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An exploration of female adolescent experiences of abortion and miscarriage from an adult retrospective bio-psycho-social perspective

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6.0 Chapter Six: Discussion

"Neither the psychology nor the pedagogy of adolescence can be treated without careful consideration of the whole problem of sex."

(Hall, 1904, p. 109)

6.1 Chapter Six Overview

Chapter five provided details of the data collection, data analyses, and findings for the studies that comprise this thesis: (a) phase one: the Adult Self-Perception of Retrospective Perinatal Death in Adolescence Questionnaire (AAA) (n = 23); and (b) phase two: retrospective adult semi-structured interviews (n = 6). This chapter summarises the converged results obtained from the two studies

This chapter focuses on presenting the key converged findings to address the research aims (see chapter four), and are presented in alignment with the bio-psycho-social framework consistent throughout this thesis (Bronfenbrenner, 1986).

6.2 Summary of Key Findings

This section presents summaries of the converged findings from phases one and two that explored the research question: "is there a bereavement impact on females across the life course following adolescent perinatal deaths?".

A total of 23 AAA questionnaires were either fully or partially completed and submitted online via the online Qualtrics™ platform for phase one (see chapter five). The analysed responses provided an

exploratory overview of transnational experiences prior to, during, and following a perinatal death during adolescence utilising a bioecological framework.

Phase two comprised of six semi-structured adult retrospective interviews following the AAA data analyses. The interviews provided contextual narratives to add depth to the breadth of the bio-psycho-social data collected in phase one.

The main summarised findings for the present study are discussed in the following section.

6.3 Discussing the Results: Introduction

This section presents the meaning of the results from phases one and two for the current thesis. As detailed in chapter four, a sequential explanatory design was employed for this research, with the AAA survey in phase one designed to collect exploratory data from a bio-psycho-social perspective from adult participants who had experienced a perinatal death during adolescence. The AAA results provided an insight into how a sample of transnational women perceived their experiences, both at the time of the event, and across the lifespan, from a research perspective hitherto previously unexplored. Subsequently, the semi-structured interview questions employed in phase two were informed by the data analyses from the phase one respondents. The interview narratives provided a depth of understanding within which to further understand the experiences relayed in the AAA responses.

The converged interpretive analyses for both phases one and two are presented within the relevant bio-psycho-social themes, mapped to the research question, and aligned to the nested systems within the Multidimensional Theory of Bereavement (MTB).

6.3.1 The Individual Ecological System

Chapter two details the MTB, constructed and modified from Bronfenbrenner's Ecological Systems Theory, which positions the developing individual at the centre of the nested systems model (Bronfenbrenner, 1979/1986). The MTB expands the concept of personhood within the "individual" into two constituents; the biological element and the behavioural element.

6.3.1.1 Biological Characteristics

The biological element within the "individual" component of the nested systems model of the MTB is represented within the study as demographic data. The known geographic location of the respondents submitting questionnaires for phase one, and the nationality of the interview participants within phase two, are presented in Table 19 on the next page:

Table 19

Geographic Location of all Research Participants

Country	Phase One Participants	Phase Two Participants
England	8	3
Republic of Ireland	3	1
United States	3	
New Zealand	1	
Northern Ireland	1	
Scotland	1	
Uganda		1
Germany		1

All survey respondents confirmed they were biologically female (n = 23) and all interview participants confirmed they were biologically female (n = 6).

Twenty two (n = 22) of the questionnaire respondents self-identified their ethnicity as "white" and one participant self-identified their ethnicity as "black". Five of the interview participants presented as ethnically white and one participant presented as ethnically black.

The self-disclosed participants’ ages at the time of data collection, across both studies collectively, ranged from 19 years old to 57 years old. The disclosed ages at the time of the adolescent perinatal death, reported by the adult participants in both studies, are presented in Table 20:

Table 20

Age of all Participants at Time of Adolescent Perinatal Death

Age at Time of Perinatal Death	Phase one Participants	Phase two Participants
14 years old	1	1
15 years old		1*
16 years old	6	2*
17 years old	3	1
18 years old	7	2
19 years old	3	

Note. *One interview participant experienced two abortions, one at fifteen years old and one at sixteen years old.

6.3.1.2 Behavioural Characteristics

The second element within the “individual” component of the MTB is the behavioural component. This is represented within this study as data pertaining to the behavioural aspects of the participants prior to, during, and post adolescent perinatal death.

6.3.1.2.1 Adolescent Mental Health

The data analyses revealed that almost half of the questionnaire respondents in phase one, 43% (n = 10), and half of the interview participants in phase two, 50% (n = 3) self-identified as experiencing mental health problems prior to becoming pregnant during adolescence. The sample size is too small to conclude that poor adolescent mental health contributes to adolescent pregnancy. However, alongside the self-perceived identification of adolescent mental health problems, the themes of stigma, ACEs, vulnerability, and consent, all generated within phase two, and scholarly evidence of sociological factors that contribute to adolescent pregnancy, as detailed in chapter one, suggest that environmental variables may contribute to poor mental health outcomes and subsequent early life pregnancy. Consequently, this study suggests that bio-psycho-social factors are interdependent during human development and prior events during childhood may play a contributory role in subsequent mental health issues and resultant pregnancies (Luster & Small, 1994).

Within phase two, the AAA respondents were asked whether they consider their experience of adolescent perinatal death to have been a positive, negative or neutral experience. Data analysis revealed that 50% (n = 9) of the questionnaire respondents stated their experience of perinatal death during adolescence; "was a traumatic experience that has enabled me to change my life in a significantly positive way; I wouldn't be the person I am today if it hadn't happened". A further 22% (n = 4) of respondents provided a neutral answer to the question, and the resultant 28% (n = 5) stating it was a negative experience that still affects them in this way today.

Moreover, within the phase two theme of "constructing and reconstructing identity narrative" all six participants stated that their experience at the time of the adolescent perinatal death had a negative impact on them, but across the lifespan the adult women had re-constructed the meaning of the experiences, and impact on their identity, to reflect a positive growth mentality (Krosch & Shakespeare-Finch, 2017).

Overall, the combined results suggest that adolescent females with poor mental health may be at greater risk of pregnancy, however, for most adult women who experienced an adolescent miscarriage or abortion a key finding for this thesis is that there is evidence of resilience and post traumatic growth, with a minority reflecting long term negative impact (Bonanno et al., 2002; Seery et al., 2010; Tedeschi et al., 1998).

6.3.1.2.2 "Bereaved Mother" Identity

As highlighted in chapter three, authors of the LR publications referred to adolescents who had experienced a perinatal death as a "bereaved parent" (e.g., Barnickol et al., 1986). However, there was no presenting evidence of co-construction, or self-identification, of the conferred bereaved mother identity. Therefore, participants in both studies were asked if they self-identified as a "bereaved parent" to ascertain the ascription of personhood, and to explore the self-construction of parental identity in relation to the adolescent perinatal death (Layne, 2000; Maguire, 1989).

The results from the phase one AAA surveys revealed that 36% (n = 6) of respondents self-identify as a "bereaved parent" in direct response to the adolescent perinatal death. These women were more likely to have

experienced an adolescent miscarriage (n = 4), than an adolescent abortion (n = 2), but the sample is too small to form any generalisable conclusions. A further 12% (n = 2) of respondents neither agreed nor disagreed, and 52% (n = 9) of respondents disagreed with the statement.

The phase two adult retrospective interview participants reflected similar responses with 33% (n = 2) of the participants self-identifying as a "bereaved parent". A further 17% (n = 1) of participants responded neutrally, and the remaining 50% (n = 3) of participants disagreed that they self-identified with the term "bereaved parent" as a result of their adolescent perinatal death. Within phase two, the two women who self-identified as a "bereaved parent" were the 19 year old participant who experienced a miscarriage at seventeen, and the participant in her forties that experienced an abortion during adolescence, but subsequently experienced baby losses, and fertility treatment, during adulthood.

It is therefore a key finding for this thesis that not all women who experience a perinatal death during adolescence self-identify as a "bereaved parent". It can be concluded that females should be asked whether they identify as a bereaved parent following an adolescent perinatal death, and not have the identity assumed.

6.3.1.2.3 Adolescent Contraceptive Use and Consent

The results from the phase one AAA questionnaires revealed that almost 60% of respondents were not using contraception at the time of the adolescent conception. The reasons relayed for the lack of contraceptive use was generalisable as; (a) lack of confidence; and (b) ignorance. The

phase one responses encompassed perinatal deaths experienced between the ages of 14 and 19 years old thereby indicating that stage of development was not a factor.

The phase two interview participant narratives further revealed that only one participant was using contraception at the time of the adolescent conception. The reasons provided by the phase two participants for lack of contraceptive use reflected the phase one responses; lack of confidence and ignorance.

Overall, a key finding for this thesis was that the female participants were not planning to become parents during adolescence, and that issues of confidence, education, and consent were prevalent owing to the multifarious contributors prior to, and during, adolescent development within the nested systems.

6.3.1.2.4 Religiosity

With many religious doctrines ascribing personhood from the moment of conception, the researcher had expected to see the self-identification of parenthood associated with women involved with religious practice (Maguire, 1989). In contrast to this view, whilst analysing the phase one AAA survey responses, it was noted by the researcher that the six respondents who declared affiliation with a religious or spiritual group, did not self-identify as a "bereaved parent". Furthermore, the phase two participant responses supported the findings in phase one for this study.

It is therefore a key finding for this thesis is that despite religious discourse conferring personhood at the point of conception, individuals who identify with a religious group espousing those views, who experience perinatal death, may not ascribe the same meaning to the pregnancy.

