

IS DEATH EDUCATION IMPORTANT FOR YOUNG PEOPLE?

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JANUARY 2017
THIS RESEARCH HAS BEEN
SUPPORTED WITH FUNDING FROM
HEALTHWATCH SHROPSHIRE



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INTRODUCTION

This research follows a 2-year project that ran from July 2014 to November 2016 to develop a death education programme in response to the needs of a number of bereaved young people in Shropshire who had developed anti-social, self-harming, or low self-esteem issues associated with both personal and public social isolation related to their losses. In July 2014 the Office of Police & Crime Commissioner of West Mercia (OPCC) and CEDAR Education CIC (CEDAR) funded the initial development of the death education project, which came to be known as *Life Lessons* (LL). Support was also given by the NHS Shropshire Clinical Commissioning Group via the Young Health Champion Scheme (YHC). The Life Lessons programme, which will be described hear-in, raised questions around whether or not death education for young people would be beneficial; at what age it should be taught; whether or not it should be done in or out of schools; and what the Shropshire public thought about death education in general. In order to find out the answers, research was funded by Healthwatch Shropshire (HWS) to explore these questions. This report outlines the three-part study and presents the outcomes with recommendations regarding death education going forward.

Why Death Education?

According to the Office of National Statistics of the UK (2015), there are over 550,000 deaths per annum in England and Wales. This amounts to one or more persons dying every minute. Further statistics from Childhood Bereavement UK show that a child will lose a parent on average every 22 minutes. Unacknowledged loss can take a toll on human emotions and create profound feelings of social isolation. W. Hocker (1989) & L. Redmond (1989) have suggested a significant proportion of the bereaved, around 10%, experience complications which can be exacerbated by social isolation. They also suggest that each individual death affects from 8 to 10 family members and persons close to the deceased. Therefore, in the UK it is estimated we have around 5.5 million new mourners per year; 550,000 of which may suffer complications related to their loss. Understanding death and loss can help reduce the consequences of social isolation that include, but are not limited to:

- Alcoholism or drug abuse
- Self-harming
- Absenteeism, listlessness & low productivity
- Clinical depression or low self-esteem
- Escalating violence

In his article in the *Independent on Sunday* in May 2015, Lewis Smith reports that more than two-thirds of the population still regard death as a taboo topic, and as a result leave issues unresolved or avoid talking about it with others. This only exacerbates the issues surrounding social isolation regarding bereavement. In other words, if 5.5 million people experience a bereavement annually in the UK and two-thirds of the population avoid talking about it, who are the bereaved going to talk to?

In 2011 Professor Jenny Hockey noted in her inaugural talk to the Association for the Study of Death and Society (ASDS) that the side effects and symptoms that are associated with having experienced death, bereavement and trauma, such as those mentioned above, may be reduced with Death Education:

...fear and ignorance around death in western societies can still deprive those facing the end of life. Death Studies has begun to erode this fear and change attitudes so that all carers can respond to dying and bereaved people in helpful ways. To foster the growth of a 'big society', an understanding of dying and loss is crucial, within families, neighbourhoods, leisure organisations and the workplace. Where health services are under pressure, the support we receive from one another during these challenging experiences is critical to individual and social wellbeing.

In this research supported by Healthwatch Shropshire we will question this reality and ask 'Is death education important?' More specifically, we will tackle the question: 'Is death education important for young people?'

The Need for Research

There is a great need for research on this subject, as previous research on the effects of death education is limited and there have been no studies conducted in Shropshire on whether or not death education is beneficial to young people in particular. Studies have shown that there can

be negative long-term impact through experiencing bereavement and that specialist intervention and programmes can help. Akerman, R., and Statham, J (2014) showed in their study on bereavement in childhood, and its impact on psychological and educational outcomes, that a holistic approach which aims to strengthen the protective factors within a child's life is the most effective response. One recommendation is to provide support by strengthening communication for all those affected by a death, which includes all members of the family, as well as the child in order to reduce problems associated with social isolation (Akerman & Statham, J. 2014).

Death, dying and loss is an area of knowledge we all have to face at some point in our lives, research on its impact upon our health and wellbeing has been recorded by Arndt, J. and Vess, M. (2008). They suggested that even the awareness of mortality and the fear of death have been shown to have negative impact, such as death anxiety, that leads to the formation of psychological problems. This therefore highlights the importance of dealing with death appropriately.

This research, once disseminated, will therefore enhance best practice around the bereaved, and those who interact with them. This will aid Shropshire residents and professionals to improve provision around death education and reduce the need for specialist interventions. By educating our youth, adults, and healthcare professionals on how to talk about death, dying and loss in healthy and appropriate ways, they become empowered to engage in appropriate communication around a difficult topic.

This research will highlight the benefits of death education for young people, and expose the gaps in knowledge, which need to be addressed. In particular, the aim is to expand upon current approaches by recording the affects that training around the topic of death can have. Principally, this research will give an up to date record of the impact of educating and supporting young people in Shropshire as they learn about death through an educational approach using social-cultural context.

The Research Objectives

The objectives of this research were to ascertain and record the value of educating young people on the topic of death and discover whether or not there is a perception that death education could improve communication around a death or bereavement within an individual's

peer group, family, and/or community. Another objective was to determine what benefits death education might have on the individual. In addition, we aimed to explore the gaps in this area of education; and if, when and how it is being taught.

We wanted to know how much, if any, people had heard about death education and whether they thought it would be a beneficial subject for young people to study in or out of secondary school. Most significantly, we wanted to know what kind of benefits might be perceived from taking such a course. Once the door was opened to talk and express their opinion, we ended up almost doubling the goal we originally set for our general public surveys.

The Research Questions

This research investigated whether or not young people are afraid to talk about death; or whether they simply do not know how to approach the subject appropriately. We also wanted to know if the general public were aware of death education and asked: Is it appropriate to teach young people about death? Can young people talk about death appropriately? Is the subject of death a taboo and difficult to talk about among peer groups? Does teaching about Death get positive or negative feedback from the participants? What do people think and understand about the concept of death? Will learning about death encourage people to communicate their own personal experiences with others? The main focus was on how, if at all, death education is delivered in schools or if there is a need for further development in this area.

Methodology: a three-part qualitative and quantitative study

The first part of this research follows-up a two-year teaching and learning experiment using an Action Research model (McNiff & Whitehead, 2011) of co-creating a death education programme, developed by Dr Judith Wester, for thirty-three young people ages 10-24yrs. Dr Wester, a death education expert, developed the academic and educational material that was used in the initial teaching and development work with the young people. The Office of Police and Crime Commissioner of West Mercia (OPCC) funded the teaching of the original programme in 2014-2016. Staff assistance, transportation of the young people to the teaching sites, and some of the initial teaching supplies were provided by the NHS Shropshire Clinical Commissioning Group via the Young Health Champions' (YHC) initiative. The OPCC also funded the data collection and feedback from these students during the preliminary programme that included participant-observation from our social anthropologist, Kathryn Walker; student

feedback surveys (Appendix A); and video recorded interviews with the young people (see bibliography). The Healthwatch Shropshire Research Grant funded the review and analysis of this large amount of data collected on the course participants.

Part two of the Healthwatch Shropshire funded study involved the collection and analysis of feedback from recorded interviews with parents/carers; written feedback from teachers/youth workers who interacted with the graduate participants; and feedback from those involved in creating and teaching the course.

The third part of the study funded by Healthwatch Shropshire involved the data collection and analysis of general public surveys on their views about death education; and the analysis, writing up and delivery of some of the results from the study to the Centre for Death & Society's International conference on *Death & It's Futures*, at the University of Bath in June 2015 (Wester & Walker, 2015).



THE RESEARCH AND FINDINGS

Our investigation had three main levels of enquiry:

- **Part I: Young people (participants)** – Can and should death education be taught to young people? How do young people respond to death education?
- **Part II: Parent/carers & supervisors (respondents)** – from the perspective of the observing adults, were there any changes in behaviour of the young people after attending death education classes?
- **Part III: General Public opinion (respondents)** – what do the general public think about death education, is public perception in favour of or opposed to death education and particularly for young people?

Following the action research model of enquiry (McNiff & Whitehead, 2011), some of the qualitative data results were gained through undertaking participant observation of the 33 young people as they attended CEDAR Education 'Life Lessons'. Kathryn Walker, a social anthropologist, who observed and interacted with the students while Dr Judith Wester was teaching the classes, collected this data. Mrs Walker participated in the exercises and Q&A portion of the lessons alongside the students. She also sat with the young participants during break and lunch times to hear their casual thoughts about the lessons as they were being delivered. The young people were recommended to the Life Lessons programme via the Young Health Champion Scheme, and through participating Shropshire County Secondary Schools,

which will not be named here due to the anonymity request from participating students. All of the students who participated in the Life Lessons project had experienced a bereavement or deep loss that involved the death of a close loved one or friend, or trauma from parental divorce. Most of the students had begun to develop or had developed anti-social or harming behaviours or had been bullied in school because of their loss. Others had self-esteem issues, low confidence, and had disengaged with work or education, to name but a few of the issues they experienced.

