunctionality (body does not work); and 5) causality (something in the body prevents it from functioning) (Corr, 2010; Slaughter & Griffiths, 2007; Walker, 2010). Once they comprehend these characteristics of death, children begin to understand the emotions that accompany the realization of death.

The child’s ability to understand the concept of death will parallel the child’s general cognitive development; hence, children who are very young or have developmental disabilities will not understand abstract concepts of death (Walker, 2010). These children may repeatedly ask when a classmate is coming back or believe that the body will start working again. Children between the ages of five and seven often associate nonphysiological reason for death, such as punishment or wishing the person dead. Death is often personified as an entity (e.g., ghost) from which one can escape (Corr, 2010; Walker, 2010). Teachers instruct students at all ages and levels of understanding and without understanding the developmental nature of the concept of death, teachers may be unable to effectively assist students with terminal illness, parents, or classmates.

When students have a terminal illness, their death is differentiated from a sudden death (such as from accident, suicide, homicide) in that there is

the element of time. When there is a child with a terminal or life-limiting condition, teachers and school staff have time to determine the parents' feelings about the impending death, important cultural considerations, ways to address the dying child's questions and concerns, and how they prefer classmates' concerns be addressed (Rice & Gourley, 2003). Parents often need support and suggestions as well. They may turn to the teacher for information about the condition, and necessary school adaptations. Teachers need to be prepared to provide this information or find out how to obtain it.

School-age children with terminal or life-limiting conditions often are aware of the seriousness of their illness. If they are able, continuing in school is important, even if it is for short periods of time since it allows them to participate in purposeful activities. In addition, when students with terminal illness realize their future is shortened, they often adapt and shift their focus to the more immediate future, such as the next significant event (e.g., holiday, school event) (Beale, Baile, Aaron, 2012). Sometimes these children will seek out a teacher to talk about their concerns and wishes or just have someone listen to them. Teachers will need to use reflective listening skills and help provide needed adaptations or supports to allow students with terminal illness to participate in significant events they have identified as important. Teachers need to have supports in place to assist their interactions with students with terminal illness that not only help them understand the students' particular condition, but provide ways of assisting students with terminal illness.

Some students with terminal illness will receive pediatric hospice services to address physical, psychological, social, and spiritual aspects of care when death is expected to occur within six months. The purpose is to enhance the quality of life of the child, focus on comfort rather than cure, provide support to the entire family through an interdisciplinary team (e.g., nurse, social worker, physician, chaplain, nursing assistant), and deliver hospice services in the student's environment (Wolfe, Hinds, & Sourkes, 2011). It also includes emphasis on family-centered practice, cultural sensitivity, continuing education, and awareness of community resources (Crozier & Hancock, 2012). Hospice care may also extend to the school setting. In one example, "school staff worked together with a hospice team to help a dying child remain involved with his class he was attending while attending school and as he declined at home. Support for students continued after their classmate's death, individually and school wide." (Ramer-Chrastek, 2000, p. 52).

Classmates of all ages will need support when they experience the death of a classmate. Grief reactions can vary greatly between having the appear-

ance of no reaction to a death to having reactions of intense longing, experiencing an inability to concentrate, asking multiple questions, exhibiting a range of emotions, and having physical symptoms. Each student will grieve in his or her own way and new grief reactions may occur long after the death (Cowan, 2010; Koehler, 2010). Having open discussions and finding ways to express grief in a safe environment is important (Cowan, 2010).

Teachers and counselors may use several approaches to support students who have lost a classmate such as: 1) using children books that have death and dying themes; 2) participating in rituals (such as attending funerals, drawing pictures, writing cards); 3) memorializing (such as planting a tree, making a memory box, making a collage of photographs); 4) creating legacies (such as scholarships, charity drives, dedicating an activity); and 5) creating peer support groups (Cowan, 2010). Teachers, school counselors, and other members of the educational team will need to have a good knowledge base in place to address classmates' concerns. Local hospices may provide occasional or ongoing support to school systems on how to help grieving children, including finding appropriate activities and assisting in helping bridge "the discomfort zone" where teachers struggle to find the right words when talking to grieving students (Naierman, 1997). In order for teachers to effectively help grieving children, it will be important that they also find ways to address their own grief (Lazenby, 2006).

The need to address issues of death and dying in schools has never been more critical. Teachers are typically more accessible to family members than doctors or social workers. In addition, daily contact with their students makes them a logical and pivotal source of information and comfort. They are an important part of a team that includes nurses, counselors, administrators, school psychologists, and others in the educational workplace. However, their effectiveness to support children's learning and emotional development begins with their own knowledge and self-competence (Chan & Tin, 2012).

The purpose of this study was to examine teachers' knowledge and support when working with students with terminal illness or having experienced a student death. This included examining the types of supports they had in place as well as determining the types of supports they would like to have in the future. Results of this study were also compared to results from the original questionnaire taken 21 years ago to examine any changes that have occurred over time. In addition, participants were also asked to respond to two areas not included in the original study, pain management and hospice, to determine knowledge and support in these areas.