6.3.1.2.5 Bereavement and Grief Response

The PGIS findings from phase one indicate that 74% of adult females experience a normative adjustment to an adolescent miscarriage or abortion death over time (n = 14). A quarter of respondents, 26% (n = 5), exhibited increased PGIS scores over time, which may indicate a higher risk of potential for PGD (APA, 2013; ICD-11, 2018). These findings are consistent with general bereavement outcomes across a spectrum (see chapter two) and support Sefton's (2002) assertion that the majority of women in her study had experienced a normative grief adjustment over the year following the perinatal death, with a few participants showing signs of depression or PGD.

A further key finding for this study was a lack of evidence of any significant differences in PGIS scores between the women who had experienced adolescent miscarriage and the women who had experienced adolescent abortion.

The PGIS was not administered to the interview participants, however, semi-structured questions were asked about, and related to, grief, both at the time of the perinatal death and subsequent responses in adulthood. The interview narratives supported the results generated from the PGIS scores in phase one, with five of the six adult women interviewed

in phase two evidencing normal bereavement adjustment to perinatal deaths over time. Moreover, only one theme was generated from the thematic analysis employed in phase two related to grief, and this was entitled; "some grief reactions".

Furthermore, chapter two presented the three potential outcomes following the bereavement process: normative adjustment, Prolonged Grief Disorder (PGD) and Post Traumatic Growth (PTG) (Bonanno et al., 2002; Calhoun et al., 2010; Maciejewski et al., 2016), with the focus of bereavement literature on establishing "recovery" as a stable, non-changing outcome. Thus, a further contribution of this thesis is a fourth possible outcome arising from adult re-grief phenomena which supports Pearce's (2019) argument that attempting to "complete" the bereavement process in order to attain perpetual happiness is naïve and prescriptive.

A further key finding for this thesis is that, contrary to the evidenced support in the babyloss community for perinatal losses within an adult context (see chapter one), adolescent perinatal death responses generated themes of stigmatising and societal labelling.

6.3.1.2.6 Educational Attainment

Twenty two respondents in phase one were either attending, or had completed, third level education at the time of participation. Only one respondent indicated that they had completed secondary education to date and were not currently studying. Within phase two, one of the participants (aged 19) was starting an undergraduate course, three participants had

obtained undergraduate degrees, one participant held a master's degree, and one participant had completed a PhD.

Assuming a gross potential total of twenty nine participants for this study, only one woman had not attended third level education at the time of investigation. The findings are a contribution for this thesis suggesting that becoming pregnant during adolescence, and subsequently experiencing a miscarriage or abortion, does not adversely affect educational attainment across the lifespan. Additionally, the ages the participants report "leaving education" range from seventeen years old to forty five years old, further indicating that education may be a lifelong experience; with some participants returning to higher education at later ages (Jarvis, 2004) .

However, the researcher acknowledges that the participants for this study may have educational, and/or social advantage, which enabled them to access and respond to this study (Koo & Skinner, 2005). Furthermore, as participant recruitment for phase two was undertaken during the beginning of the SARS-CoV-2 pandemic, the identification of social disadvantage was illuminated further, and participants without adequate digital access may have been precluded from participating within phase two (CBBC Newsround, 2021).

6.3.2 The Microsystem

This section explores the key findings from the data collected pertaining to the microsystem interactions during adolescence between the participants and their family, their peers, the medical professionals, the school professionals, and any other significant bereavements.

6.3.2.1 Family

Within this thesis, family relationships were examined within phase two due to the multiplicities of familial structures. This study confirmed earlier assertions that the mother exerts influence on the developing female, regardless of nationality, age, or ethnicity. Further contributions for this this are the key findings provided by the three sub-themes generated from the participant interview thematic analysis results; (a) the importance of not letting the family "down"; (b) the prevalence of Adverse Childhood Experiences (ACEs); and (c) silence and lies within the family environment.

6.3.2.2 Other Bereavements in Childhood

Approximately one third (n = 6) of the AAA respondents stated that they had experienced a significant bereavement prior to the perinatal death. An additional comment was provided by one respondent who considered herself bereaved by divorce.

The two respondents in phase one who reported the death of a father, and a "nasty" divorce that resulted in the loss of the father, both exhibited high PGIS scores. A key finding is therefore that increased PGIS scores may indicate grief from the prior losses may contribute to a cumulative response following the perinatal death (Lloyd, 2018).

6.3.2.3 Friends

A key finding from phase two revealed that four of the six interview participants did not discuss their pregnancy, or perinatal death, with their

friends at the time of the adolescent event. As detailed in chapter five, across all bio-psycho-social contexts the themes of stigmatisation and silence were prevalent due to relational societal influences.

Bella (English) and Afiya (Ugandan) conveyed narratives of communication, participation, and support of their friends during, and following their pregnancy experiences. Conversely, the narratives of Rosemary (English), Roisin (Irish), Denise (English), and Sabine (German) all detailed reluctance to disclose their pregnancy to their peers, thereby evidencing influence of individualised social environments, and internalised stigma, at a multisystemic level (Fulcher & Scott, 2007; Taylor, 2020).

6.3.2.4 Teachers

Phase one of this study provided the first insight into how adult respondents retrospectively viewed the responses by their secondary school teachers following a perinatal death. Approximately half, 55% (n = 11), responded that their secondary school, or teachers, could have supported them better. Furthermore, additional comments provided by some respondents within the AAA survey text boxes generated two themes; (a) lack of support from the teachers and/or no access to counselling; and (b) silence.

The phase two adult retrospective interview participants provided confirmation of the phase one themes of lack of support, lack of information and signposting, and silence. The thematic analysis conducted within the cross case analysis of the interviews also provided two additional themes; (a) pregnant girls drop out of school and "disappear"; and (b) teachers contribute to judgemental attitudes.

It is therefore a key finding for this thesis that bereavement policies, and SPHE curriculum, should include information and signposting on sexual health topics that are relevant, inclusive, and non-judgemental.

6.3.2.5 Medical Professionals

The survey findings in phase one revealed that 80% (n = 16) sought medical services, and a further 20% (n = 4) did not procure medical attention during these events. Notably, all of the AAA survey respondents who experienced an adolescent abortion (n= 11) procured medical support, whereas 50% (n – 4) of the women who experienced an adolescent miscarriage did not.

No themes were generated within the medical microsystem from the phase two participant interviews as the experiences were individualistic. However the key findings within this chapter are relevant to all medical professionals who provide services to pregnant adolescent females.

6.3.2.6 Techno Subsystem

Of the survey respondents in phase one that did have access to the internet at the time of the adolescent pregnancy, 21% (n = 4) "somewhat" agreed that online resources helped them during, or following, their perinatal death. A further 21% (n = 4) of the adult AAA respondents answered that they "neither agree nor disagree" that online resources were helpful either during or subsequent to their adolescent perinatal death.

Within the phase two interview narratives, Denise (English) speculated that social media "makes things worse" within contemporary

society. Conversely, Sabine (German) stated that she experienced a largely positive in response to posting about her adolescent miscarriage on Instagram.

A key finding is that provision of information and support on adolescent pregnancy, adolescent miscarriage, adolescent parenting, and adolescent abortion should be widely available and accessible within the techno subsystem.

6.3.3 The Mesosystem

Chapter five presented the Bio-Psycho-Social Model of Female Experiences of Adolescent Perinatal Death (BELATED), which indicated a lack of evidence from phases one and two of structural cohesiveness within the mesosystem related to adolescent perinatal experiences.

6.3.4 The Macrosystem

This section presents the key findings from phases one and two related to themes within the macrosystem.

6.3.4.1 Religion

The phase one AAA survey instrument did not seek to examine the multifarious influences of religious organisations across the nested systems; however, one questionnaire respondent provided the following statement in a free text box: "This was before the internet and research was limited. All the advice I received (including from my GP and nurse) was biased and religious".

The phase two participant interview narratives, particularly pertaining to Case Study A, illustrated how influential religious organisations can be on societal perceptions of females who become pregnant outside of marriage (see chapter one). One particular sub theme was generated from the interview transcripts that directly addressed religious influence; "religious dogma influences societal stigma".

6.3.4.2 Sex and Relationship Education

A key finding for this thesis suggest that RSE curriculum, and parental involvement, are collectively failing to provide adolescents with the knowledge, and confidence, to make informed relationship and sexual decisions. Shtarkshall et al. (2007) argue that: "Literacy involves more than learning facts and identifying symbols; it encompasses the skills needed to combine knowledge in a meaningful way, allowing one to express ideas, make decisions and solve problems…The absence of sexual literacy can be the source of many health and social hazards, including STDs and unintended pregnancy." (p. 116).

6.3.4.3 School Bereavement Policy

All of the phase one (AAA) respondents stated their school either did not have a bereavement policy or that they were unaware if one existed. These findings suggest that whilst US discourse have conferred bereavement status on adolescent females following perinatal deaths, there is no evidence of school recognition of either perinatal, or indeed, general bereavement for any of the study participants, either in Ireland or elsewhere.

However, many schools have, in recent years, introduced general bereavement policies both within, and outside of, Ireland but there is inconsistency in content and implementation (Holland, 2016; Kennedy et al., 2021; McGovern & Tracey, 2010; O'Brien, 2015). Further, of the Irish secondary school bereavement policies obtained online by the researcher, none acknowledged perinatal death losses. Moreover, to date, the Irish curriculum still does not mention miscarriage or abortion within their SPHE Toolkit (Department for Education, 2022).

Alternatively, the Department for Education in England has recently introduced curriculum guidance on educating secondary school pupils on miscarriage and abortion within the RSE curriculum (Department for Education, 2019). This policy change will contribute to educating young people about the potential for complications regarding reproductive events and choice (Brady et al., 2008).

6.3.4.4 School Response to Adolescent Pregnancy

As detailed in chapter five, the themes generated for the school microsystem included the aforementioned historical inadequacy of RSE, and also mirrored societal marginalisation, and stigmatisation, of adolescent girls who became pregnant.