Additional feedback was collected from the participants on the third day of the lessons via video interviews while the students were participating in a birds of prey day. Further observations from the young participants were gathered at a focus group for the Life Lesson participants four months post LL workshops. A thematic analysis was completed of the videoed interviews taken during the Life lessons workshops that included their thoughts around expectations of what death education is and what it might include.

The parental/caregiver and health and social care responses were also gathered post Life Lesson workshops through semi-structured interviews and open-ended surveys done one-to-one. Lastly, quantitative data was gained through conducting structured random sampling surveys, gathered face to face with the general public in three locations within Shropshire: Shrewsbury, Oswestry and Craven Arms over six visits to these areas (two events per location).

Part I: Teaching Death Education to Young People

During the Life Lessons workshops participants were shown the powerful effect of language when discussing death, dying and loss in appropriate and inappropriate ways through real life examples and videos. They were taught about language use, communication and, the potential effects of human imagination around understanding death. Other death-related topics included the social context of death, cultural views from around the world, ritual and meaning, perceptions of time and how it affects experiences of loss. Also covered were lessons on the biology of dead, ecological considerations and historical changes in attitudes toward death and dying.

The young participants aged between ten to twenty-four were taught together in groups of seven to ten over four separate 3-day workshops. All of the participants engaged with the project on a purely volunteer basis, with parental consents acquired for those under the age of



sixteen. At the end of the final session participants were then asked about whether they thought other young people should be taught about the subject of death:

If you use it in the correct manner and it's how you explain it, it will be appropriate but if they do it in the wrong manner, the way you say it in the wrong way, then young kids would not know what to do, what to say, because they don't understand at the end they're still developing what they think's going to happen. Participant L

It was observed that the way in which death is communicated and spoken about is a key factor. Participants acknowledged that speaking about death in appropriate ways is important and that communicating to young people in a considered manner is essential to their understanding of death and its social context.

To engage participants in the Life Lessons course they were initially asked to explore the question: What is Death? They were then shown examples of how different societies define the concepts of heaven and hell, for example. Death was depicted in different ways, as spiritual, philosophical or in a scientific way. No bias was shown toward any particular belief system and all rituals were spoken about in an indiscriminate and non-judgemental way. Some participants found their views changed throughout the workshop and they began to openly ask questions of their peers as well. Life Lessons encouraged the engagement of participants to respond to different ways of thinking about death and encouraged questioning and thoughtfulness towards other perspectives and each other:

I have realised that death can be viewed in multiple different perspectives, both positive and negative sides. Participant C.

Talking about mythology in relation to death gained positive feedback: it was apparent that participants could make links with the depiction of characters that were associated with death in fictional stories, and they learned how the stories could be re-told over time, changing meanings and depicting imagery in different contexts to suit political and cultural changes. As one participant stated:

I found it really interesting about the Greek Mythology and how it fits in with death; also I now understand the true meaning of death. Participant L

The concept of time and temporality was deliberated. Participants learned about death anxiety and how concepts are understood in different cultures. Personal experiences were discussed, listened to and understood by the participants with intrigue and keenness, which was indicated by their asking questions of other participants whom they felt comfortable enough to open up to and share thoughts and experiences with.

During the workshops participants were encouraged to discuss the concept of death as a social construction. Participants were taught about different cultures and how in different areas of the world death is dealt with in different ways. Participants showed eagerness to learn about the methods other people adopt worldwide and their ways of dealing with death, particularly when hearing about Asian cultures and the Chinese paper burning rituals for deceased loved ones, for example. Participants verbalised their understanding:

I understand, the difference of western [death] anniversaries are about being sad but other eastern anniversaries are happy or more a celebration of a person's life. Participant C

Everything I had thought previously has been turned upside down! Participant D

All the participant's responses showed that the Life Lessons had widened their understanding about death, as they were able to engage and explore questions looking from different perspectives through the development of the course. This showed a broader understanding of the concept of death and the ability to view wider society, acknowledging alternative cultures.

Each 3-day workshop with the young participants involved a day visit to Feather Perfect Falconry to engage with birds of prey. Participants showed enthusiasm and excitement for this opportunity. An outdoor environment at the chosen location was different to the previous two days teaching which was held in more of a classroom setting and this seemed to enable participants to express themselves more confidently and comfortably. For example, they were seen to enjoy interacting physically with the birds. The change in environment showed support for Social Learning Theory, which recognises the importance of environment towards teaching and a correlation between the impact of environment and peer influences on students' academic performance (Korir, D. and Kipkemboi F. (2014). During the Life Lesson workshop, the falconers told individual stories of the birds and related the life experiences of the birds with the subject matter of death. This included the importance of birds and the symbols of birds in the Zoroastrian funerary traditions and in the Ancient Egyptian cultures. The participants were encouraged to hold the birds of prey and watch them in flight and in doing so



gained insight into looking at the cycle of life from a wider perspective through the trials of animals in the wild.

Part Ia: Findings from Focus Group with Young People

About six weeks after the Life Lessons workshops had taken place the participants attended a focus group and follow-up session. At the focus group the participants were asked about their experience of the Life Lessons programme. It was here that the understanding of the relationship between the birds of prey experience and the death and dying Life Lessons was conveyed:

It just showed how much power there was behind these birds and how we really aren't the only ones on this planet and actually they could do some damage to us and you know we are not actually that powerful. Participant E1

It is clear the participant shows an understanding that the birds of prey helped her to recognise something beyond herself as a human being - acknowledging she was part of a wider society and that being near to the animal's presence incited this understanding:

It puts more emphasis on the cycle of life and it being a natural part, such as with the story of Ickle [an American kestrel] and how his life-long partner died, that was, you know, it was a lovely story and the fact that he's come through that and that there's life afterwards and yeah, you know, they are birds of prey, you know they kill. Participant E1

Participants saw a relationship between death and life and connected personal experiences with the birds of prey and the birds' own challenges of survival. One participant was asked about the life lessons on death and dying and whether it was difficult to talk about death:

It's quite interesting that it's about not what normally people think, and it's not actually that hard to talk about it [death] because at first when I thought about coming here I wouldn't have actually sat down and been able to talk about death. I wouldn't have been that confident but now after having these lessons it's much more relaxed and I'm more confident about talking about death with other people. Participant C

Here it was observed that through the Life Lessons course a comparison is made between interpersonal levels of confidence before and after the LL programme. Through the duration of the course confidence grew; empowering the young person to talk in a relaxed way about the



topic of death with other people. Participants were also asked about their thoughts on the Life Lessons programme in general and how they might explain it to other people:

I just explained it as a completely different way of looking at death. We didn't look at it as a bad thing. We almost sort of cleared the slate and went at it in a completely different way, and we saw the different views of it, the different cultures and we saw the way it can actually be a positive thing and how it's not always the end and it shouldn't be a taboo subject. It's you know it should be okay to talk about it, everyone experiences death, everyone dies and so why can't everyone talk about it? Participant El

Here the participant is showing that with newly found insight and greater understanding about death he is now more comfortable to think about it and is becoming more accepting of it as part of life. In addition, he is willing to communicate with others about this subject, which he did not do prior to taking the course. Participants were also asked about whether they would like more death education and if so what future lessons should include:

I think there should have definitely been more stuff on how to deal with it, when someone is about to pass away, your mother, your father, your sister, your son, how do you talk to someone, how you would help them? Participant El