METHOD

PARTICIPANTS

The questionnaire targeted special education teachers who worked with students with physical disabilities and multiple disabilities (including students with severe and profound intellectual disabilities) since they were more likely to have experienced a student death and have students with terminal conditions. The questionnaire was also sent to school nurses. Two national organizations were targeted: the Division for Physical, Health and Multiple Disabilities (DPHMD) of the Council for Exceptional Children (which is the only national teacher organization in physical, health and multiple disabilities) and the National Association of School Nurses (NASN) (which is the national organization specifically for school nurses). In addition, since students with physical disabilities are more likely to have conditions that are terminal or life-limiting, two states that had teacher certification in Physical and Health Disabilities and consortia specifically for these teachers were targeted. These were the Georgia Orthopedic Impairment Consortium and the California Association of Physical and Health Impairments.

An email was sent to members of these groups explaining that the purpose of the questionnaire was to better understand the training, knowledge, experiences, and supports of teachers and school nurses who have experienced a student death or who have worked with students with terminal conditions. The letter contained a link to the questionnaire. Several weeks after the initial email letter was sent, a second reminder e-mail letter was distributed. In addition, an explanation of the research and link to the questionnaire was posted twice electronically in the National Association of School Nurses Weekly Digest. In the consortia and DPHMD meetings, an identical paper copy of the questionnaire was available if the participants preferred this to the electronic copy.

QUESTIONNAIRE

The questionnaire was comprised of 40 questions divided into 5 sections: a) demographics, b) terminal illness, c) death of a student, d) pain management, and e) hospice. The first three sections of the questionnaire were based on the original 1991 questionnaire in order to make some comparisons in responses over time. The last two sections were new. The demographics section included information on employment, state the respondent worked, number of years teaching or practicing as a school nurse, and amount of training they had in the area of death and dying.

The section of the questionnaire on terminal illness had questions pertaining to: availability of support; availability of a source to answer questions;

source to discuss respondents' role with student, family or classmates; desired support; and willingness to teach another student with a terminal illness. A question not included on the original questionnaire inquired about how knowledgeable respondents felt about their student's terminal illness.

The section of the questionnaire on the death of a student, questions pertained to: availability of support to the teacher or nurse following a student death; availability of support to the student's classmates; desired support; and attitudes regarding whether continuing in school as in the best interest for the student. Added to this section was a question about how knowledgeable respondents felt about the student's medical or health condition.

The two new sections of the questionnaire addressed the issues of pain and hospice. The pain section contained a background question to ascertain if the respondents had students who experienced pain and the number of these students. Other questions then dealt with ability to recognize pain, how knowledgeable the respondent felt about the student's pain medication, and who assisted them in assessing or managing student pain. The hospice section also started with a background question identifying if the respondent had any students receive hospice services. Topics in the hospice section included: how knowledgeable respondents were about hospice, if they wanted support or information from hospice personnel, and if they wanted to learn more about hospice.

DATA ANALYSIS

Two versions of the questionnaire were created: online and print. Questions on both versions were identical. Several types of questions were used in the questionnaire. Some multiple-choice questions required the respondent to choose one single answer (e.g., level of knowledge options from very knowledgeable to no knowledge at all) while other questions allowed multiple responses (e.g., check all sources of support that apply). Three questions about hospice were set up using a Likert-type rating scale. The remaining questions were open-ended and required respondents to type into an answer field (e.g., list questions classmates had about a student's death).

The online questionnaire was created using IBM Statistical Package for the Social Sciences (SPSS) Data Collection Web Interviews software. This software allows researchers to create various types of questions (e.g., single and multiple response multiple choice questions, Likert-type scales) which are answered online. Data are stored on a server and must be downloaded into SPSS Statistics software for analysis. When respondents clicked the link, they were taken to the consent page which explained the purpose of the questionnaire, described the voluntary and confidential nature of the questionnaire,

and provided contact information of the researchers.. If they consented to participate, they were routed to the first question in the Demographic and Training section. SPSS Data Collection Web Interviews software saved respondents' data after each response; however, if participants closed the browser window prior to completing the last question, they were considered to be "incompleters" and their data were not included in the analyses. Most questions were displayed one question at a time on the screen. If the responder did not have a student with a pain, a terminal illness, or death, the rest of the section would be skipped. When respondents indicated they had a student in one of these areas, the software provided a reminder on the screen if respondents missed answering a question. The questionnaire was tested for proper construction.

The print questionnaire was created in Microsoft Word and was 8 pages in length. It was identical to the on-line questionnaire and also contained a consent page for the participants to sign. Data from print questionnaires were entered into the SPSS Data Collection Software so that all data were available for analysis.

Once all responses were collected, data were downloaded and analyses were completed using SPSS. For the purpose of this study, teachers' responses were separated from the original data set. This study used descriptive statistics including frequencies, percentages, valid percentages, and cumulative percentages. Valid percents of this current questionnaire were compared to the valid percent data in the original questionnaire.

Data were compared to the original questionnaire to find any general differences in responses. With over two decades between the two questionnaires, and increasing awareness of a need for greater teacher support, it was hypothesized that supports and knowledge bases would have changed over time.

RESULTS

A total of 1,723 questionnaires were sent by the researchers (although those receiving the email letter could forward it to other special education teachers or school nurses). Of these , 65 email addresses were returned with an error delivery message, making the total number distributed by the researchers as 1,658. A total of 589 questionnaires were returned for a return rate of 35.5 % .