A key finding was that the whole school environment has been found to reflect the wider societal conditions, behaviours, and cultural norms within which it exists (Simon & Downes, 2020). The BELATED model, a contribution for this thesis, illustrates the school as a

multitudinous construct that contributes to the stigmatisation of girls who become pregnant whilst attending secondary school.

6.3.5 The Chronosystem

The Bio-Psycho-Social Model of Female Experiences of Adolescent Perinatal Death (BELATED) commences with the context of the chronosystem, illustrating bioecological stigmatisation of adolescent females who are blamed for their pregnancy status within inherent sociohistorical patriarchal structural norms (de Londras, 2020). The model progresses to illustrating how societal variables influence females within the microsystem, and interactions within the mesosystem, via the school environment and the home environment. Sex and relationship education was deemed unfit for purpose by the research participants; of all ages and nationalities, who spoke of teachers perpetuating societal views of gender based behavioural expectations, and a lack of information, signposting, and knowledge, which contributes to female under confidence and under preparedness for sexual activity (e.g., De Vere, 2018; Cole, 2020). Within families, it is evident that mothers are influential and ACEs are prevalent, thus further complicating individual perceptions of expected societal behaviour and views (Hillis et al., 2004; Jaccard et al., 1996).

The individual context was subdivided between early development (adolescent: immediate) and impact across the lifespan (adult: dividual). Within individual discourse, adult women recounted narratives of adolescent confusion, silence, mental health issues, and stigma. Consent, manipulation, and blurring of consensual comprehension were complicated

by early life stressors, particularly ACEs, within the home (Felitti et al., 1998; Silvers, 2019). Impact across the lifespan was evident with identity creation, and re-creation, a continuous navigational process that does not end when girls are deemed "adults" (Pals, 2006). The emotional attachment to the pregnancy was enduring, whether the women self-identified as a "bereaved mother" or not (McAll & Wilson, 1987).

The bioecological BELATED model is encased within the relational "dividual"; that which is outside of us, is also within us (Davies, 2020). We cannot separate the individual from society; we absorb, and contribute to, external influences throughout the lifespan.

6.4 Chapter Conclusion

The current chapter has provided a summary of the key converged findings from phases one and two within a bio-psycho-social framework for this research. Presentation of the study findings for this thesis are proffered with a view to informing policy and practice for individuals who may provide personal or professional support to females who are experiencing, or have experienced, these events. It is however explicitly stated that the findings for this thesis are restricted by the small sample size and should be considered within this context.

The next chapter will conclude this thesis with a discussion of the key findings in relation to the study aims, highlight the contributions and limitations of this study, and will provide suggestions for policy and practice improvements from the participants, along with suggestions for further research and implications.

7.0 Chapter Seven: Conclusion

"In the fell clutch of circumstance, I have not winced nor cried aloud.

Under the bludgeonings of chance, My head is bloody, but unbowed."

(Henley, 1888)

7.0 Chapter Seven Overview

As detailed in chapter one, the World Health Organization (WHO) estimates that globally over nine million 15 to 19 year olds will experience either an uninduced or induced perinatal death (WHO, 2020). There are no global estimates for pregnancy occurrence in adolescents under the age of 15. Despite these statistics, the dearth of research exploring female adolescent perinatal death experiences was identified by the researcher's professional experience and further evidenced in the Literature Review (LR). This thesis provides a modest contribution to addressing the significant gap in knowledge by providing a comprehensive overview of the bio-psycho-social experiences of the study participants, with a view to informing policy and practice.

As this study has illustrated, social narratives acknowledge the potential grief impact of perinatal deaths, but the experiences are predominantly portrayed from the perspective of adults in consenting, committed relationships with imputed personhood (Layne, 2000). Additionally, academic discourse presents adolescent perinatal death experiences from a US-centric medical perspective, with associated assumptive determinants (see chapter three). The current study thus

contributes modestly to the expansion of knowledge to encompass global bioecological perspectives of human experiences across the lifespan.

The current chapter is presented in two individual but associated sections. The first main section of this chapter provides a summary highlighting the key findings for the current thesis. The second main section of this chapter details the contributions of the current thesis, suggestions for policy and practice from the research participants, and the strengths and limitations of the current study. The implications for future research are also discussed, followed by concluding statements.

7.1 Summary of Key Findings for the Current Thesis

This section presents a summary of the key findings for phases one and two that investigated the research question: "is there a bereavement impact on females across the life course following adolescent perinatal deaths?". To answer the research question the research aims were determined in chapter four as:

- To explore "personhood" of pregnancy within the adolescent perinatal death loss cohort and potential impact on identity creation or identity reconstruction across the lifespan (Bright, 1987; Fenstermacher, 2014; Hatcher, 1973; Sefton, 2002; Welch & Bergen, 2000).
- To gain insight regarding any other issues pertaining to the experience from a bio-psycho-social retrospective perspective; "When researchers invite people to talk about their reflections on

> experience, they can sometimes learn more than they set out to discover." (Hammarberg et al., 2016, p. 499).

The key research findings addressed all of the research aims and were detailed in the preceding chapter. The summarised results were also illustrated in the Bio-psycho-social Model of Female Experiences of Adolescent Perinatal Death (BELATED) in chapter five.

As detailed in chapter three, a review of the literature supported Murphy-Lawless' s (2020) assertion that there is a lack of woman-centred research that centres female views first and foremost. Despite spanning 40 years, the 20 publications identified for the LR were replete with unproven assumptions (Harrington & Harrison, 1999). Examples include; (a) that all females who experienced an adolescent perinatal loss self-identify as a "bereaved parent"; and (b) that grief is determined as either "normal" or "pathological" based on a prescribed set of psychiatric criteria (Hutti, 1992; Pearce, 2019). Further, whilst there has been a significant body of empirical research to advance understandings of grief impact and bereavement experiences following perinatal deaths, predominant narratives of adolescent experiences within the LR promote universal determinants, neglecting multisystemic context-dependent contributors (Bonanno et al., 2002; Mulrine, 2020; Parkes et al., 2015; Pearce, 2019; Tedeschi et al., 1998).

As chapter two detailed, most humans will adapt to the death of a significant attachment by adjusting over time (Bonanno et al., 2002; Davies, 2020; Walter, 2017). However, cultural diktats, and social expectations,

can influence the process of adaptation, including pathologising what may be considered normal in antipodal bioecological environments (Hall, 2014; Lloyd, 2018; Pentaris, 2011; Stroebe & Schut, 2018). The results from the Perinatal Intensity Scale (PGIS), embedded within the Adult Self-Perception of Retrospective Perinatal Death in Adolescence Questionnaire (AAA) in phase one, revealed most respondents experienced normative adaptation to adolescent perinatal deaths, with only 25% (n = 5) exhibiting increased grief intensity scores over time. Thus, this thesis supports Slade's (1994) and Hutti et al.'s (2018) assertions that ascription of personhood, and the potential for resultant grief responses, are not universally conferred, with some females minimally impacted following an adolescent perinatal death. Moreover, the findings for this study suggest that Adolfsson's (2011) suggestion that approximately 10% of females experience prolonged grief reactions following perinatal loss may be under-representative for adolescent experiences. The small sample size for this research necessitates the proviso that further studies would be required to confirm or deny these findings.

The PGIS was also used to investigate adolescent abortion experiences from an adult retrospective perspective to investigate Lee's (2003) contention that long term emotional costs are largely ignored in Euro-Western societies following these events. The PGIS results, detailed in chapter five, suggest that grief may occur following abortion, and social recognition of the range of emotional responses to any type of perinatal death, either at the time of the event, or across the lifespan, would be beneficial (Florida, 1991; Lee, 2003; Smith, 1988).

Whilst this study was designed to investigate grief and bereavement responses following female adolescent perinatal deaths, the inclusion of potential contributory social factors to these experiences pivoted this thesis into the realm of feminist discourse (Storkey, 1985; Taylor, 2020). The BELATED model (see Appendix 25) illustrates the dynamic interactions within and between the nested systems, and the pervasiveness of sociohistorical influencers, including systemic patriarchal norms, that contribute to internalisation of experienced and perceived stigma (Luddy, 2011). This study therefore supports Mahon et al.'s (1998) suggestion that females may lack the communication, social, or personal skills to control sexual experiences in ways that they would have wanted due to bioecological contributors. Further, this study suggests that adolescent experiences, and impact across the lifespan, may be influenced by earlier childhood experiences, for example ACEs (e.g. Berger, 2014; Fry & Elliott, 2017; Hillis et al., 2004; Juhasz & Pap, 2018; Silvers et al., 2017).

The BELATED model, and therefore this thesis, also supports Conlon's (2006) assertion that; "Women's response to and management of pregnancy in the Irish context takes place against a background whereby highly proscribed sexual morality – particularly through the control of women's bodies and sexuality – has been central to cultural expressions of Irishness" (p. 24). The researcher posits that due to the global nature of this study, the findings suggest that sociohistorical factors contribute to current systemic control of women's bodies, not just in Ireland, but universally. Whilst there were constraint narratives throughout all of the interviews in phase two due to overt religious influence in Ireland and Uganda,

patriarchal structural control was also evident within other cultural discourses including, for example, England and Germany, where participant narratives evidenced implicit control within, and across, all thematic contexts.

The BELATED model also provides evidence that grief responses, and bereavement experiences, cannot be considered in medical isolation, as previously evidenced in the LR. Therefore this thesis supports Pearce's (2019) argument for a shift away from pathologising grief into "normal" and "abnormal" based on deterministic psychiatric criteria, and the management of grief as a Euro-Western societal norm, to a more nuanced acceptance of; "When recovery, completion and happiness are no longer positioned as the ever out-of-reach goal to which each individual is encouraged to desire and achieve…embrace the liminal space that grief can provide, rather than erasing it in the name of normalisation" (p. 222).