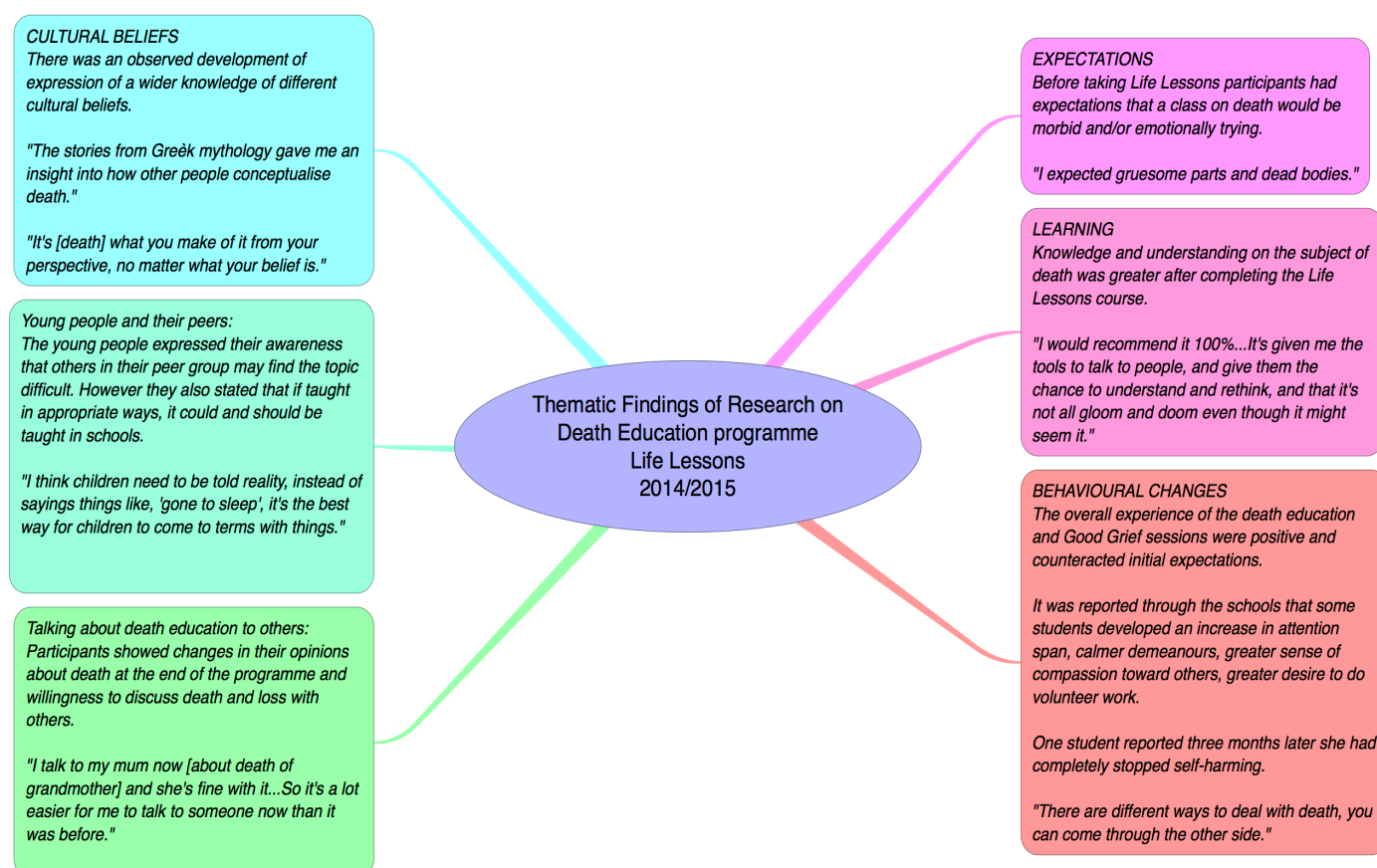
Participants therefore highlighted that they were keen to learn more and that they had been inspired to find out more themselves.

I wanted to learn both really, I have lost family members and I wanted to learn about people and how to deal with it in the right way so I thought I would come--just to discover it really and how to help someone else. Participant L

From this quote, it may be seen that the young people had moved from an egocentric perspective to one of outward looking and began to suggest a keenness and willingness to help other people in need. The participants were asked how the life lessons might help them carry on as volunteers with the Young Health Champions, to which one participant responded:

It's not about going on and doing something with it, but now we have it we can pass it on in day-to-day conversation... it's a lesson that we've learned and that can be taken forward. Participant EL

Participants here showed the ability to reflect upon their new knowledge of death education and how they could use their knowledge further to help others. The chart below shows the most popular themes that arose from the focus group research regarding participant's perception of what death education entailed, behavioural changes and widening awareness of viewpoints outside their own.



Results from the Life Lessons portion of the study shows that the young participants can and are willing to talk about death. Some of the benefits of doing so included,

- an increase in personal confidence,
- reduction in self-harming activities,
- re-engagement with education and/or work,
- increased communication with parents/carers and adults in supervisory roles,
- reduction in social isolation, and
- increased willingness to help others who are bereaved, and
- desire to discuss death, dying and loss with those who have not experienced a loss.

As one student put it, she found the course 'empowering' and 'uplifting' and it gave her permission to talk about death. Students reflected an eagerness to learn more about death,

dying and loss; as well as an increased level of compassion toward others and understanding of different responses to loss.

The subject of death does not appear to be a taboo amongst young people per se, but rather it is a lack of education around the topic that prevents them from discussing it more openly among their peer group. Nevertheless, the LL participants have shown that with the appropriate guidance, support and knowledge such an obstacle can be overcome. This study has shown teaching young people about death has gained positive feedback. The young people in this study have shown that they are able and willing to learn about death and dying from the taught Life Lessons course, and they have shown that the concept of death can be thought about reflectively and understood through a variety of approaches.

This Life Lessons study has also shown that through learning more about death young people are encouraged to communicate their own personal experiences. This created a means of open communication of a topic that would otherwise be ignored. Therefore, giving young people the opportunity to study death and dying, as academic subjects, shows they are more than capable of learning and communicating their understanding. This is important in order for young people to help themselves gain confidence and knowledge about an inevitable part of life, but also to go on and assist other people to deal with their loss and grief in healthy and appropriate ways.

The Life Lesson project has established that the teaching and discussion of death and dying in appropriate and sympathetic ways is beneficial, worthwhile, relevant and important for young people. Therefore, such teachings could be used in the future to aid young people in their knowledge and experience of death and loss.

Lastly, a number of the participants strongly suggested that death education be offered to adults. In particular they wanted their parents and teachers to take the course: “so they will know how to talk to us about death...they are very bad at it.” The participants also unanimously agreed that death education should be taught in secondary school to everyone, including those students who had never experienced a loss, in order to help them understand and communicate in more compassionate ways with their peers who have experienced a loss.

At the end of the project the OPCC sent Graham Oliver, an ambassador for the police and crime commissioner’s office, to review the project and interview some of the young participants and

those involved in delivering the workshops. His report to the OPCC on the final outcomes of their grant included the following comments:

Over thirty young people have attended the Life Lessons course; all with issues relating to bereavement or loss. Without a doubt, some would have gone onto reoffending or even offending for the first time. CEDAR gives answers and comfort and helps those that attend to understand the process of dying and the ramifications on family, friends and how people deal with you. Evidence presented confirms that without CEDAR some would have been dealt with by the court system.

...what CEDAR has done is put these youngsters back on the tracks, understood their needs, their fears and talked them through scenarios and how to deal with grief. Does it work? – A 100% success rate thus far, you just can't get better than that.

For every young person that does not offend the nation saves £71,000. This subject that will and does play a part in all our lives is coped with in many different ways, if you don't have family support, and you don't have help, you fall foul of the bullies that don't understand death and its consequences.

I am in total admiration for this group; the PCCs grant has changed lives, and has brought closure to so many questions by these young people.

Part II: Parent/caregiver and pastoral care/professional staff responses

Since completing the Life Lessons courses it became evident, from feedback gathered from the parents/carers, pastoral care staff and attending youth workers of the participants, of the on-going effects that the death education had upon individual participants and their relationships with others. Adults involved directly with the participants saw first-hand, and with immediate effect, a positive change in behaviour and responses from the young people at home, school or work. Additionally, some went on to pursue volunteer activities with the YHC, incorporating lessons learned in death education or taking that information back into their schools. Other interest shown was to re-engage with their education or pursue further education in the topics of grief and bereavement. Some parents reported there was a significant opening up of discussion and communication about death and loss with their child.

Furthermore, those adults who experienced improved communication with their child enquired if they could take the Life Lesson workshop themselves. In the fall 2015 adult classes for *Death Education for Health & Wellbeing* were set up as a result of these requests from parents and pastoral care staff. (See section 7: Conclusions.)

Qualitative data was collected from parents of the Life Lessons participants, from Youth Health Champion staff, from the Feather Perfect falconry staff, from carers of Life Lesson participants, from pastoral care staff of participating secondary schools, and from the CEDAR Education volunteers. Responses showed the following results:

- All parents/carers gave feedback stating that death education has benefited their young person who attended the Life Lessons class.
- The advantages of Death Education were stated as being mentally and emotionally beneficial, socially beneficial and that the lessons had improved overall confidence levels and interpersonal communication.
- All responses given showed that parents and carers of the young people involved in the Life Lessons class believed death education to be important and should be offered to all children in schools and to bereaved children out of schools.

Some comments from this group include:

Death is part of life and the skills to understand and deal with bereavement is essential to the development of adulthood.' Parent of Life Lessons participant

The subject of death, dying and dead is quite a taboo subject in British culture. I have seen and experienced first-hand how CEDAR Life Lessons have helped young people understand more about the subject without them feeling pressured to partake. All participants who I have spoken with have been extremely positive about their experiences through Life Lessons and suggested that other young people should have access to such programmes.
Andrew Cutts, Volunteer.