Although the larger data set included school nurses, this article examines the smaller data set of special education teachers to determine teacher's current knowledge and support in the area of terminal illness and death as well as compare it to teacher responses from about 20 years ago. Of these returned questionnaires, 190 questionnaires were from special education teachers with:

74 from teachers of students with physical and health disabilities; 110 from teachers of students with moderate, severe, profound intellectual disabilities or multiple disabilities; and 6 from hospital/ home bound teachers. This closely compares to the earlier study which had a return rate of 189 responses with: 74 teachers of students with physical and health disabilities; 96 teachers of students with moderate, severe, profound intellectual disabilities; and 19 other such as hospital/homebound. The 190 respondents in the current study were from 22 states and 70% had been teachers for longer than 10 years.

KNOWLEDGE BASE OF TEACHERS

In reporting their training, 33.2% of the respondents said they had no prior preparation in the area of death and dying, 47.4% had the topic discussed in university/college courses, 21.1 % had in-services or workshops on death and dying, and 13.2% had training from other sources (e.g., hospice, life experiences). Respondents were asked four questions about their knowledge of students' terminal illness, medical condition of students who died, pain medication, and hospice (see Table 1).

On a 5-point Likert-type scale with 5 being very knowledgeable and 1 having no knowledge; respondents reported a mean of 3.78 regarding knowledge of

Table 1.

Teacher's Reported Knowledge Level Reported as Percentages

	Very knowledgeable/ Knowledgeable	Somewhat knowledgeable	Not very Knowledgeable/ No Knowledge
How knowledgeable do you feel about students' terminal illness? (n = 165)	64.2	29.7	6.1
How knowledgeable do you feel about medical condition of the student who died? (n = 157)	70.7	26.1	3.1
Do you feel knowledgeable about the pain medication your students receive? (n = 124)	44.3	41.1	14.5
How knowledgeable are you about hospice? (n = 190)	32.1	41.1	26.9

their student's terminal illness. Stated in another way, only 64.2% rated themselves as very knowledgeable or knowledgeable about student's terminal illness. Respondents reported a mean of 3.87 regarding knowledge of medical conditions of students who had died. In this case, 70.7% rated themselves as very knowledgeable or knowledgeable about the medical conditions of students who had died. In rating their knowledge of the pain medications their students received, there was a mean of 3.43 with 44.3% of respondents reporting as being very knowledgeable or knowledgeable. When asked about hospice, there was a mean of 3.14 with only 32.1% indicating they were very knowledgeable or knowledgeable about hospice.

TERMINAL ILLNESS

Of those who responded to the questionnaire, 86.8% reported that they had at least one student with a terminal illness. The majority of respondents (25.8%) reported having 2 or 3 students with a terminal illness. This was followed by 20% having 4 to 7 students with terminal illnesses, 4.2% having more than 12 students with a terminal illness, and 14.2% having 1 student with a terminal illness.

Teachers' Source of Support When Students Have Terminal Illness. Respondents were asked if they had a source of support available to them in working with students with terminal illnesses. As seen in Table 2, 14.5% answered that they had no such source of support. Of those who answered that they had a source of support, the school nurse (62.4%), coworkers (60.6%) and supervisor/administrator (26.1%) were the three most frequent sources of support within the school system. The top three sources outside the school system were family (47.9%), reading/internet (37%), and friends (26.1%). The 15.8% who identified "other" as a source of support primarily identified nurses (not with the school system) and parents of the student.

In the original 1991 questionnaire, 32% of the teachers reported having no source of support in working with students with terminal illnesses. For those who had support, 49% identified school counselors and/or school psychologists as being the greatest source of support within the school system, followed by co-workers (25%), and social workers and nurses tied for third (12%). The most frequent sources of support outside the school system were physicians (36%), organizations (17%), and clergy (14%).

Available Sources to Answer Teachers' Questions. In the current study, respondents were asked if they had a source available to answer questions about the student's terminal illness or condition. Only 2.4% reported they had no source of support. Of those that had a source of support, the school nurse (77%), co-worker (33.9%) and school psychologist (17.6%) were the

Table 2.

Source of Support When Teaching a Student with a Terminal Illness Reported as Percentages (with 1991 Questionnaire in parentheses)

	Source of Support		Answer Questions		Discuss Role: Class	
	Current Study (n = 165)	(Original Study) (n = 189)	Current Study (n = 165)	(Original Study) (n = 189)	Current Study (n = 165)	(Original Study) (n = 189)
<i>No source of support</i>	14.5	(32)	2.4	(44)	9.7	(57)
<i>School support</i>						
School nurse	62.4	(12)	77.0	(27)	49.7	
Co-worker	60.6	(25)	33.9	(28)	49.1	(31)
Supervisor/						
Administrator	26.1	(2)	16.4	(25)	40.6	(6)
School counselor/	23.6/	(49)	7.9/		13.9/	(41)
School psychologist	22.4		17.6		18.2	
Social worker	21.8	(12)	15.2		15.2	(19)
<i>Outside school support</i>						
Family/	47.9/	(11)	40.0/	(41*)	26.7/	
Friends outside						
school	26.1		8.5		12.7	
Reading/Internet	37.0	(8)	54.5	(15)	24.8	
Physician	13.9	(36)	27.3	(11)	9.7	
Clergy	12.1	(14)	2.4		3.6	
Professor	10.3	(4)	12.1		9.7	(3)
Organization	10.3	(17)	9.1	(33)	7.9	
Health Department	2.4	(2)	6.1		1.8	
Hospice personnel	6.7		5.5		4.8	
Other	15.8		15.2		6.7	

*The term family was not differentiated in the current study, whereas in the original study this percentage referred to the student's family.

three most common sources within the school system. Outside of the school system, the most common sources of support to answer questions about the terminal illness or student condition were reading/internet (54.5%), family (40%), and physician (27.3%). The 15.2% who selected the category of other, primarily identified nurses (not associated with the school system), physical therapists, students guardians as their source of information.