Having provided a synopsis of the results for both studies, the following section will present the contributions that this thesis makes to new knowledge concerning adolescent perinatal death experiences and potential impact across the lifespan.

7.2 Contributions of the Current Thesis

This research study was planned, executed, and analysed between 2016 and 2022. It should be noted that this period included two years of SARS-CoV-2 pandemic lockdowns, and restrictions, which presented particular challenges. This section presents a summary of the modest contributions this thesis makes to the field of death studies (also known as "thanatology" in the US), education, psychology, sociology, and medical disciplines.

This study is the first (to the best of the researcher's knowledge) exploration of female adolescent perinatal death losses from a bio-psycho-social perspective. It is also the first study to investigate potential impact of these events across the lifespan.

Chapter two detailed the theoretical framework for this study which involved the construction of the Multidimensional Theory of Bereavement (MTB). The MTB sought to create a synergistic model for grief and bereavement theories by situating them within a bio-ecological structure, thus providing another contribution for this thesis (Bronfenbrenner, 1979/1986; Corcoran, 1999). The MTB incorporates existing grief theories, whilst flexing to accommodate new research, and as a matrix structure, it can be modified for use in multiple ways (Mc Guckin & Minton, 2014). Furthermore, the construction of the MTB framework for this study enabled the creation of the AAA. The questionnaire contributed to knowledge by gathering exploratory bio-psycho-social data hitherto uncharted. The data derived in phase one from the AAA analyses provided exploratory inductive findings that informed the questions employed during the semi-structured interviews in phase two.

Utilising the inclusive criteria of females who experienced any perinatal death (see Appendix 1), during adolescence (bounded with the criteria of secondary school ages), chapter three presented the LR which identified and reviewed the published empirical, non-empirical, and anecdotal literature that existed during the database searches. The summarised results identified a lack of knowledge relating to experiences of

adolescent perinatal bereavement outside of the US, from non-medical perspectives, and particularly within the school environment. This thesis therefore makes a unique modest contribution as the first international, interdisciplinary, study that considers the school environment, and educational impact, for the topic area.

Utilisation of the Perinatal Grief Intensity Scale (PGIS) within the AAA questionnaire to measure adolescent abortion grief responses is a further contribution of this research: a central tenant for this study has been the focus on the impact of the event to the individual woman, not imposed Euro-Western societal values of which deaths warrant "grievability" (Baird, 2022; Doka, 2008; Smith, 1988). The inclusion criteria for this study therefore encompassed all gestational and neonatal deaths from conception to 28 days post birth, necessitating a clear definition of the term "perinatal".

The current thesis also made a contribution to developmental studies with the creation of the BELATED model which modestly addresses the lack of interdisciplinary empirical research that utilises an ecosystemic research design (Breen & O'Connor, 2007; Guckin & Minton, 2014).

Having summarised the contributions of the current thesis to theory, methodology, and literature, the next section will identify the post completion considerations of the current research.

7.2.1 Post Completion Considerations of the Current Research

The current section presents several considerations for this research that arose upon completion of the thesis. In retrospect, as with any project, a

review should be undertaken to identify any areas for future work or lessons to be learnt for future projects.

Firstly, the participants were self-selecting so there were potentially barriers to entry through this recruitment method (Hartman, 2011). These included; (a) multiple physical barriers such as the researcher's geographic location; and (b) potential biases inherent in internet recruitment (Koo & Skinner, 2005). There were also potential social barriers recognised by the researcher, and the PhD supervisor, as difficult due to the sensitivity of the research topic and continued social stigma, particularly directed at adolescent pregnancy and the politicisation of abortion in Ireland (de Londras, 2020; Luddy, 2011; McLysaght, 2012).

A second consideration was that people who volunteer to participate in a research study have a "story to tell" (Wiederman, 1999). Evidential research suggests that following a perinatal death grief is positively correlated with perception of personhood, and socially mediated narratives (e.g. Conklin & Morgan, 1996; Layne, 2000; Withycombe, 2018). This study therefore recognises that self-selecting participants may be ascribing personhood to the pregnancy, with the sample not necessarily representing the population. Many women may have experienced little or no grief following an adolescent abortion or miscarriage, either immediately following the event or across the lifespan, and therefore may not have a "story to tell".

A third consideration for this study is that whilst the research was based in Ireland, it proved incredibly difficult to recruit any adult Irish

female participants willing to interview for phase two. Following extensive word of mouth snowballing, and multiple social media campaigns, only one Irish woman, "Roisin" agreed to a retrospective semi-structured interview (see chapter five). Despite many Irish citizens relaying that they knew someone who met the inclusion criteria for this study, and they had provided the potential participant with the researcher's contact details, later conversations revealed that the women simply would not talk about the events. This thesis therefore suggests confirmation of previous empirical findings that the Irish public participate in performative rituals immediately following a death, for example attending wakes, but are uncomfortable talking about death, dying and bereavement (e.g., McCarthy et al., 2010; Ryan, 2016; Sheehy, 1994).

A fourth consideration for this study was the lack of racial diversity. Only two participants, one in phase one and one in phase two, self-identified as black, all the other participants self-identified as white.

As the participants in both phases one and two ranged in age from 19 years old to 57 years old, a fifth consideration for this retrospective study is the fallibility of memory (Hasher & Zacks, 1988; Levine et al., 2002). Empirical data suggests that cognitive ageing can contribute to reduced ability to access context specific historical details, which could challenge the validity of some childhood and adolescent narratives provided by the adult participants (Hardt & Rutter, 2004).

7.2.2 Participant Narratives for Policy and Practice Improvements

The prior dearth of research on female adolescent perinatal death experiences has implications for evidence-based policy, and service provision, particularly in secondary schools (Banks & Smyth, 2021; Cooke et al., 2022; Murphy-Lawless, 2020). Accordingly, the participants in phase two were explicitly asked if they had any suggestions for professionals working with, or supporting, females who had experienced an adolescent perinatal death.

The researcher positionality throughout this study has been to provide a voice to women who experienced a perinatal death loss during adolescence. Consequently, the suggestions provided by the interview participants were anonymised, and duplicated phrases were truncated, but are otherwise quoted in their entirety.

The first participant, “Bella”, is a white English woman in her 20’s who experienced an abortion at 18. Bella’s suggestions for school professionals are as follows:

> there could be a programme for girls and a programme for guys…separate programmes…and programmes together…but I think that actually sometimes we feel empowered with our same gender and more able to talk about certain things…that also covers women’s rights and talks about, actually teaches us what to do when we’re in situations that we don’t want to go through…to empower us to say “actually I want you to put something on your penis right now”, to feel confident in… I didn’t speak to anyone at school but I

> think that if there was a programme that explored all of those, you know the whole, the whole subject…if you ever get in the situation there this is the space…we can create, we can talk together and decide what your next steps are gonna be, we can support you to talk to your parents if you feel that that you can do that because that would have been the other thing I wouldn't have trusted; that if I'd gone to school that they wouldn't just have phoned home straight away.

The second participant was "Rosemary", a white English woman in her 40's who experienced an abortion at the age of 18. Rosemary's suggestions for professionals interacting with adolescent females during or following an adolescent perinatal death, were:

> if this was a teenager who came to you how would you treat them, what would you say to them?...I thought I would be kind… I think nowadays things are easier because people can look stuff up quite well and they're quite good at it…just the practical side of things, I still wouldn't know actually, if someone said your parents are kicking you out what are you going to do, I wouldn't have the first idea, I wouldn't know anything about that side of things; is there any kind of signposting for people that aren't sure to know what their options are in reality?

The third participant was "Denise", a white English woman in her 50's who experienced an abortion at 14 years old. Denise's suggestions for school professionals were:

> there was…no kindness at school at all…I don't know how you get rid of stigma and shame I think…that is the biggest thing to try to assist with…is this feeling of shame and I should imagine now with social media…and WhatsApp groups I should imagine its absolutely horrendous for young girls now… it's just that society generally dismisses the roles of the boys…to actually educate the boy I mean let's face it the best education in this is about contraception and you know taking care of yourself and having a bit of self-pride in what your body is and all the rest of it but girls like me didn't have that you know I needed to be cared for…I think educating boys but I also think its education teaching; the staff that teach us… at the end of the day this is something that does go on, its as old as time…it will continue to go on…I think that yes it should be part of teacher training definitely, it has to be a part of it…awareness this is how…young women feel in a way that young boys don't get slut shamed they don't…it isn't a boy's fault…but its society's view that its always the woman, you know, that's in the wrong.

The fourth participant was "Roisin", a white Irish woman in her 50's who had to travel to England to obtain a legal abortion at 16 years old. Roisin's suggestions for school professionals are as follows:

> if there could be a person within the school either a teacher or…an outside person who was available should anybody find themselves pregnant, but also for teachers to be educated, to be made aware that what they say when there's a vulnerable child in the classroom

> impacts on them, especially with a child who is pregnant without having told anyone or thinks they may be pregnant or is vulnerable in some way, we hear things differently, what might seem a passable remark by a teacher about…for example, “Oh I hope none of you now are having sex and end up pregnant” even something like that can compound and prevent somebody from speaking out and seeking help from going to talk to somebody…I think if people with experience of personal experience, counselling experience, could then advise teachers that what they say in certain classes matter…secondly that there is a place in the school where a child knows they can go to where there is only compassion and empathy…I got pregnant through a willing experience, a consensual experience, for those girls who are raped, for those girls who are abused by a family member, and get pregnant, and particularly for…the narrative around I was pissed, I don’t remember, apparently we had sex…the shame and the guilt of the victim, so I think that would be…vitally important to let young women know that regardless of the circumstances that they found themselves, that they found themselves pregnant, that there is a space within the education system where they can go and speak, you know, where there’s compassion.