Appendix B shows the survey tool used to talk with parents/carers about the death education. Within the survey, a large majority of parents/carers responded 'Yes' when asked whether knowing how to talk about death and loss in interesting and healthy ways would be beneficial? When asked in what ways, (see Appendix B) responses indicated that knowing how to talk about death and loss would be beneficial physically, mentally, emotionally, socially, and financially.

I think it would strengthen communities and enable them to care for each other and deal with tragedy, which is shown on the media, or war or loss from accidents. i.e. in our community we have had two children which have died on the busy roads and this has affected individuals as well as the community. The road memorial reminds children and adults alike but is never really spoken of. Also, more recently terrorist attacks: a work colleague was in Tunisia on holiday when a bomb exploded; at the time this affected our

work community and the children she had been working with. We have no vocabulary to voice our concerns and bereavement as a collective as well as individuals.'

(Parent of Life lessons participant)

One parent attended the Life Lessons course along with her daughter. The mother was diagnosed with a terminal illness at the time of participating. Mother and daughter explained how the CEDAR death education programme had enabled the beginning of communication between both mother and daughter during the course and discussed this during a videoed interview on the last day of the course:

I think it's been really unique; I've never come across anything like it. I know we've heard of organisations that deal with death such as Samaritans, that deal with trying to prevent death, but this is a whole new different approach, and it just gives people permission to think about their own mortality. What is death? What is dying? What is dead? It is done through a really interactive programme, which I found fascinating. Mother/participant

I think for me it was something that I found would help and comfort me in the future, as mom's got incurable cancer and she really wanted me to come to kind of try and start thinking about it and try and prepare in some way. Daughter/participant

We don't actually tell children the truth, perhaps that's because we can't actually cope with the truth ourselves, but maybe getting a more positive language would help with that I think. 'Mother

Like I said even people my age don't know how to talk about it so, I think teaching kids how to at a younger age would be really beneficial. Daughter/participant aged 20yrs

Professional staff members from the Young Health Champion team were highly supportive of this project. They were also very keen to observe the responses from the young participants from their group who attended the courses.

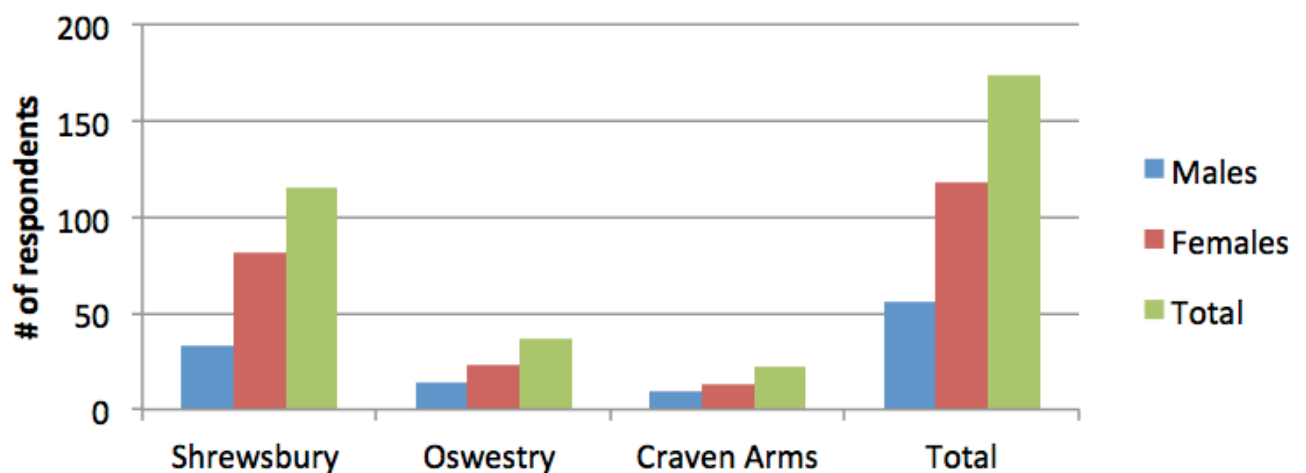
Life Lessons has enabled our Young Health Champions to not only cope with their own loss, but more impressively, support friends and peers in their time of grief. This became particularly clear recently when one of our young people died tragically and Liam, who had taken the course, stepped up to assist others in his peer group with their grief over their friend. As one youth worker reported: 'Liam was brilliant, he spoke so easily with his peers about their friend's death and made suggestions about activities they could do to help them remember and grieve—he was probably better than us!' Karen Higgins, Project Manager, YHC

Part III: General Public Perception of Death Education

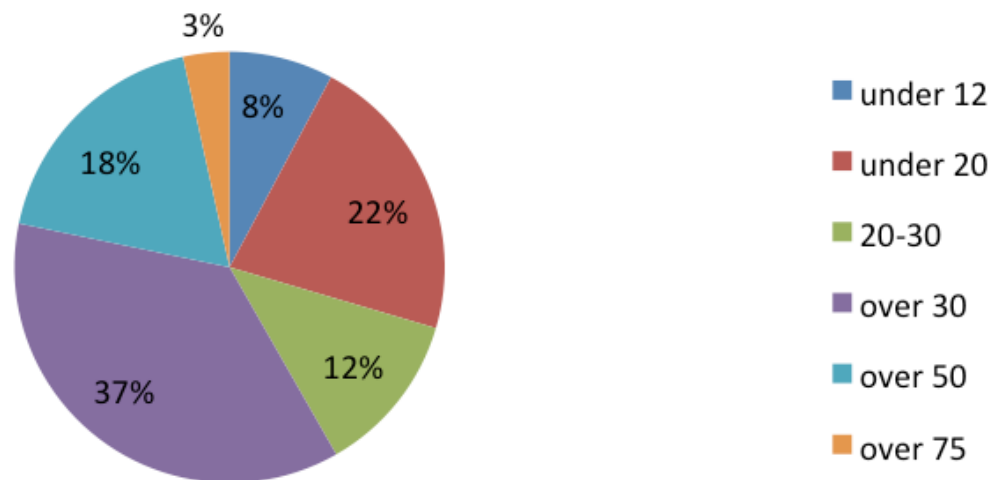
The following quantitative data was gathered from surveying 174 members of the general Shropshire public from three different locations covering six community events between March 2015 and January 2016. Shrewsbury events drew in people from Telford & Wrekin, Market Drayton & Whitchurch; Craven Arms events drew people from Ludlow, Bishops Castle & Bridgnorth; and Oswestry events drew people from Wrexham and surrounding communities. These locations were chosen in conjunction with events that were being held whereby the researchers could conduct surveys with members of the public with the support of the event organisers that included the OPCC, Oswestry Library and QUBE, and the Craven Arms Community Centre. In total through random selection 56 males and 118 females were surveyed using the form in Appendix C.

The highest age category surveyed was 30-50 years old (37%), 18% were over 50 years of age, with 22% under 20 years old and 8% under 12 years of age.