In the original study, 44% of the teachers responded that they had no support to answer questions about the terminal illness. For those who had a source of support, co-workers (28%), school nurse (27%) and supervisor/administrator (25%) were the leading responses. Outside of the school system, the students' parents (41%) were the most common source of support, followed by organizations (33%) and reading/internet (15%).

Available Support to Discuss Teachers' Role. In the current study, 9.7% responded that they had no source of support to discuss their role in interacting with the student, family or classmates. Of those that had a source of support, the school nurse (49.7%), co-worker (49.1%) and school psychologist (18.2%) were the three most common sources in the school system. Outside of the school system, the three most common sources of support were family (26.7%), reading/internet (24.8%), and friends outside school (12.7%).

In the original 1991 questionnaire, 57% of the teachers responded that they had no source of support to discuss their role in interacting with the student, family or classmates. The top three sources of support in the school were identified as the school counselor and/or school psychologist (41%), co-worker (31%) and social worker (19%).

Providing Support When Students Have Terminal Illness. Respondents reported providing support to students with terminal illness, their parents, and their classmates.

Supporting Students with Terminal Illness. Respondents reported that they provided support to students with terminal illness by answering their questions about terminal illness. Although 38.2% of respondents reported that students were unable to ask questions due to cognitive issues, 17% had students asked them questions. There were four major categories of inquiries from students with terminal illness: a) condition and prognosis, b) faith-based questions, c) school adaptations, and d) family concerns. The majority of questions (52%) dealt with the students' condition and prognosis, such as: "Am I going to die," "Will I get better," "How fast do they [brain tumors] grow," and "How long will I live?" The next most common type of question asked was faith-based (28%) where students asked such question as: "Do you believe in heaven," and "How does God decide who dies?" Some students asked about adaptations (12%), such as one student wanting a different assignment from one dealing with financial planning for old age and another student was concerned about how to get the teacher's attention when he can no longer raise his hand. Family concerns (8%) included the parent not wanting the student to know about his condition, and questions about how to help the family deal with medical expenses. Some respondents reported trying to be supportive and encouraging and also utilizing other members of the educational team to help with these questions.

Supporting Parents of Students with Terminal Illness. Twenty percent of parents who had children with a terminal illness asked teachers questions that were divided into five major categories: a) school issues, b) prognosis or student condition, c) resources, d) discussions with the child about terminal illness, and e) effective transition between home and hospital. The majority of questions (43.7%) pertained to school issues. These included: "How does their illness affect the educational process," "How long can they keep the child in school," and "How much emphasis should be placed on academics; how much should they push a student to achieve?" There were also questions pertaining to Do Not Resuscitate (DNR) orders.

The next most frequent category of questions pertained to prognosis or questions about the students' condition (21.9%). Families asked such questions as: "How long do you think they have," "Is there a cure," and "What happened to a child with a similar diagnosis?" Parents also wanted to know about resources (18.7%) with some questions pertaining to the type of help hospice can give, as well as questions regarding alternate treatments or suggestions of alternate doctors.

The last two categories respondents identified as questions from parents dealt with discussing the illness (9.4%) and effective transitioning (6.3%). Respondents reported questions regarding how to tell the student about his terminal illness, and questions about the classmates understanding of the student's condition. Respondents also reported questions regarding having an effective transition between home and hospital settings.

Supporting Classmates with a Student who has a Terminal Illness. Respondents found themselves supporting classmates with 46.7% reporting that they talked with the classmates about the child with a terminal illness. Other people who talked with classmates were: parents (8.5%), students with terminal illness, themselves (6.1%), and other (12.7%) which consisted primarily of school nurses, psychologists, school counselors. Several respondents reported that the student was receiving services at home, so they had limited peer contact. Many respondents also reported that peers who had cognitive impairments did not seem to understand what was happening. However, one respondent reported that although the peers had cognitive challenges and could not verbally ask, their behaviors and communication attempts made obvious their sense of situation and their concern and care.

For those respondents who had students who were verbal, peer questions divided into six main categories: a) condition and medical equipment, b) prognosis, c) contagious, d) dying issues, e) how to help, and f) adaptations. The majority of questions (34.9%) asked by peers dealt with the condition of the student and any medical equipment they might have, such as: "What is that in their neck [tracheostomy tube]," "What kind of cancer

does he have,” “Why is there an oxygen tank,” “What’s wrong with him,” and “Why is he in a wheelchair?” One respondent elaborated upon the struggle with finding simple answers without violating Health Insurance Portability and Accountability Act (HIPPA) and staying respectful of religious beliefs.

Many questions also dealt with prognosis (27%) and dying issues (11.1%). The respondents encountered such questions as, “Is the student going to be OK,” “Is he coming back to school,” and “How long does [my] friend have to live?” Some respondents remarked about the difficulty of explaining the outcome of the condition and in some instances explain what death meant. Discussions often led to questions pertaining to dying, such as, “Where will he go when he dies,” “What is it like, and “Why him?” Respondents reported peers became very upset and some peers questioned the fairness of the situation. Many students (15.9%) asked if the student’s terminal illness was contagious and if they would get it. This topic also raised concern for students with various medical conditions as to whether their own condition was also terminal.