The fifth participant was “Afiya”, a black Ugandan woman in her 30’s who experienced two illegal abortions at the ages of 15 and 16 years old. Afiya’s cultural background, and abortion narratives, centred around the illegality of abortion in Uganda, the unavailability of contraception, the

medical misinformation provided by the medical professionals, and how schools exclude pupils upon finding out they are pregnant. She also relayed how newborns are discarded by unwed mothers in the absence of abortion services or adoption agencies, and how schoolgirls are physically interrogated by school nurses to ascertain if they might be pregnant. Therefore she proffered no advice to school professionals from a Ugandan perspective as the issue is structurally embedded throughout society as "taboo".

The sixth participant was "Sabine", a white German woman who was 19 at the time of the interview, who had experienced a miscarriage at 17 years old. Sabine's suggestions for school professionals was:

> Maybe not what they can tell the girls, more like how they should react not in like a disgusted way and like your life is ending right now because yeah sure there are girls that quit school and never go to work or university or anything like that but I think there are also a lot of girls that figure out how to still live their real life with a child…it would really be benefitting if in school, for example, they would tell you about miscarriage because I thought hey ok it can happen but not that often, I don't know it wasn't really existing in my mind until it happened to me…I didn't think it would be so many yeah and I think it's really helpful if people share their stories and encourage others to do the same so you don't feel as alone.

The commonalities evident in the above phase two participant suggestions reflect two themes identified in the text boxes provided by the analyses of the AAA questionnaires in phase one:

(a) The lack of support (or signposting) by school personnel, and;
(b) The perceived stigma of becoming pregnant in school leading to females feeling silenced.

Educators are perceived within society as trusted members of the community and are in a privileged position that influences the lives of their students (O'Brien, 2015). However, as societal norms influence teacher perceptions and behaviour, there is clearly room for improvement in educating school personnel in person centred, trauma-informed compassionate attitudes towards adolescent pregnancy, and following perinatal death. Additionally, teachers play an important role in providing Relationship and Sex Education (RSE) and the participant suggestions include topics of gender based stereotyping, issues of consent, signposting to appropriate agencies and services for information, and bereavement support.

This thesis therefore supports O'Brien's (2015) assertion that social change involves schools as a critical element in contributing to communities becoming "Compassionate Cities" (Kellehear, 2015), and that they are integral to: "communities that recognise that all natural cycles of sickness and health, birth and death, and love and loss occur every day within the orbits of its institutions and regular activities" (p. 454). The

BELATED model illustrates how societal influencers affect individual lives and this thesis suggests that through embracing inclusive practices within schools (i.e. recognising and respecting all human experiences, including those of perinatal losses by female adolescents) communities can become compassionate (Banks, 2021; Banks & Smyth, 2021).

7.2.3 Further Research and Implications

The current study argues that contemporary death studies scholars rarely explore the experiences of female adolescent perinatal death losses, either at the time of the event, or across the lifespan. Further, as the LR detailed, whilst some professionals within the medical profession have conducted research following these events in the US, there is an absence of identified studies outside of this discipline that met the inclusion criteria for this study. Moreover, this thesis has provided an exploratory global introduction to the bio-psycho-social variables that may contribute to these experiences. However, the limitations to this study have been detailed, including contextualising the findings to the small sample size, therefore further research would be welcomed.

Whilst attachment theory was detailed in chapter two, ascertaining the attachment style of each participant was outside of the scope of this study (Ainsworth, 1978; Ainsworth & Bell, 1970; Bartholomew & Horowitz, 1991; Bowlby, 1969/1979; Hazan & Shaver, 1987 Maine & Hesse, 1990). Therefore further investigations into attachment theory and potential impact on grief responses following adolescent perinatal deaths,

and impact across the lifespan, could provide further enlightening contributions.

This study also contributes the following postulation; do adults experience regrief phenomena following an adolescent perinatal loss? As children respond to death according to their developmental stage at the time of the event and re-interpret the death as their understanding expands, the study of re-grieving as children progress and mature through developmental stages is well documented but previously unexplored throughout adulthood (Johnson, 2015; Oltjenbruns, 2001). However, as this study examined the adjustment of grief to the adolescent perinatal death loss over the life course, the researcher asserts that adults "re-grieve" in response to adult events such as further miscarriages, abortions, baby losses, non-death losses etc. in the same manner as children re-grieve. Evidence to support this position is situated within the increased PGIS scores presented in chapter five and the narrative of participant "Rosemary" who discussed her changing grief reactions to her adolescent abortion in response to later adult life events. Further specific research of this potential phenomena would allow for comparability of findings.

Additionally, research specifically designed, and executed, within secondary schools would be helpful to ascertain teacher knowledge, and perceptions, of adolescent perinatal death experiences and impact. This would allow for the views of school professionals to be heard; their challenges, perceptions, limitations and so forth.

7.3 Chapter Conclusion

The aim of this research was to explore the retrospective experiences of females who became pregnant during adolescence, and subsequently experienced a perinatal death loss, from a bio-psycho-social perspective. The research question was conceived with the intention of informing policy and practice for individuals who may provide personal or professional support to females who are experiencing, or have experienced, these events and to make a modest contribution to the field of death studies. Whilst several contributions have been made, specifically with regards to the MTB framework, the AAA questionnaire, the PGIS analyses, the BELATED model, and self-identification of "bereaved mother" status, the findings have also revealed how the inclusion of historical and social variables contribute to perceptions of expected female behaviour in contemporary society. From the findings of this study, we can conclude that adolescent development, sexual behaviour, and perinatal death loss response is a multi-systemic phenomena that involves a variety of individual biological predispositions, behavioural factors, and multidirectional environmental variables (Biglan et al., 1990; Bronfenbrenner, 1992; Cadoret et al., 1996; Corcoran, 1999; Dodge & Petitt, 2003).

The first words to this thesis are a quotation from a gravestone, dated in 1875, detailing the death by (illegal) abortion of a young woman who was vilified for being pregnant and unwed (Evon, 2019). The findings of this study suggest that women of all ages globally are still battling against the political and religious attitudes to socially unacceptable

pregnancies and opposition to abortion, and are still being stigmatised for being pregnant and unwed.

We still have work to do.

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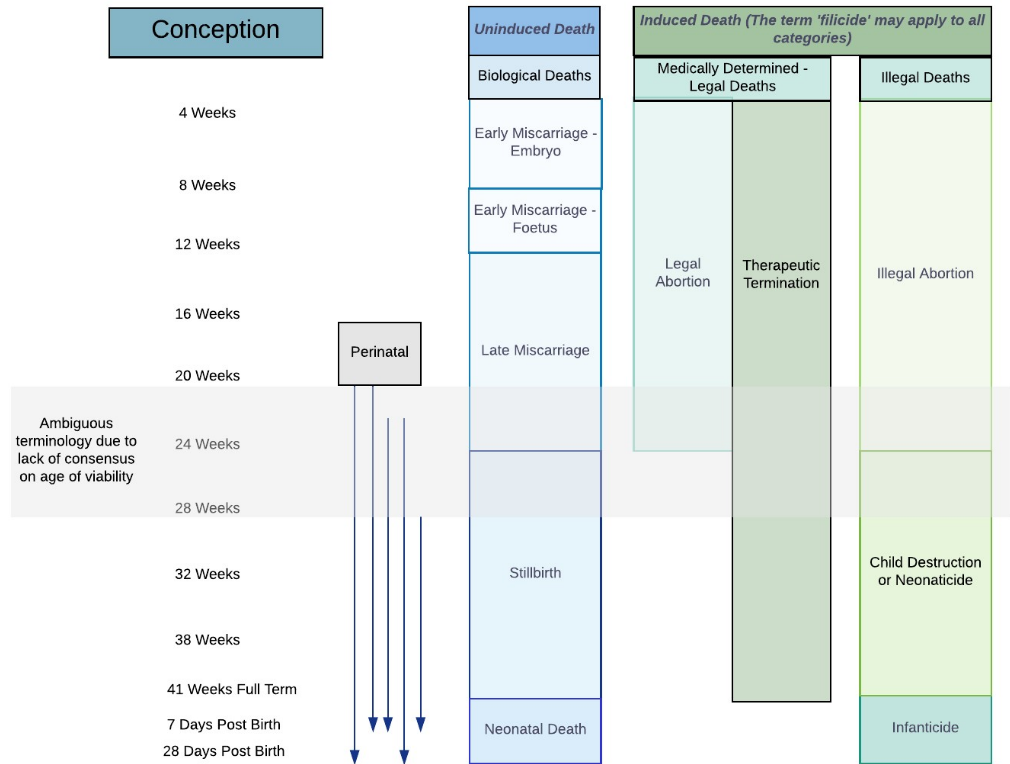
66&context=etd

Appendices

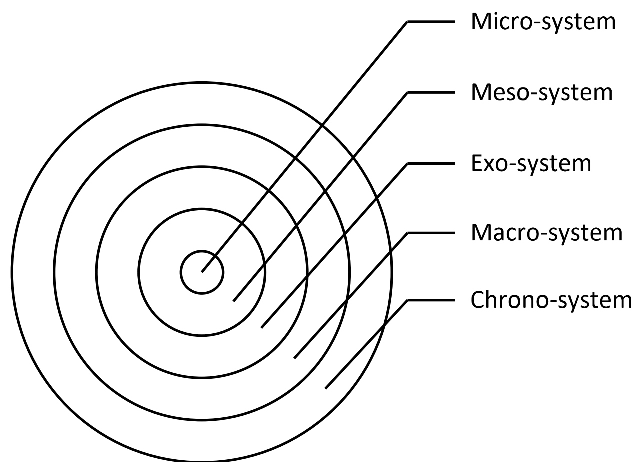
Appendix 1 – Embryonic, Foetal, and Neonatal Deaths Diagram