Gender of General Public Survey Respondents

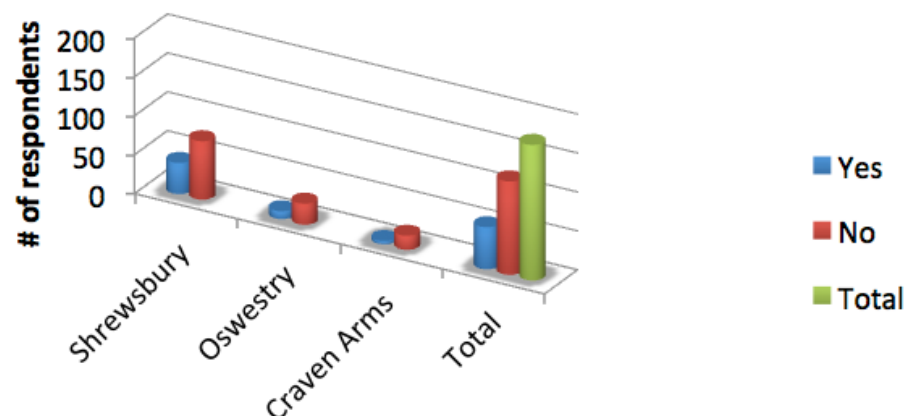


Age of Respondents

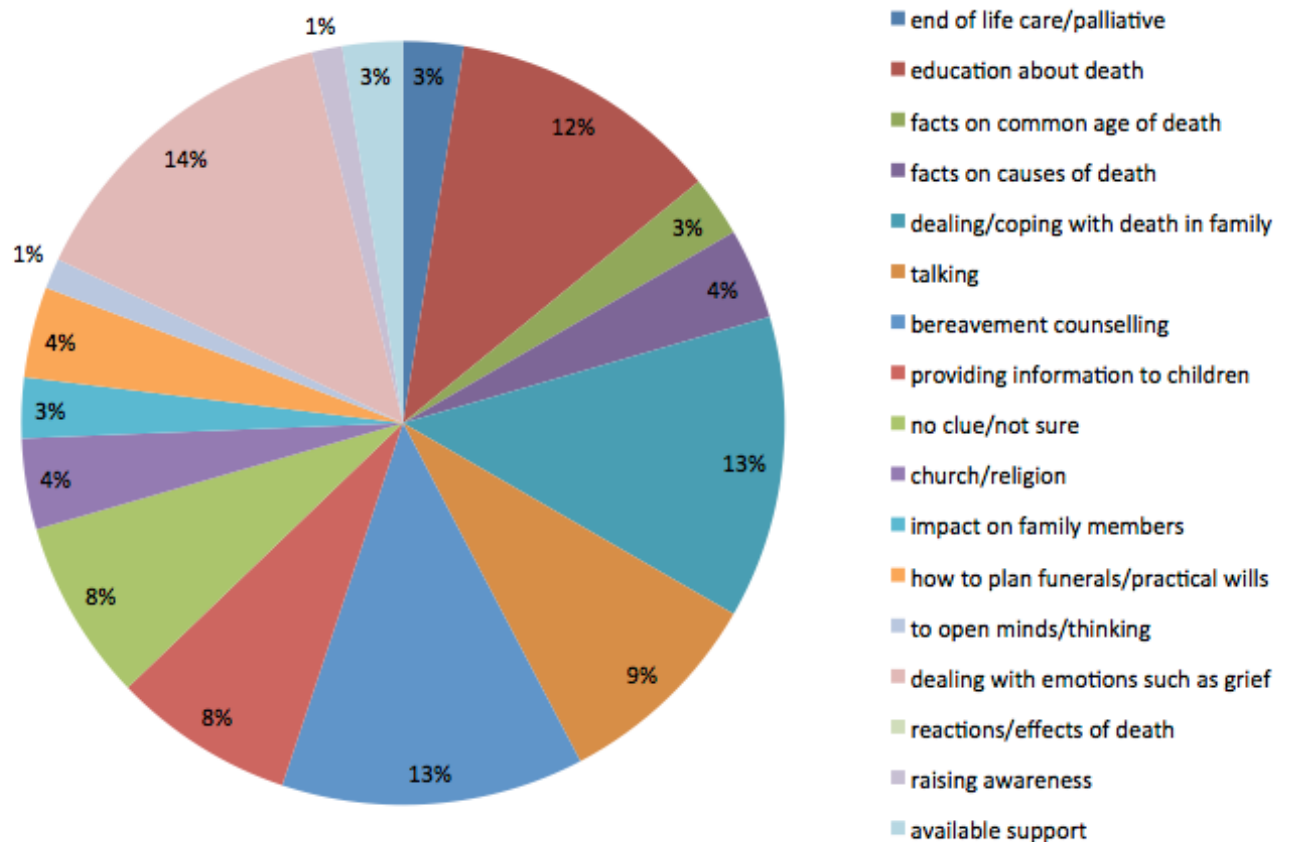


When asked whether they had heard of death education, results showed that 69% of the general public had never heard of death education. Results showed that when respondents were asked what they thought death education was, the responses totalled 147 and the thoughts given were thematically categorised in 'What do you think death education is about?'. Fourteen per cent thought death education was dealing with emotions such as grief. Eleven per cent of thought it was education about the subject of death, 13% of stated that death education would be about dealing/coping with a death in the family, 8% of didn't know or said they were not sure.

Have you ever heard of death education?



What do you think death education is about?



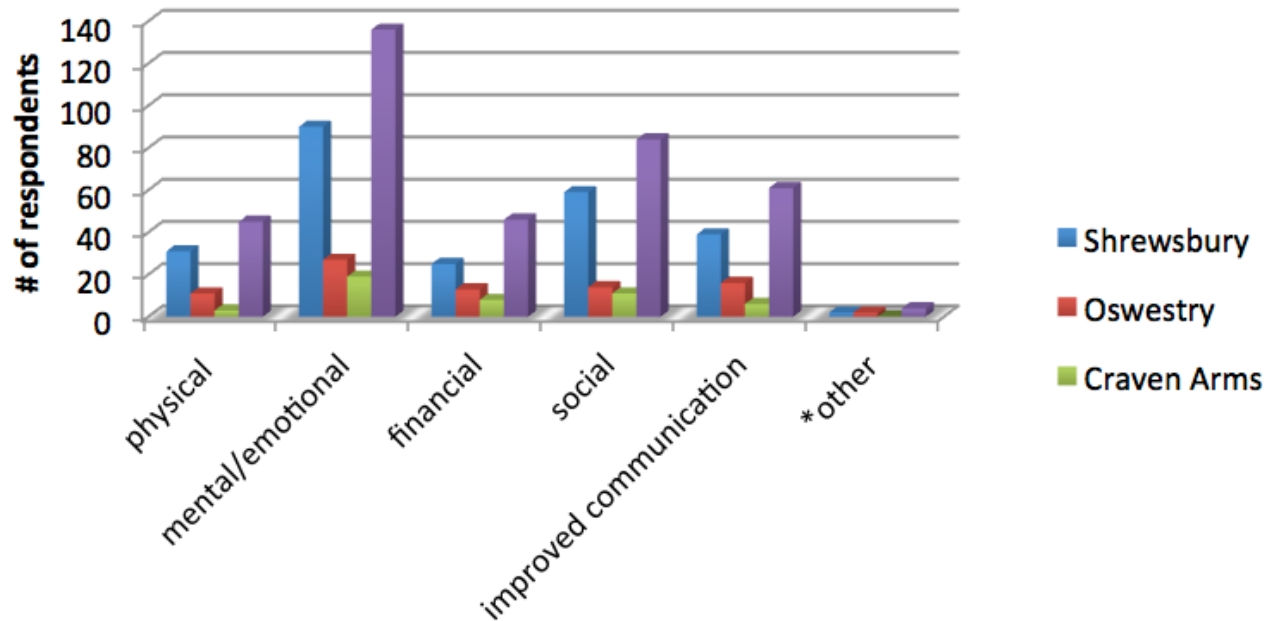
When asked if learning to talk about death and loss in interesting and healthy ways would be beneficial? 93% of the general public said yes. General perceptions of the benefits of death education focussed on five main categories:

- Mental and emotional wellbeing;
- Improved social contact and reduction of social isolation
- Improved overall communication with others;
- Recognition of financial cost of a death and how to minimize the impact
- Improved physical health as a result of lowering grief-related stress

The majority of respondents thought that the greatest impact would be mental and emotional improvement. Other perceived improvements to personal health and wellbeing included better-quality social interactions, better communication around the topic of death, and greater understanding of financial impacts from loss. Further perceived benefits included increased interest in education and improved ability to cope with loss.



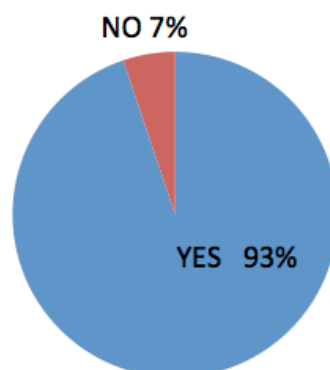
Perceived benefits of death education



*Other benefits suggested were educational /youth work/coping/work

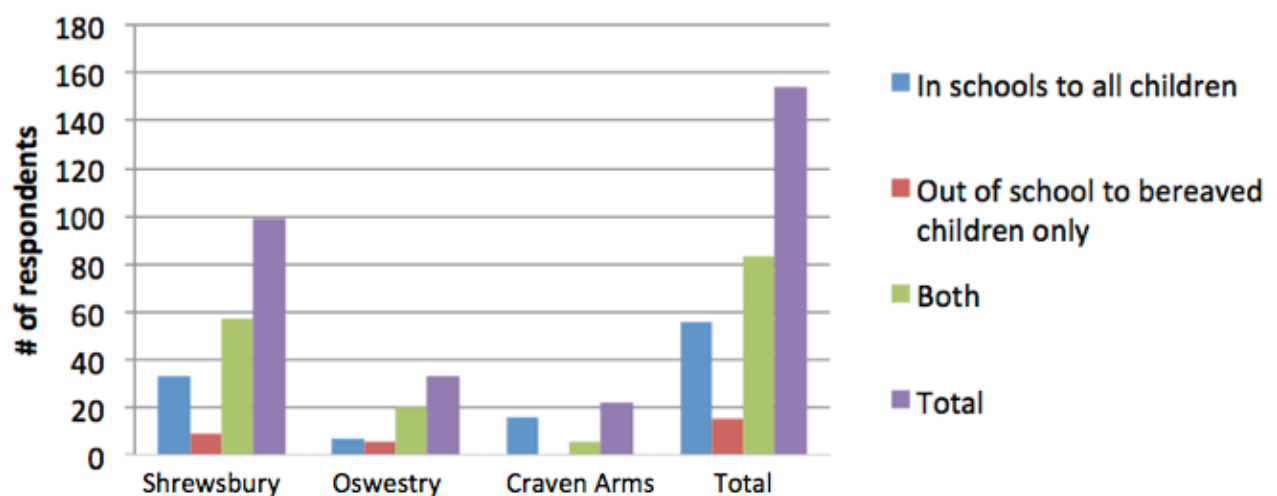
An important question in the study was - Should death education be taught to young people? Results showed that 93% of the general public said yes, death education should be taught to young people.