Several students wanted to help (9.5%) and directly asked “Can we help him?” Other questions dealt with providing support as peers, such as: “Can we still be friends,” “Will I hurt her,” and “Can he go to the home of a classmate?” Some students found ways of helping by assisting with adaptations such walking to class with the student, carrying the student’s books, or getting lunch for the student. Some students asked about helping the student with schoolwork such as typing a paper. However, sometime adaptations raised questions (1.69%) such as why the student does not have homework

Future Supports for Teachers with Students with Terminal Illness. Respondents were asked if they would be comfortable teaching another student with a terminal illness. The majority of respondents (53.9%) answered yes with no changes. However 39.4% answered yes with changes to the support system. The 6.7% who answered that they would not be comfortable teaching another student with a terminal illness, gave such reasons as they are not qualified, do not have enough training, and find it is very hard emotionally.

Respondents were asked what supports they would like if they were to work with another student who has a terminal illness. As seen in Table 3, 55.8% answered they would like support from the school nurse, followed by 26.7% from the school counselor and 25.5% from the social worker. Outside of the school, 52.1% of respondents answered that they would like help from parents and 26.7% help from hospice staff. This is in contrast to the original study in which the majority of teachers (29%) wanted support from either the school counselor or psychologist.

Table 3.

Supports Wanted by Teachers in the Future When Having a Student with a Terminal Illness Reported as Percentages

	Current Study (n = 165)	Original Study (n = 189)
<i>Inside of school</i>		
School nurse	55.8	4
School counselor/ Psychologist	26.7/ 20.6	29*
Social worker	25.5	5
<i>Outside of school</i>		
Help from parents	52.1	3
Hospice staff	26.7	N/A
<i>Delivery and type</i>		
More medical information	70.3	34
Inservices	47.3	14
<i>Other</i>	18.8	11**

* This number reflects a combination of school counselor/psychologist

** This number reflects a support group

In terms of delivery and type, 70.3% wanted more medical information and 47.3% would like it delivered as in-services. For respondents who selected “other,” 18.8% of the respondents identified wanting support from school administrators, support from physicians, communication among team members regarding the illness, and support to classmates.

STUDENT DEATH

The majority of respondents surveyed (82.6%) reported that they experienced student death; 26.8% reported 2 or 3 deaths, 17.9% reported 1 student death, 15.8% reported 4 to 7 student deaths, and 5.3% reported more than 12 student deaths. Respondents were also asked if continuing in school was in the student’s best interest. In this study, 78.3% responded with positively, 16.6% responded that they don’t know and 5.1% responded no. In the original study, 92% responded that continuing in school was in the student’s best interest, while 8% were unsure.

Teachers’ Source of Support When a Student Dies. Respondents were asked about sources of support available to them when a student died. As seen in Table 4, 21% of the respondents answered that they had no source

Table 4.

Source of Support When a Student Dies Reported as Percentages (with 1991 Questionnaire in parentheses)

	Source of Support for Teachers		Source of Support for Classmates	
	Current Study (n = 157)	(Original Study) (n = 189)	Current Study (n = 157)	(Original Study) (n = 189)
<i>No source of support</i>	21.0	(83)	20.4	(53)
<i>Inside school</i>				
Co-worker	65.6	(43)	28.7	
School nurse	39.5		23.6	
Supervisor/Administrator	32.5	(2)	20.4	
School counselor/ Psychologist	20.4/ 19.7	(46)	38.2/ 21.7	(37)
Social worker	17.8	(9)	18.5	
Teacher talked to classmates	NA	NA	46.7	(63)
<i>Outside school</i>				
Clergy	8.3	(50)	0.6	
Family/ Friends outside school	43.9/ 29.9	(33)	14.0/ 5.1	
Reading/Internet	13.4	(12)	2.5	
Hospice personnel	3.8		2.5	
Physician	2.5		1.9	
Professor	1.3	(5)	0	
Health Department	1.3		1.3	
Organization	5.1		3.2	
<i>Other</i>	14		28.0	

of support. Those who had a source of support named co-workers (65.6%), school nurses (39.5%) and supervisor/administrators (32.5%) as the three most frequent sources within the school system. The top three sources of support outside the school system were family (43.9%), friends outside of school (29.9%), and reading/internet (13.4%). The 14% of respondents who had other sources of support primarily identified nurses (who were associated with hospitals or agencies such as student's own nurse), and private counseling and grief support groups. One respondent reported receiving support from the crisis team while another had access to an employee assistance program.

In the original 1991 questionnaire, 83% of the teachers reported having no support when a student died. Of those with support, 46% identified school counselors and/or school psychologists have being the greatest source of support within the school system, followed by co-workers (43%) and social workers (9%). The most frequent sources of support outside the school system were clergy (50%), family/friends outside of school (33%) and reading/internet (12%).

Providing Support to Classmates When a Student Dies. Although no source of support was available to classmates as reported by 20.4% of respondents, 46.7% of respondents identified themselves as talking to students about terminal illness and death. Other sources of support for classmates were: school counselors (38.2%), co-workers (28.7%), and school nurses (23.6%). Outside support was primarily from the family (14%). The "other" category was selected by 28% of the respondents; they identified additional sources as hospital personnel, paraprofessionals, or administrators. The majority of comments in the "other" sections were comments of there either there being no classmates (due to homebound status) or "just me." Respondents reported such activities as: discussing student death with the class, making butterflies, and reading books pertaining to death and dying. In the original article, 53% of the teachers reported they had no support. When support was provided, the persons identified were the teacher (63%) and school counselor/ psychologist (37%).