Appendix 2 – Summary of Adolescent Development Theories

Context	Summary
Biological	Universal determinants of adolescent development that are not affected by other factors
Psychoanalytic	Importance placed on childhood events and the unconscious; everything happens *to* you
Attachment Theory	Four attachment styles that provide a framework for understanding how children learn from the models of behaviour exhibited to them in their immediate social environment
Cognitive Stage Theories	Biological linear progression through stages of cognitive ability as children mature
Psychosocial Theories	Acknowledges the interaction between the developing psychological needs of the child and social needs of the environment through progressive stages
Social Learning Theories	How social influences within the environment contribute to childhood development
Social Identity Theory	How individuals determine their identity within a group setting
Ecological Systems Theory	A framework for understanding the interactions within and across the nested systems

Appendix 3 – The Bioecological Model (Bronfenbrenner, 1986)

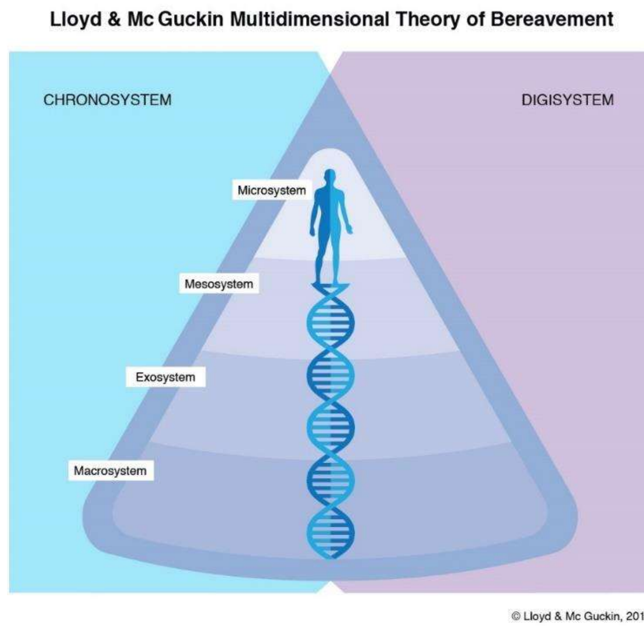


Appendix 4 – Literature Review Publications in Chronological Order by Discipline

Academic Researchers (PhDs)	Journal Article	Welch, K. J., & Bergen, M. B. (2000). Adolescent Parent Mourning Reactions Associated with Stillbirth or Neonatal Death. *OMEGA - Journal of Death and Dying, 40*(3), 435-451.
Nursing	Journal Article	Schodt, C. M. (1982). Grief in Adolescent Mothers After an Infant Death. *Image, 14*(1), 20-25.
Nursing	Book Chapter	Barnickol, C. A., Fuller, H., & Shinners, B. (1986). Helping bereaved adolescent parents. *Adolescence and death*, 132-147.
Nursing	Book Chapter	Joralemon, B. (1986). Terminating an Adolescent Pregnancy: Choice and Loss. *Adolescence and death*, 132-147.
Nursing	Journal Article	Bright, P.D. (1987). Adolescent Pregnancy and Loss. *Maternal Child Nursing Journal, 16*(1), 1-12.
Nursing	Journal Article	Shaefer, S. J. (1992). Adolescent pregnancy loss. A school-based program. *The Journal of school nursing*, *8*(2), 6-8.
Nursing	Online Article for Educators	Nykiel, C. (1996). Working with the Bereaved Adolescent Mother: Challenges, Lessons, and Guidelines. *WISSPers, 3*(1).
Nursing	Journal Article	Wheeler, S. R., & Austin, J. (2000). The Loss Response List: A Tool For Measuring Adolescent Grief Responses. *Death Studies, 24*(1), 21-34.
Nursing	Journal Article	Wheeler, S.R. & Austin, J.K. (2001). The impact of early pregnancy loss on adolescents. *The American Journal of Maternal/Child Nursing, 26*(3), 154-159.
Nursing	Booklet	Nykiel, C. (2002). *After the Loss of Your Baby: For Teen Mothers.* Omaha, NE: Centering Corporation.

Nursing	Journal Article	Sefton, M. (2002). The long-term effects of an early miscarriage for Latina adolescents. *Hispanic Health Care International, 1*(2), 71-78
Nursing	Journal Article	Sefton, M. (2007). Grief Analysis of Adolescents Experiencing an Early Miscarriage. *Hispanic Health Care International, 5*(1), 13-20.
Nursing	Journal Article	Fenstermacher, K. H. (2014). Enduring to Gain New Perspective: A Grounded Theory Study of the Experience of Perinatal Bereavement in Black Adolescents. *Research in nursing & health*, *37*(2), 135-143.
Nursing	Book Chapter	Wheeler, S., & Sefton, M. (2015). Early pregnancy loss during adolescence. *Perinatal and Pediatric Bereavement in Nursing and Other Health Professions. New York, NY: Springer Publishing Company*, 137-57.
Psychiatric	Book chapter	Barglow, P., Istiphan, I., Bedger, J., & Welbourne, C. (1973). Response Of Adolescent Mothers To Infant Or Fetal Death. *Adolescent Psychiatry, 2,* 285-300.
Psychiatric	Journal Article	Perez-Reyes, R. G., MD, & Falk, R., PhD**.** (1973). Follow-Up After Therapeutic Abortion in Early Adolescence. *Archives of General Psychiatry, 28*(1), 120. doi:10.1001/archpsyc.1973.01750310096016
Psychology	Journal Article	Hatcher, S. L. (1973). The adolescent experience of pregnancy and abortion: A developmental analysis. *Journal of Youth and Adolescence, 2*(1), 53-102. doi:10.1007/bf02213922
Social Worker	Journal Article	Horowitz, N (1978). Adolescent mourning reactions to infant and fetal loss. *Social Casework, 59,* 551-559
Social Worker	Journal Article	Soto, M. (2010). Anticipatory Guidance: A Hospital-Based Intervention for Adolescents with Perinatal Loss. *Child and Adolescent Social Work Journal, 28*(1), 49-62.

Appendix 5 – Multidimensional Theory of Bereavement



Appendix 6 – Major Euro-Western Grief Theories and LR Citations

Darwin, 1872	Biological			
Freud, 1917	Psychoanalytic			
Lindemann, 1944	Stages: Shock, Anger, Sadness, Resolution			
Bowlby,1961	Processes of mourning			
Parkes, 1972	Phases: Numbness, Searching, Depression, Recovery			
		1973	Barglow, P., Istiphan, I., Bedger, J., & Welbourne, C.	Bowlby, 1960; Freud 1917; Lindemann, 1944
		1973	Hatcher, S. L.	No theoretical references
		1973	Perez-Reyes, R. G., MD, & Falk, R.,	No theoretical references
		1978	Horowitz, N	Bowlby, 1961
Sanders, 1979	Pre bereavement, stages of grief, post			

	bereavement outcomes			
Bowlby, 1980	Phases: Numbness, Searching, Disorganisation Reorganisation			
Rubin, 1981	Two track model			
		1982	Schodt, C. M.	Bowlby, 1980; Freud, 1917; Lindemann, 1944; Parkes, 1972; Sanders, 1979
Worden, 1983	Phases: 1. Accept the reality of the loss 2. Process the pain of grief 3. Adjust to a world without the deceased 4. To find an enduring connection with the deceased in the midst of embarking on a new life			

Rando, 1984	Phases: 1. Recognise the loss 2. React (emotionally) 3. Recollect and re-experience (memories) 4. Relinquish (the world has changed) 5. Readjust (return to daily life) 6. Reinvest (Freud's reattachment)			
		1986	Barnickol, C. A., Fuller, H., & Shinners, B.	Bowlby, 1977; Freud, 1917/1957; Parkes & Brown, 1972; Sanders, 1979
		1986	Joralemon, B.	No theoretical references
		1987	Bright, P.D.	No theoretical references
Doka, 1989	Disenfranchised grief			
Dyregrov, 1991	Grief in children			
		1992	Shaefer, S. J.	Bowlby, 1960; Dyregrov & Mattiesen, 1987;

Prigerson, 1995	Prolonged Grief Disorder			
		1996	Nykiel, C.	No theoretical references
Stroebe & Schut, 1999	Dual Process Model			
Martin & Doka, 2000	Variations of grieving styles			
		2000	Welch, K. J., & Bergen, M. B.	Doka, 1989; Rando, 1986
		2000	Wheeler, S. R., & Austin, J.	No theoretical references
		2001	Wheeler, S.R. & Austin, J.K.	Doka, 1989; Sanders, 1989
Bonanno & colleagues, 2002	Post Traumatic Growth			
		2002	Nykiel, C.	No theoretical references
		2002	Sefton, M.	No theoretical references
		2006	Tonelli, M.	No theoretical references
Neimeyer et al. 2002	Meaning making			

		2007	Sefton, M.	Sanders, 1999
		2010	Soto, M.	Doka, 1989; Rando, 1986; Sanders, 1989
		2014	Fenstermacher, K. H.	Bonanno & Kaltman, 1999; Laurie & Neimeyer, 2008
Klass, 2006	Continuing bonds			
Parkes, Laungani & Young, 2015	Cultural variations			
		2016	Wheeler, S., & Sefton, M.	Doka, 1989; Sanders, 1989

Appendix 7 – Consent Form for Online Questionnaire

The researcher requests your consent for participation in a study about the experiences of adolescents who lose a baby whilst in school. This consent form asks you to allow the researcher to store and view the questionnaire answers and to use any comments that you make to enhance understanding of the topic.