Should death education be taught to young people?



Respondents who wanted death education for young people were asked where it should be taught and what was an appropriate age to start death education. The next two charts show the range of responses that varied from classes starting in primary school to *age appropriate lessons only, which they noted depended on the level of understanding about death a young person may have, to include those with learning disabilities. The majority of respondents (53.89%) felt that death education should be taught in schools to all children and out of schools in special programmes for bereaved children starting with secondary school age young people. Over 36% said death education should be taught in schools only with no need for external programmes, and 9.74% said out of school to bereaved children only.

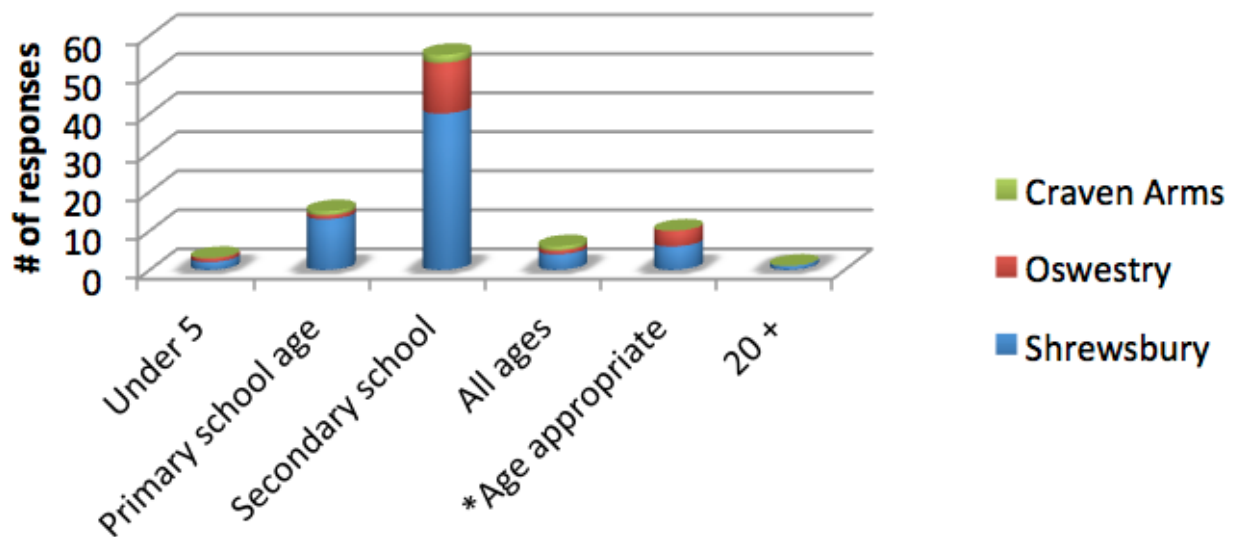
Where should death education be taught?



Almost 50% of those surveyed gave opinions as to what age they thought young people should be taught death education. The results showed 40.74% thought that teenage/high school age was the most appropriate group to teach death education to. While 29.6% said that death education should be taught at an age appropriate level of understanding of the individual child, 7.4% said that death education was for all ages.



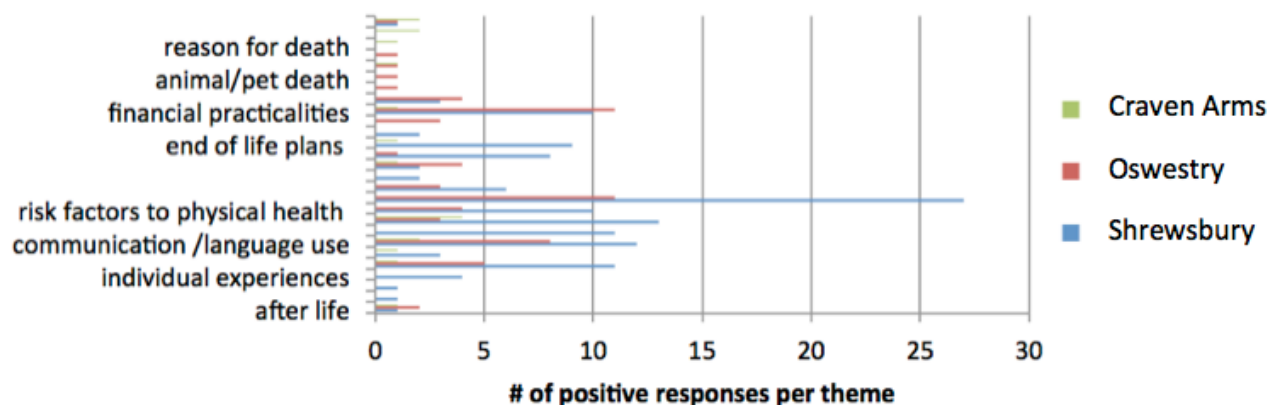
From what age is it appropriate to teach death education?



The public were asked what they would expect a death education class to cover. Results showed 27 different themed responses, of which the most significant responses are shown on the following chart. Respondents gave more than one response to this question, with 219 total responses. The highest response was 17.35% who said they expected death education class to cover types of emotions and feelings. Other responses included:

- 10.04% of respondents felt language use and communication techniques should be taught.
- 10.04% expected financial practicalities should be taught.
- 7.76% of respondents indicated that family networks and outside support should be discussed.
- 6.39% expected risks to physical health should be taught,
- 5% expected the class to cover how to deal with loss.
- 1.82% expected classes to be about individual experiences, decreasing the taboo of the subject, different cultural beliefs and rituals, end of life plans, and bereavement counselling.

What should death education cover?



It may be seen from these responses from the general public that death education is a topic that is not widely known about around Shropshire. Nor have they heard of such a topic being taught in local schools.



RESEARCH OUTCOMES & RESPONSES

The results from all three parts of this Healthwatch Shropshire supported study have shown that death education, in a variety of forms, whether it is taught in school as part of the everyday curriculum, or out of school in special programmes such as the Life Lessons workshops, are needed and wanted by the general public, young people, and by parents and carers. As indicated in parts one and two of this study, there were significant benefits to young people who received death education.

Death education was also deemed to be an appropriate topic for secondary school age and older young people by a high majority of those who responded to the surveys. Parents and carers, likewise saw first-hand the improvements in communication and overall attitudes of the young people who attended the Life Lessons programme. Ideas and opinions about what death education *might* be from the general public are matched by the ideas and opinions about what death education *ought* to be from the young LL participants. Overall the general public, parents and carers, and young people identified there is a gap in current education, with the need to deliver death education as part of the standard curriculum.

Impact on Respondents involved in Life Lessons Project

Although it has been almost 2.5 years since the initial Life Lessons programme was started, we continue to receive feedback from parents, teachers and the participants themselves about positive outcomes from taking the course. These include:

- Ten of the original 33 students in the Life Lessons programme have formed the CEDAR Youth Advisory Team to help co-create death education learning packs for secondary schools;
- Parents reported re-engagement with education from students who had dis-engaged previously and are now striving for university;
- Motivation to work, including doing volunteer work in the community;
- Stopping self-harming behaviours
- Responding to and helping others who are bereaved
- Improvement in ability to communicate their needs to others and in particular improvement in parent-child communication
- Significant decrease in feelings of anger, in most cases anger issues have completely subsided
- Four students have chosen to go into health & social care studies in higher education as a result of taking the Life Lessons programme

Dissemination of Data

Since beginning the Life Lessons/Death Education project and subsequent Healthwatch Shropshire research and follow-up, Dr Wester and Mrs Walker have delivered their findings to an international body of scholars at the conference on *Death and Its Futures* at the University of Bath (June 2015). This was part of an annual conference on death run by the Centre for Death and Society at the University of Bath. This paper, which was sponsored by Healthwatch Shropshire, was videoed by the University of Bath and can be watched online (see bibliography).

Subsequently, an even greater number of scholars interested in the field of death education and death studies have been able to access this presentation resulting in an invitation to deliver the paper again at the National Dong Hwa University in Haulien, Taiwan (Republic of China), which took place in March 2016 and was delivered by Dr Wester. Additionally, since the

dissemination of the research, the CEDAR Education website has increased the number of users to almost 9,000 with a significant increase in international views from countries such as the USA, Brazil, Germany, Russia, Canada, Japan, China and others. What this indicates is that the lack of appropriate ways and means to teach and engage young people in death education is problematic in both Eastern & Western parts of the world.