Respondents were asked to list questions the classmates had about death. Questions were divided into six main categories: a) information about death, b) painful death, c) difficulty understanding death issues, d) if it will happen to them, e) faith-based, and f) how to help. Several respondents reported that their students who were unable to verbalize due to cognitive impairments, showed a behavior change (e.g., appeared sad). Of those students who were able to ask questions, 30.5% asked information about the death, such as, "What made him die," "Where did his things go" and "Why is he dead?" An addition 11.1% asked specifically if death was painful and if the student suffered.

Some students were reported as having experience with pets or other classmates dying. The older students had an understanding of death; however, younger children or students with intellectual disabilities (30.1%) had difficulty comprehending death issues, as seen by such questions as: "Why did he die at a young age," and "Why can't he turn into a superhero?"

Although one respondent reported that some of her students became analytical regarding the death and asked many questions to obtain specific information, other students became fearful. 17.5% of the respondents reported they had students asking it if would happen to them or their family members. Young students without the same diagnosis were reported as becoming fearful due to focusing on the effects of the disability (e.g., my friend used a power chair and

he died, I use a power chair so I'm going to die [even though the friend had muscular dystrophy and the student had cerebral palsy]). One respondent commented she had students learn about their conditions before they are high school age, if they are cognitively able and parents provide permission.

Several questions regarding death were faith-based questions (7.9%) and mostly dealt with the topic of heaven. One respondent reported that the students believed in an afterlife where the child was free of cancer and no longer had disabilities.

The last category of questions and comments dealt with helping (3.2%). Some students asked about going to the funeral and one student with moderate intellectual disability was reported as attending the funeral. Some respondents had classmates make cards for the family, write letters, make picture boards, write articles in school newspapers about the student, and cook food to be available after the funeral service.

Future Supports for Teachers When a Student Dies. Respondents identified several areas of support they would like in the future: help assisting family members of students who died (59.2%), help assisting classmates with the loss of a student (58.6%), and help to support themselves cope with loss of a student (36.9%) (see Table 5). Many respondents wanted more information surrounding student death (39.5%) and many respondents wanted inservices (35.7%) on issues surrounding student death. Also, respondents reported that they wanted additional support from supervisor/administration (21%), school nurse (19.1%), and other teachers (16.6%). One respondent commented that she wanted release time to go to funerals, and discussed the need to allow teachers involved with the student to come together to support each other. It was also commented that it is acceptable for the crisis teams to check up later with others who are involved with the death. In the original questionnaire, support from school counselors/school psychologists (27%) was the highest ranking area.

Respondents identified five categories of questions at the time of a student death: a) supporting classmates, student's family, and staff; b) obtaining more information; c) dealing with emotions; d) worrying if enough support was provided; and e) resolving school conflicts and issues.

The majority of questions (44.1%) dealt with providing support to classmates, student's family, and staff. Respondents asked how to talk with classmates, how to share information within the bounds of confidentiality and how to handle differing belief systems of students with varying backgrounds (e.g., responding in a supportive manner to students' religious beliefs about heaven, while also responding in a supportive manner for those students who do not believe in heaven). Respondents also questioned how to best address fears of students with the same disability. Questions for family support pertained

Table 5.

Type of Additional Support Wanted by Teachers Concerning Student Deaths Reported as Percentages

	Current Study (n = 157)	Original Study (n = 189)
<i>Support wanted by teachers</i>		
Support help me assist family members of student who died	59.2	12
Support help me assist classmates with loss of student	58.6	12
More information on issues surrounding student death	39.5	
Support help me cope with loss of student	36.9	
<i>Desired added support</i>		
Inservice	35.7	9
Support group with others who have lost a student	19.1	25
Funeral home visit	10.2	3
<i>Added support from individuals</i>		
Support from Supervisor/Administrator	21.0	
Support from School nurse	19.1	
Support from School counselors/ School Psychologists	12.1/ 10.8	27
Support from Other teachers	16.6	
Support from Hospice staff	12.1	
Other	8.4	

to how to help the family, and if they should maintain contact with the student's family.

Many respondents (23.7%) felt that they should have more communication and information surrounding student's death. Some of them expressed surprise by the sudden decline or sudden death and wanted more information about how the disability impacted the life span or the exact reason of death. One respondent commented that during the beginning of her career there was less information and support, but now teachers have received additional training. She added that her school has two nurses serving 250 students, and she asked her nurses questions and received updated information from them. One respondent commented how difficult it is when the family does not communicate the details of the death.

Some respondents wanted more support and resources from the school. This included release time for funerals as well as ways to address conflicts with coworkers who felt it was not in the best interest of the student to be at school. One respondent commented that it was difficult to balance the benefits of having the dying student attend school with new testing/accountability regulations and negativity from administrators when dying students perform poorly. Another respondent questioned if she should have brought up the topic of death at meetings (even though it seemed taboo) so decisions could be made about issues related to students' decline and impending death.