Participation in this study is completely voluntary. If you decide not to participate there will not be any negative consequences. Please be aware that if you decide to participate, you may stop participating at any time and you may decide not to answer any specific question.

The researcher will maintain the anonymity of the research records or data, and all data will be destroyed in accordance with the regulatory requirements of Trinity College, Dublin.

By submitting this form you are indicating that you have read the description of the study, are over the age of 18, and that you agree to the terms as described.

The researcher also requests participation in interviews, whether you complete this questionnaire or not. If you would like to receive information on the interviews and what that might entail, please email Caroline Lloyd at Lloydca@tcd.ie and full details will be provided. Please note that this questionnaire is anonymous and any email enquiries will not assume that you have participated in this online study.

If you have any questions on the study, the questionnaire, or would like a copy of this consent letter, please contact me at Lloydca@tcd.ie

If during your participation in this study you feel that the information and guidelines that you were given have been neglected or disregarded in any way, or if you are unhappy about the process, please contact Professor Conor Mc Guckin, School of Education, Trinity College, Dublin at +353 1896 2175 or conor.mcguckin@tcd.ie Please be assured that your concerns will be dealt with in a sensitive manner.

Thank you in advance for your participation!

Caroline Lloyd

1. I agree to participate in the research study. I understand the purpose and nature of this study and I am participating voluntarily.

○ Yes

○ No

2. I understand that I can withdraw from the study at any time before the answers are submitted at the end, without any penalty or consequences.

○ Yes

○ No

3. I grant permission for the data generated from this interview to be used in the researcher's publications on this topic.

- Yes
- No
- I grant permission under the following conditions:

4. I grant permission for the questionnaire to be securely stored and saved for purpose of review by the researcher and researcher's supervisor. I am aware my data will be kept anonymous and kept within the regulations of the GDPR and will be securely shredded at a future date.

- Yes
- No

5. I am fully aware that there is a risk that responding to this questionnaire may lead to a range of emotional responses. I confirm that I am aware that signposting to suitable reputable support organisations will be provided at the end of the questionnaire.

- Yes
- No

6. I have read and understood the Information Sheet.

○ Yes

○ No

7. I understand that once the questionnaire has been submitted I cannot request that it be withdrawn. The reason for this is that the data is anonymous and the researcher will not know which questionnaire is yours.

○ Yes

○ No

Participants were automatically exited from the questionnaire if they did not agree to the above questions.

The online questionnaire was constructed so that each question was optional

Appendix 8 – Consent Form for Paper Questionnaires

In agreeing to participate in this research I understand the following:

Caroline Lloyd is a Ph.D. student in the School of Education, Trinity College Dublin. As part of this work, she is conducting research in the area of adolescent experiences of pregnancy during secondary education which resulted in a gestnatal death (from conception to 28 days post birth). The thesis is investigating the effects of the event (the pregnancy and death) on the adolescent, the school response and educational impact. The study is an investigation from an adult retrospective perspective of their experiences when they were in formal education as adolescents. The aim of the research is to inform school personnel, policy makers e.g. governmental officials and school guidance counsellors of these effects so that adolescents can be effectively supported. Caroline can be contacted at lloydca@tcd.ie.

If you agree to take part in this study, you will be asked to complete a questionnaire and to take part in an audio-recorded interview. The questionnaire will take about 20 minutes and the interview will take between 30 minutes to 1 hour. Both will take place at a time of your convenience and may be undertaken separately. Both the interview and the questionnaire will be stored anonymously i.e. your name will not be kept with the data. If you participate in both the questionnaire and the interview, they will be kept separately and not linked together in order to maintain anonymity.

I can foresee no risks for your participation in the study beyond those experienced in everyday life, however, should you experience any discomfort or upset, a list of support organisations will be provided to you. The information given by you will be treated with privacy and anonymity and within the GDPR regulations. No information regarding you will be revealed in the research. Information will be stored safely with access only available to the research team and examiners and it will all be destroyed after 10 years. The anonymised results from the study will be included in a thesis and may be discussed at conferences or published in a book or a journal.

Please answer all of the following (tick the appropriate box):

Yes No

- I have read and understood the information sheet. □ □
- I understand what the project is about, and what the results will be used for. □ □
- I am fully aware of all of the procedures involving my participation in the study. □ □
- I am fully aware of any risks and benefits associated with my participation. □ □
- I am fully aware that I may refuse to answer any questions. □ □
- I know that my participation is voluntary and that I can withdraw from the project at any stage (until the data has been anonymised) without giving any reason. □ □
- I am aware that my results will be kept anonymous. □ □

- I am aware that I may ask any questions at any point before, during or after the conclusion of the study. □ □
- I understand that the interview will be carried out in a sensitive and empathic manner and that I may stop or pause the interview at any time. □ □
- I understand that the interview will be audio recorded and transcribed. □ □
- The data will be held within the regulations of the GDPR (copy of guidelines attached). Within this framework, I can ask that all information given by me can be destroyed upon request, at any time, without giving a reason. □ □
- I understand that this research study does not constitute any kind of counselling or medical treatment and that the study will not form any kind of medical or psychological diagnosis. □ □
- I understand that my identity will be protected via a code number □ □
- I understand that my electronic data will be stored in password protected files and my physical data will be stored in locked cabinets □ □
- I have been provided with a list of support organisations should any issues arise as a result of my participation. □ □
- I understand that I will be asked questions of a personal nature that will include whether the pregnancy was planned, the significance of the baby to me, my responses to the loss, what kind of support I received and how I feel the experience affected me. □ □

You do not have to take part in this study if you do not want to and you can withdraw from the study at any time without saying why until the data has been submitted anonymously. Once the questionnaire and/or interview data has been completed and anonymised it will not be possible to withdraw from the study.

Please understand that you are permitted to present concerns, questions, or queries at any point before, during or after the study.

Provision will be made for a proper debriefing of participants following the interview questions. This will ensure that all participants have an opportunity to ask any questions about the interview or the study and ensure that the researcher has identified any issues that may have arisen that would require signposting to support organisations. The researcher will also use the debriefing session to ensure that no participant leaves the interview in an emotional state where they are worse off than when they started the interview. This can be done by talking about positive ways of addressing these issues, including seeing a qualified counsellor or obtaining support from specialised organisation.

Finally, thank you for taking time to read this and thank you for participating in this study if you decide to participate.

If during your participation in this study you feel that the information and guidelines that you were given have been neglected or disregarded in any way, or if you are unhappy about the process, please contact Professor

Conor Mc Guckin, School of Education, Trinity College, Dublin at +353 1896 2175 or conor.mcguckin@tcd.ie Please be assured that your concerns will be dealt with in a sensitive manner.

I agree to participate in this study:

Signed & Dated

____ Participant

Signed & Dated____Researcher

Appendix 9 – Study Information Sheet

This research is exploring the experiences of adolescents who become pregnant in secondary education and subsequently lose the baby

You are being invited to take part in a study. Before you decide, it is important for you to understand why the study is being done and what it will involve. This Participant Information Sheet will tell you about the purpose, risks and benefits of this study. If you agree to take part, we will ask you to sign a Consent Form. If there is anything you are unclear about, we are happy to explain it to you. Please take as much time as you need to read this. You should only consent to take part in this study when you feel that you understand what is being asked of you, and you have had enough time to make your decision. Thank you for reading this.

WHO I AM AND WHAT THIS STUDY IS ABOUT

My name is Caroline Lloyd and I am a Ph.D. student in the School of Education, Trinity College Dublin. I am undertaking this study because we would like to understand how girls in secondary school in Ireland are affected when they get pregnant but the baby dies. The overall aim of the study is to a. better understand the impact of these types of losses to the adolescents b. better understand the school responses to these girls and their experience, and c. better understand if the girls' education and future prospects are affected in the longer term.

WHAT WILL TAKING PART INVOLVE?

The study has two components;

(a.) An interview with the researcher that may last up to an hour, in a location agreed by both parties. This interview would be recorded and transcribed, and all data will remain anonymous. Your data will be stored in protected electronic files and locked filing cabinets.

(b.) Completion of a questionnaire either electronically or by paper which should take no longer than 10-15 minutes to complete. This data will remain anonymous. Your data will be stored in protected electronic files and locked filing cabinets.

(c.) You may choose to participate in either/or component or both.

A debriefing session will be included at the end of both components and further information on support organisations will be provided.

WHY HAVE YOU BEEN INVITED TO TAKE PART?

Any woman who has experienced a teenage pregnancy and subsequent gestational (from conception to birth) or neonatal (up to 28 days post birth) death whilst in secondary school (between the ages of 12 to 19 years old) is invited to take part in this study. These losses can include miscarriage, stillbirth, neonatal death, abortion, therapeutic termination, or ectopic pregnancy. To minimise any potential risks to participants you should not have experienced a significant bereavement in the two years prior to participation.

DO YOU HAVE TO TAKE PART?

Participation in this study is voluntary and you may refuse to answer any question or stop the interview at any time. You may also request to withdraw your questionnaire submission or interview transcript for any reason, at any time until the data is anonymised, without any consequence whatsoever. You may review your transcript, or any data given by you, until the data is anonymised. Once your questionnaire and/or interview transcript has been anonymised the researcher will not be able to identify your data so it will no longer be possible to request to withdraw it.

WHAT ARE THE POSSIBLE RISKS AND BENEFITS OF TAKING PART?

Talking about personal experiences may be difficult for some people and may lead to a range of emotional responses from mild discomfort to significant psychological distress. However, despite these potential difficulties, participants in sensitive research studies often report cathartic effects from undertaking an interview; they are often grateful for the opportunity to tell their story and may find increased self-awareness, empowerment, emotional relief and a sense of healing. All interviews will be conducted at a time and location that's comfortable for you so as to ensure a feeling of safety and respect. You may answer as many questions as you feel able to, may refuse to answer questions and may take a break or stop the interview at any time. The same principles apply to the questionnaires.