Since the completion of this initial research, Dr Wester has also published a reflection piece for the journal *RE Today*, published by the National Association of Teachers of Religious Education. These findings will also be presented at the University Centre Shrewsbury Friday, 17 March 2017 at 1:00pm as a keynote public lecture on '*Why teaching death education to young people is important*'. This is part of the UCS Mini Lecture Series, which is free and open to the public. This will be advertised closer to time through their network.

In May 2016 Dr Wester also delivered a talk on the Healthwatch Shropshire supported research at the Oswestry Library Lunchtime Learning programme. Members of the public who were keen to learn more about the Life Lessons programme were in attendance, and another talk for 9 May 2017 has been scheduled.

The Office of Police & Crime Commissioner of West Mercia also received a full report on the Life Lessons (LL) Course development and student evaluations. However, this did not include the data within this Healthwatch Shropshire portion of the research, which includes the surveys with the general public and feedback from parents/carers/teachers involved with the LL young people. We hope the full research report will become available to them once this report is published online via the Healthwatch Shropshire website. Links to this report will be widely disseminated once it is published, from which we hope to generate interest in the continuation of this project.

Conclusions

When the Life Lessons project was started, the goal was to create a programme to teach young people about death in a way that was encouraging and beneficial to the participants. In particular, we wanted to improve the overall behaviour, health and mental wellbeing of the participants by teaching them about a fundamental part of life: everyone dies. In order to do that we needed to engage the young people to assist in their own learning process and become co-creators of the course through active participation in it. We would not have been able to

deliver the teaching portion of this programme without the initial 2014 funding from the Office of Police and Crime Commissioner of West Mercia and support from the Shropshire CCG Young Health Champions. However, in order to determine whether or not we achieved what we set out to accomplish, we needed the research grant funding provided by Healthwatch Shropshire. This special funding gave us the authority to reflect on the developed programme and further explore whether or not adults, carers and the general public would support such a programme going forward. This project has raised awareness across the county and within the Police & Crime Commissioner's Office of the need for further development of death education in secondary schools and the wider community. As result, in May 2016, the OPCC further funded CEDAR to create a Youth Advisory Team with the purpose of co-creating death education learning packs for secondary schools across the region. CEDAR has begun this project, but need more funding to complete it and put it in five pilot schools to see how the programme will work with the current curriculum.

The NHS Shropshire CCG (2014-15) has reported an increase in issues around rural and social isolation, which can be exacerbated by bereavement, as suggested previously (Hocker 1989, Redmond, 1989). As Graham Oliver of the OPCC previously suggested, death education has shown to decrease these negative consequences by helping the individual to open up and talk about his/her loss with those around them and admit they need help with their grief. Consequently, more professionals, such as GPs, and those in social and healthcare are coming to CEDAR for training. Since conducting this research the CEDAR Death Education programmes for professionals have doubled with more being scheduled for 2017. The courses have been taught in Oswestry under the title: *Death Education for Health & Wellbeing*. This course has been well received and attended by parents/carers, pastoral care staff from secondary schools, British Transport Police, solicitors for the elderly, GPs, nurses and hospice staff, teachers, psychologists with the prison services and those in other professions.

This recognition and need for education around the social-cultural context of death has motivated us to start development of an online programme for both adults and young people, which we hope to roll out by end of 2017. In addition, we have begun work on a textbook on the Life Lessons project along with a website that would be made available to schools across the county. We aim to follow-up the textbook project with another research project that explores the development, dissemination, and measurement of usage of the death education textbook and website to determine if changes in student behaviour can be measured after studying the topic of death at the secondary school level in short, subject-specific lessons.



RECOMMENDATIONS GOING FORWARD

CEDAR Life Lessons is a highly innovative project that produces a different perspective of what death education is and how it can benefit the adults and youth of Shropshire and beyond. Nevertheless, without the funded support Healthwatch Shropshire provided it would not have been possible to determine how significant those benefits are and how important death education is to the overall health and wellbeing of an individual young person who is bereaved. Nor would we have known what the wider public think about death education and its implications for the community supporting those who have had a loss. Research on the Life Lessons project and research among the general public within Shropshire, indicate the actual benefits and perceived benefits of learning about death, dying and loss in appropriate ways are important.

It is also clear that to those who are bereaved death education can improve community and self-reliance by diminishing social isolation through healthy and appropriate communication. This in turn has an impact on emotional, physical, and general health and wellbeing of a community, thus reducing reliance on the NHS, police and health and social care institutions.

It is recommended that death education be developed, supported and promoted across Shropshire, both in and out of secondary schools. Programmes should also be supported for adults and professionals and volunteer groups who must interact with those who are bereaved in order that they are able to reduce social isolation through healthy communication.

Whilst funding from government agencies is limited, investment in education around any mental health and physical health issues have historically always given a greater return via a reduction in reliance on public services, whether it is the NHS, constabulary or voluntary sector. This was evidenced in Graham Oliver's previous statement from the OPCC whereby it was estimated that the CEDAR Life Lessons programme helped save £71,000 per young person on a £5,000 investment into the project. That is an excellent return on investment by any standard.

Finally, the most important aspect of death education is that it is *generative*—meaning that once learned, it cannot be unlearned and is most often passed on to others. This is different from going to a doctor or counsellor whereby only the patient is attended to for grief-related issues and no one else. But if one young person teaches two other young people to talk about their loss, rather than harm themselves, all of their futures are changed for the better.

Some statistics from the 2015-2016 Study

3

In-depth recorded interviews were conducted with parents of young people who had taken the CEDAR Life Lessons/Death Education programme in 2014-15. These interviews determined the amount of benefit the young people received from taking a course on death.

6

Sites around Shropshire county were accessed throughout the yearlong study to get an overview of opinions on death education from the general public. The main catchment areas included Shrewsbury, Oswestry, and Craven Arms.

11

Parents, teachers, pastoral care staff, youth workers, and those involved with the LL participants gave extensive feedback on the benefits of the course to young people. Some went on to take the death education course for adults and professionals developed and delivered by CEDAR Education.

33

Young People completed the Life Lessons Pilot programme on death education from three Shrewsbury secondary schools in Meole Brace, Harlescott Grange, and Sundorne. All of the participants showed some level of positive behavioural changes. Almost all of the participants had experienced the bereavement of a significant loved one or parental loss from a divorce.

12

Videos interviews were produced and put online discussing the benefits of the Life Lessons course to the young participants. These can be viewed at: <https://www.youtube.com/channel/UCRzk-3jDcteCEHuwCDgi99w>

174

Members of the general public completed our Death Education Survey on attitudes toward death education and its need.

250+

People engaged with CEDAR Stands put up for Q & A/Surveys at events such as OPCC of West Mercia; VCSA; Young Health Champions; MYP Youth Parliament; CCG; AgeUK and others.

405

People attended talks about death education around the county for various groups such as the Royal Volunteer Service; Glyndwr University School of Social Care; Children's Trust Forum, AgeUK and Oswestry Library and others. Dr Wester delivered the talks free of charge to the public.

8,984

Registered users have engaged with the CEDAR website since it launched in Feb 2014. This website has been viewed by people from around the world including USA, Brazil, China, Japan, Russia, Canada and many others; with the majority living in the UK. The majority of our website users are 18-34 years old.

The Work of CEDAR Education CIC

CEDAR, which stands for Community Education in Death Awareness and Resources, is an academic-based non-profit organisation established in April 2011 to provide specialist education on the topics of death, dying and remembrance to young people, adults, carers and professionals. The focus of our education is to improve communication and broaden understanding about this inevitable part of life using the social context of death as a key factor. We also provide specialist education to those who work in human resources and the public sector about the physical, emotional, economic and social costs to the community or business a death can cause. This includes the deaths of the critically ill, or sudden, traumatic and accidental deaths.

CEDAR can provide educational tools and information to help individuals learn how to prepare for death, adjust to life after a loved one dies, or help others who are bereaved. We also help raise awareness of the impact death can have on the individual, family and wider community. The main objective of CEDAR is to deliver educational programmes and information about death-related issues through:

- Classes for young people, adults and professionals;
- Specialists training for police and emergency services, teachers, social workers, psychotherapists and those in healthcare, occupational health, and human resources;
- Access to an online resource centre offering educational material and links to helpful websites (in development)
- Books and downloadable articles that are topic-specific (in development)
- Online support for public service employees in need of specialist information (in development).
- Development of death education learning packs for schools (TBA 2017)
- Connections with the community through our CEDAR Youth Advisory Team (2017) and our CEDAR Action Team (2017)

We believe that by bringing this topic back into everyday awareness an individual can build confidence, prepare for death and help those who are bereaved avoid further problems with better communication. Everyone has a responsibility to talk about death and dying, not only

because we will have to face it at some time in our lives, but also to support our family, friends, neighbours and co-workers in their time of loss.