Respondents also had concerns over their own emotional response (10.2%), such as, "What is my role and where do I put these feelings?" One respondent commented that, "My student's death was one of the hardest experiences that I have had as a teacher." Emotional responses also included struggling with questions as to why some children have to die while others have long life and how the death helps us all to grow. In addition to these, respondents were concerned if they provided sufficient care to the dying student, and asked such questions as: "Did I do all that I could for the student?" and "Did I do all that I could do to make the student comfortable?" There were also comments that their student was loved.

PAIN MANAGEMENT

There were 95.8% of respondents who reported that they taught students who experienced pain. The majority of respondent reported that they had more than 12 students experiencing pain (27.4%) or had between 4 to 7 students experiencing pain (24.7%). Only 44.7% of respondents answered that they were able to recognize pain in their students, with 37.9% being uncertain of recognizing pain in one or more students; 15.8% finding it difficult to recognize pain in one or more students and 1.6% being unable to recognize pain.

Respondents reported that 65.3% of students experiencing pain received pain medication at school. Medication was administered by the following personnel: 85.5% by the nurse, 27.4% by the teacher, 25.0% by the teacher's aide, 9.7% by the secretary, and 12.1% by other (e.g., student self administered, nursing assistant, private duty nurse, and clinic worker). When asked if the respondent felt knowledgeable about the pain medication, 15.3% responded very knowledgeable, 29.0% knowledgeable, 41.1% somewhat knowledgeable, 12.9% not very knowledgeable, and 1.6% no knowledge at all. 30.2% of the respondents answered that they disagreed or strongly disagreed that all of the students who had pain appeared to have the pain under control.

HOSPICE

In the hospice section of the questionnaire, 26.8% of the respondents answered that they had students who were in the process of receiving or who had received hospice services. Ten percent of the respondents answered that they were very knowledgeable about hospice, 22.1% were knowledgeable, 41.1% were somewhat knowledgeable, 25.3% were not very knowledgeable, and 1.6% reported no knowledge at all (mean 3.14 on 5-point Likert type scale with 5 being very knowledgeable). Upon asking if the respondent would like hospice personnel to provide support to school personnel when a student dies, 36.8% strongly agreed and 33.2% agreed (mean 4.01). In regard to having hospice personnel to provide information on terminal illness, 46.3% strongly agreed and 30% agreed (mean 4.16).

Sixty-seven respondents wrote in comments about hospice, with many having experience with hospice due to their own family or friends. All of the comments praised their hospice experience (e.g., fabulous support), except for one respondent who questioned some hospice policies. All comments from respondents who had students on hospice were positive, such as, "Hospice was helpful and accommodating with one of my students," "Hospice was wonderful! They gave me support and helped me support my ill student and my other students," and "Hospice was able to help with having the class come visit the dying child at home during school hours."

Respondents also commented on specific ways hospice could be beneficial, such as: providing information on terminal illness and realistic expectations at child's level, supporting school staff, training in hospice care, and finding ways that hospice and school staff can work together to approach the family about this. Some respondents brought up issues of confidentiality and having hospice personnel in the classroom, while others discussed the training and support roles. Several comments indicated an unfamiliarity with hospice as well as misconceptions about its services. These included being unaware of hospice for children and thinking that hospice is a place rather than a philosophy and form of care that can occur in any location.

DISCUSSION

Special education teachers of students with physical, health and multiple disabilities often are educating students with terminal illness and life limiting conditions. This places the teacher in the unique position of providing support to the student, classmates, family, and self. The need for support also continues after the student has died. The results of this study indicate that teachers play a primary role in providing information and support, but do not

always have the tools and support that they need. Ninety-three percent of teachers are willing to have another student with a terminal illness and assume this role, but 39.4% want changes to the support system.

The amount of training teachers have had in the area of death and dying issues has increased vastly over the years, from 75% having no prior training in 1991 to 33.2% having no training in 2012. But this means that approximately one third of the respondents have no training in this area and lack an appropriate knowledge base. They have students with terminal illnesses or students who have died and are faced with providing appropriate information and support to others. In addition, some of these students with terminal conditions will have pain. The lack of training regarding pain medications, coupled with the majority of teachers being unable to recognize pain in students, can create an unsafe environment for the student. It is disconcerting that of those who could recognize pain, 30.2% disagreed or strongly disagreed that all of their students with pain appeared to have pain under control. Further research is needed as to determine why students are having uncontrolled pain in the school setting and to examine the training and procedures that need to be put in place regarding proper pain management in the classroom.

For those teachers who received training on death and dying issues, slightly under half had the topic discussed in university and college courses. With teachers encountering students with terminal illness and their deaths, it is critical that universities provide the information needed to assist teachers with this difficult topic. This study has identified several crucial skills that teachers should acquire in these courses: understanding children's developmental concept of death; learning effective methods to support the student, classmates, parents, and self; learning how to conduct discussions with classmates voicing differing religious beliefs and in compliance with HIPPA; identifying pain in students with multiple disabilities and knowing what actions to take; understanding terminal illnesses and their prognosis and management; and knowing how to identify and form support networks. For teachers who are no longer in a university setting, in-services should be offered, as requested by 47.3% of the respondents. This could be given by individuals who have the appropriate knowledge base (e.g., certain university professors, nurses trained in this area, trained teachers, counselors, and personnel associated with hospices).

The vast majority of teachers reported having support with students with terminal illness (85.5%) as opposed to 21 years ago (68% reporting having support). However, a lack of support still exists for some teachers, which can impact their ability to effectively respond to the student with a terminal illness, as well as to classmates, and the student's parents. Unlike the prior study which had most support coming from school counselors/ school psychologist,

there has been a major shift where the school nurse has been identified as the primary source of support, as well as the primary source to answer questions and discuss the teacher's role (although co-workers were almost equal in providing support in role discussions). The school nurse was also the leading source of support teachers wanted if they had another student with a terminal illness.

This shift of having the school nurse as the teacher's primary source of support may have occurred due to the increased number of students who have complex health care needs included in school setting. They often need more complex care that requires the training and skills of a school nurse. In addition to being involved in these students' care, the school nurses' role includes clarifying students' health status, explaining their impairments, and interpreting medical and other health information (NASN, 2012). School nurses are often in an ideal position to provide information and support to teachers due to their knowledge base and training and teachers should be encouraged to seek them out as a source of support. However, not all school nurses are able to fulfill this role due to high workloads and/or having deficits in this area. Further investigation is needed to examine nurses' expertise, supports, and challenges.

Other sources of major support identified by teachers included co-workers, counselors, as well as reading and the internet. The finding that co-workers (fellow teachers) are a major support and continue to be the primary support for teachers when a student dies is consistent with the literature (Lazenby, 2006). In terms of helping classmates with a student death, school counselors also continue to be the primary source of support for classmates (besides the teacher). Although school nurses are the most frequent source of support for questions about terminal illness, the present study shows a significant increase in reading and the Internet as additional sources of information. This is not surprising due to the growth of the Internet. However, Internet research may not be accurate and teachers should be cautioned about the sources they consult. Teachers should be encouraged to use people with whom they are comfortable for support, but should consider utilizing the school nurse, counselors, crisis teams (when available for the death of a child with physical, health, or multiple disabilities), or other staff who have knowledge and skills in this area.

The majority of teachers identified the school nurse as the person they wanted to receive support from in the future if they again have students with terminal illness. Many commented that they were content with the support they had in place, which tends to indicate that the school nurse is fulfilling the support role well. However, when asked about additional future supports wanted by teachers concerning student deaths, the supervisor/administrator

was the individual who was identified the most. Comments about letting teachers go to funerals and discussions regarding having more support in meetings, tend to indicate that some teachers want administration to do more. Administrators will need more information on how to be supportive, as well as the best ways to utilize members of the educational team.

This study was able to identify several categories of questions that teachers encountered from students with terminal illness, parents, and classmates, as well as questions the teachers had themselves. Students with terminal illnesses and their families often turned to the teacher for information about the condition and prognosis. Teachers will need to work closely with the school nurse, family, and team to know how to best address this type of information. Also, it should be noted that sometimes these types of questions may be more directed towards having someone listen to their concerns or find adaptations or solutions to problems, rather than providing concrete information. Teachers should learn techniques to be supportive listeners and provide appropriate adaptations and resources.

Classmate questions often reflected difficulties understanding death or terminal illness, especially young classmates or classmates with developmental disabilities. Some classmates reacted to a student's death with fear over their own mortality, whether they have the same diagnosis or not. This aligns with the literature on the various developmental stages of understanding death (Walker, 2010). The majority of teachers expressed concern over how to support classmates who don't have a mature understanding of death, as well as those who are older. In addition, teachers had questions about finding appropriate ways to talk with classmates, addressing differing belief systems, and upholding confidentiality. In order to address these difficult areas, teachers will need to continue to utilize the school counselor for classmates concerns, as well as the school nurse, and other members of the interdisciplinary team for information and support.

Teachers provided several activities and interactions to address student concerns. Several utilized activities for classmates that have support in the literature (e.g., making cards) (Cowan, 2010). Knowing the most effective words to say in a situation is more difficult and it is important that they have the knowledge base of how to do this effectively. Teachers' reflection on if they did the right thing with their interactions indicate that they need need to support themselves to mediate doubt and guilt. This is an important need with 36.9% of teachers responding that they need to have support to cope with the loss of a student.

Over a fourth of the teachers taught students who had hospice services. A lack of sufficient knowledge exists among teachers regarding these services and the majority of teachers would like assistance from hospice personnel as

well as more information about hospice. Hospices have grief counselors, nurses, educators, social workers, and others who have a strong knowledge base in such areas as terminal illness, dying process, grief reactions, and providing support. They can assist school teachers. Although some hospices have outreach programs to schools, more dissemination of information and support is needed.

This study provided important and insightful information, but it has some limitations. Readers should be cautioned when comparing the original study to the current one since the original study used teachers from a single state, while the current study had respondents from across the nation. (The current study did examine the data from the single state used in the original study to the rest of the country and found the same trends). Also, readers need to consider that in the questionnaire, the term “family” did not differentiate between the teacher’s family and the student’s family. Therefore, when family was selected as a response, it is not clear if teachers’ meant their own family or their students’ family. A final consideration pertains to the Internet information since our study did not explore what types of Internet sources were used so perhaps future research could examine this area.

Teaching students with terminal illness or facing student death will likely occur to teachers who have students with physical, health, or multiple disabilities. Many are able to find information and support with their school nurse, school counselors, co-workers and others, although there are still many teachers who lack resources. Universities and school districts need to provide information and strategies to teachers in these fields to assist them in these difficult situations. Hospices may also be a tremendous resource and more education about hospice services is needed. Examining the issues that teachers have described in this study will hopefully assist in promoting further training in these areas and promote effective support systems that will assist teachers and their students and families.

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