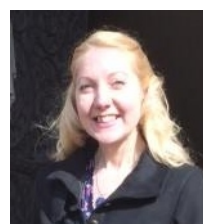
The Researchers

All of the researchers, instructors, youth workers, and all adults who interacted with the young participants in this study had up to date DBS checks. Everyone involved followed the safeguarding and ethics guidelines of CEDAR Education, the Shropshire Youth Association, and the CCG Young Health Champion criteria. We have also been reviewed by Young Solutions for the OPCC for having good safeguarding policies.

Dr Judith Wester brings much of her skills from her BSc in behavioural science and psychology into the classroom to enhance the learning experience of her students. Her MPhil research focussed on a comparative study between how death education has been taught in the USA in the 60s and 70s and how it has been subsequently developed in the UK post 1980 in higher education. Her PhD research focussed on the history of death in Western Medicine and what changes have occurred within the end of life medical treatment decision-making processes as a result. The basis of her teaching work centres on improving communication around death, dying and loss.



Judith Wester
BSc, MPhil, PhD
Founder & Instructor
CEDAR Education CIC



Kathryn Walker
Social Anthropologist
BA Hons, PG Dip Psych, MA

Mrs Kathryn Walker is a Fellow of the Royal Anthropological Institute and has an MA in social anthropology, a bachelor degree in Fine Art, and PG Dip in Psychology. In the past, she has used all of these skills in her work with the mental health group Shropshire Mind to form the well-received 'Mind@Play' group. She has been the key participant-observer and data collector for this project and assisted in the data analysis with Dr Wester.

Our CEDAR Guide to Ethics for Independent Research can be provided upon request.

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Wester, J & Walker, K (June 2015), *Life Lessons: teaching young people about death in rural England*, International Conference on 'Death and It's Futures', Centre for Death and Society, University of Bath, England. (Video/Web link to full 30-minute presentation: <https://uniofbath.cloud.panopto.eu/Panopto/Pages/Viewer.aspx?id=0368ee57-0517-4d02-9b45-6618476b78cb> at video point: 51:54 minutes into video session)

Wester, J (Autumn 2016), *Death (or Life?) Lessons – Why are they needed?*, Professional REflections in RE Today, National Association of Teachers of Religious Education, Autumn 2016, Volume 34, Number 1, 67-69pp.

For Further Information:

CEDAR Youtube Videos: <https://www.youtube.com/channel/UCRzk-3jDcteCEHuwCDgi99w>

CEDAR website: cedareducation.org.uk

CEDAR Facebook: <https://www.facebook.com/CEDAR-CIC-544394212333072/>

Death education does make a difference...





Appendix A:

Death Education/Life Lesson Course Evaluations with Young People from PCC project.



CEDAR LIFE LESSONS EVALUATION

Tell us what you think!



Please Print Clearly

Your Name: _____ (or keep it a secret...) Date _____

Best way to reach me: _____

What I felt about the course: (Tick One)

Absolutely Fabulous!

☐


Really Liked it.

☐


It was OK.

☐


A bit boring...

☐


Yuk!

☐


I learnt. . .

What I enjoyed most. . .

What I enjoyed least. . .(if anything)

I want to join the **Youth Advisory Team** and work on the
Life Lessons Learning Pack Project on 19th Nov 2016:

YES

☐

NOT SURE YET

☐

NO

☐

**Appendix B:**

Interview Questions and Survey with Parents/Carers/Teachers of Young People who took Life Lessons programme



Is Death Education of Value? (Parent/Carer Survey)

Return to: jrw@cedareducation.org.uk

Date _____

(Please X all answers that apply and explain your choice(s) & expand answers if you wish.)

Your name / Participant's Name / School (if applicable)

- | | |
|---|--|
| ☐ Mum of Life Lesson Participant | ☐ YHC Staff |
| ☐ Dad of Life Lesson Participant | ☐ Feather Perfect Staff |
| ☐ Carer/teacher of Life Lesson Participant | ☐ CEDAR Volunteers |

1. Has your young person benefited from Life Lessons/Death Education? ☐ Yes ☐ No

- | | |
|---|---|
| ☐ Mentally/Emotionally | ☐ Socially/improved communications |
| ☐ Other ways: | |

3. Should Death Education be offered: ☐ Yes ☐ No If so, why?

- | |
|---|
| ☐ In schools to all children |
| ☐ Out of schools to bereaved children only |
| ☐ Both |

2. Would knowing how to talk about death & loss in interesting and healthy ways be beneficial?

☐ Yes ☐ No In what way? Please Explain if you wish and expand to 2nd page.

- | | | |
|-------------------------------------|--|--------------------------------------|
| ☐ Physically | ☐ Mentally/Emotionally | ☐ Financially |
| ☐ Socially | ☐ Other - please explain: | |

If you would like info on an adult class in death education, please complete:

Your Name: _____

Organisation if applicable: _____

Email Contact: _____

THANK YOU

THIS RESEARCH IS FUNDED BY: 



Appendix C:

Survey with General Public in Craven Arms/Oswestry/Shrewsbury/CEDAR Events



Is Death Education of Social Value? (Public Survey)

Judith Wester/Kathryn Walker

2015 _____

Participant Information: Where Collected _____

- | | | |
|-----------------------------------|-------------------------------------|----------------------------------|
| ☐ Male | ☐ Under 20 | ☐ Over 50 |
| ☐ Female | ☐ 20 - 30yrs | ☐ Over 75 |
| ☐ Under 12 | ☐ Over 30 | |

1. Have you ever heard of Death Education? ☐ Yes ☐ No What do you think it is?2. Would learning how to talk about death & loss in interesting and healthy ways be beneficial? ☐ Yes ☐ No In what way?

- | | | |
|-------------------------------------|--|--|
| ☐ Physically | ☐ Mentally/Emotionally | ☐ Financially |
| ☐ Socially | ☐ Improve Communication | ☐ Other - please explain: |

3. Should Death Education be taught to young people?: ☐ Yes ☐ No Please explain:

- | | |
|---|----------------------------|
| ☐ In schools to all children | |
| ☐ Out of schools to bereaved children only | |
| ☐ Both | Minimum age to teach _____ |

4. What would you expect a Death Education Class to cover?

If you would like information on our classes for yourself or your family, please complete:

Your Name: _____

Organisation if applicable: _____

Email/Postal Contact: _____

 SPONSORED BY: 

Appendix D:

EQUALITY AND DIVERSITY POLICY

CEDAR operates within a working environment in which diversity is recognised, valued and encouraged; appreciating the multi-cultural and diverse nature of the UK workforce and society in general. We are committed to principles of fairness and mutual respect in which the concept of individual responsibility is accepted by all. It is therefore the responsibility of all employees to ensure they observe and adhere to this policy at all times. Any breach is viewed seriously and will lead to investigation and potentially disciplinary action; which may include dismissal in instances of gross misconduct.

We recognise that discrimination in the workplace in any form is unacceptable and in most cases unlawful. We have therefore adopted this policy to ensure that all job applicants and employees along with those who use our services are treated fairly and without favour or prejudice. We are committed to applying this throughout all areas of employment; recruitment and selection, training, development, benefits, rewards, promotion, dealing with grievances and in our treatment of disciplinary issues.

Our policy is maintained in accordance with current legal requirements and will be updated in the event of any change in the law. However, we recognise that equality of opportunity is best achieved by day to day commitment throughout the organisation; with support and training where necessary.

Each and every employee is a stakeholder in the success of this policy. We expect every employee to make a positive contribution towards creating an environment of equal opportunity throughout CEDAR by observing this policy at all times.

EMPLOYEE RESPONSIBILITIES:

- refrain from pursuing discriminatory actions or taking decisions which are contrary to the spirit of this policy;
- do not harass, abuse or intimidate anyone on account of their protected characteristics;
- do not place pressure on any other employee to act in a discriminatory manner;
- resist pressure to discriminate placed on you by other employees and report such matters;
- co-operate with any investigations including the provision of evidence into acts or conduct which may amount to discrimination;
- co-operate with any measures introduced to develop or monitor equal opportunity.

Discrimination is not just directly treating one person less favourably than another. It can be discrimination that takes place against someone who *associates* with a person with a protected characteristic. It can be discrimination against someone *believed to possess* a protected characteristic (even though they don't). It can also be discrimination where something *particularly disadvantages* people who share a protected characteristic more than others.

It is fundamental to your employment that you treat and are treated by other employees and those who use, or are otherwise associated with CEDAR, considerately and with respect.

Any individual who believes that they have been discriminated against should speak to their Line Manager, if possible, or to the CEO of the organisation.