An information sheet will be provided to ensure signposting to counselling professionals and reputable organisations that support bereaved parents are available, should you feel the need to avail of these services.

WILL TAKING PART BE CONFIDENTIAL?

The questionnaire replies are anonymous whether completed electronically or in paper format. All data will be stored and protected within the remit of the GDPR regulations and all Trinity College, Dublin ethics procedures will be adhered to. All data will be stored in password protected files or locked filing cabinets. Non-anonymised data in the form of signed consent forms and audio recordings are collected and retained as part of the research process but will be protected and anonymised as far as is possible. Access to any data is restricted to the researcher and the supervisor; any publications or summaries will be completely anonymised.

HOW WILL INFORMATION YOU PROVIDE BE RECORDED, STORED AND PROTECTED?

The interview will be audio recorded, transcribed by the researcher and stored in password protected files within a password protected computer or in locked filing cabinets within secure Trinity College Dublin premises. All data will be anonymised and identifiable by numeric code only. Access to the signed consent forms and original audio recordings will only be available to the researcher and the supervisor and both sets of data will be kept separately. The questionnaires and interview transcripts will be

retained securely until the thesis has been published and then will be destroyed by shredding within one year of commencement.

WHAT WILL HAPPEN TO THE RESULTS OF THE STUDY?

All anonymised data provided both from the questionnaires and the interviews will be summarised and detailed in the final PhD thesis. There is a possibility that this anonymised information will be published in journal articles and/or presented at conferences to provide information to professionals and academics.

CONTACT DETAILS

RESEARCHER:	Caroline Lloyd	lloydca@tcd.ie
SUPERVISOR:	Professor Conor Mc Guckin	mcguckic@tcd.ie

Appendix 10 – The Adult Self-Perception of Retrospective Perinatal Death in Adolescence (AAA) Questionnaire

Question	Responses	
1.1 SEX OF RESPONDENT	MALE 1 FEMALE 2 NONBINARY 3	
1.2 How would you describe your ethnicity?	White Black Asian Other (please specify)	
1.3 How old were you at your last birthday?	Years old ☐☐	
1.4 What is the highest level of schooling you completed? (CIRCLE HIGHEST SCHOOL LEVEL)	Primary 01 Secondary 02 **Tertiary without Secondary School:** Technical 03 Commercial or Secretarial 04 Preparatory 05 **Tertiary with secondary School:** Technical 06 Commercial or Secretarial 07 Teacher Training College (TTC) 08 University 09 Postgraduate 10	
1.5 Are you currently attending regular school, college or university? Full-time or part-time?	Yes, full-time 1 Yes, part-time 1 No 2	
1.6 How many more years of education do you expect to receive?	☐☐	
1.7 How old were you when you left school, college or university?	☐☐	
1.8 Was your school run by a particular religion or religious group?	Yes 1 No 2	
1.9 Is the school or university that you attend(ed) for…	Boys and girls? 1 Only boys/only girls? 2	
1.10 Now I have some questions about work. Have you ever worked for pay?	Yes 1 No 2	

1.11 How old were you when you started working for pay?	Age in years ☐☐	
1.12 Are you currently working for pay?	Yes 1 No 2	
1.13 About how many hours a week do you work?	Hours ☐☐	
1.14 What type of work do (did) you do?	………………………………………………………………………… …………………………………	
1.15 What is your religion?	None 01 Catholic 02 Protestant 03 Muslim 04 Hindu 05 Jew 06 Other…………………………………….. …………………………………………… 07 (SPECIFY)	
1.16 How important is religion in your life?	Very important 1 Important 2 Not important 3	
1.17 Have you ever discussed sex-related matters with either your mother or father? If YES Often or occasionally?	Often 1 Occasionally 2 Never 3	

Section 2: Sources of information on, and knowledge of reproductive health

		(1) Most Important	(2) Second most important	(3) Preferred
2.1 I want to ask you about sources of information on the **sexual and reproductive systems of men and women** - I mean where eggs and sperm are made and how pregnancy occurs. What has been the most important source of information on this topic? And the second most important? CIRCLE IN COLS. 1 AND 2. 2.2 From whom or where, would you prefer to receive (or prefer to have received) more information on this topic?	School teacher Mother Father Brother Sister Other family members Friends Doctors Books/magazines Films/Videos Other (Specify……………………………)	01 02 03 04 05 06 07 08 09 10 11 ………...……. ………..	01 02 03 04 05 06 07 08 09 10 11 ………...………… …..	01 02 03 04 05 06 07 08 09 10 11 ………...…… ………..

CIRCLE ONE ANSWER IN COL. 3				
2.3 Some schools have classes on puberty, on sexual and reproductive systems and on relationships between boys and girls. Did you ever attend school classes on any of these topics?	Yes No Not sure	1 2 3		
2.4 Do you think that there should be (more) classes on these topics, fewer classes or were the number about right?	More Less About right	1 2 3		
2.5 Did you consciously make a decision to get pregnant as a teenager?	Yes No			
2.6 Did your secondary school have a bereavement policy?	Yes No Unsure			
2.7 If you said yes to question 2.5, did the school follow the policy in supporting you after your gestnatal loss?	Yes No Unsure			
2.8 Is there anything your school or your teachers could have done better to support you after your gestnatal loss?	Please specify			
2.9 Did your experience of a gestnatal loss whilst in secondary school affect your attitude towards education?	No Unsure Yes (please specify)			
2.10 As an adult, do you think your gestnatal loss affected your education in any way?	Yes, in a positive way Yes, in a negative way No Unsure			

Section 3: Use and perceptions of health services and bereavement support

3.1 What happened to your pregnancy whilst you were in secondary school?	Abortion Miscarriage Stillbirth Neonatal (up to 28 days old) Other (please specify)	1 2 3 4 5	
3.2 How old were you when your gestnatal loss occurred?			
3.3 What was your relationship like with your parents when you got pregnant as a teenager?	Generally good Generally poor	1 2	

3.4 What was your relationship like with the father of your baby when you got pregnant as a teenager?	Generally good 1 Generally poor 2	
3.2 How many times did you seek services or information from a doctor or a nurse during the loss of your baby	Number of times ☐☐ Did not seek care 0	
3.3 Thinking about your last visit, did you go to a government clinic, health centre or hospital or a private doctor or clinic?	Government 1 Private 2 Other………………………………… 3	
3.4 At this facility Were you given any advice or support information?	YES NO 1 2	
3.5 What would you have liked information on: (a) Bereavement support? (b) Contraception? (c) Other (please specify)	YES NO 1 2 1 2 1 2	
3.6 Did you feel comfortable enough to ask questions?	1 2	
3.7 Were the questions you asked during the consultation answered adequately?	1 2	
3.8 Do you have any living children?	0 1 2 3+	
3.9 My gestnatal loss contributed to my decision to get pregnant again	Strongly Agree Agree Disagree Strongly Disagree	
3.10 I had mental health problems prior to getting pregnant as a teenager	Strongly Agree Agree Disagree Strongly Disagree	
3.11 Did you have any other bereavements prior to your gestnatal loss?	No Yes (please specify)	
3.12 If you said yes to question 3.11, did you receive the support you needed during your previous bereavement?	Yes No Unsure	
3.13 Online resources (websites, blogposts, social media, Watsapp etc.) helped me during and after my gestnatal loss	Strongly Agree Agree Disagree Strongly Disagree	
3.14 There is public stigma (e.g. negative emotions, stereotyping, negative	Strongly Agree Agree Disagree Strongly Disagree	

attitudes or social distance) towards teenagers who experience a gestnatal loss			
3.15 Do you feel that others understood what the loss meant to you?	School teachers Mother Father Brother Sister Other family members Friends Doctors Nurses	Yes	No
3.16 I felt confident after my gestnatal loss to tell people			
3.17 Did you, at any time, experience negative reactions to your gestnatal bereavement from others?	No Yes		
3.18 As an adult, how do you think your gestnatal loss as a teenager affected you?	1. It had a bad effect on me and it still affects me today 2. It was an event in my life that has had neither a negative nor substantial change in my life 3. It was a traumatic experience that has enabled me to change my life in a positive way		

Section 4: The Perinatal Grief Intensity Scale

	Within the first six months following the loss	Six months or more following the loss
4.1 The pregnancy did not seem real to me	Strongly Agree Agree Disagree Strongly Disagree	Strongly Agree Agree Disagree Strongly Disagree
4.2 I did not think of the baby as a person	Strongly Agree Agree Disagree Strongly Disagree	Strongly Agree Agree Disagree Strongly Disagree
4.3 I did not think of the baby as having a specific personality yet	Strongly Agree Agree Disagree Strongly Disagree	Strongly Agree Agree Disagree Strongly Disagree
4.4 I felt I had lost my son or daughter, not just my pregnancy	Strongly Agree Agree Disagree Strongly Disagree	Strongly Agree Agree Disagree Strongly Disagree
4.5 Both my pregnancy and baby seemed real to me	Strongly Agree Agree Disagree Strongly Disagree	Strongly Agree Agree Disagree Strongly Disagree
4.6 It seemed more like the loss of a pregnancy than the loss of a baby	Strongly Agree Agree Disagree Strongly Disagree	Strongly Agree Agree Disagree Strongly Disagree
4.7 In the first hours and days after my loss, if people said or did things that made me feel bad, I was able to ask them to stop	Strongly Agree Agree Disagree Strongly Disagree	Strongly Agree Agree Disagree Strongly Disagree
4.8 In the first hours and days after my loss, if something happened that I did not like, I was usually able to resolve the problem	Strongly Agree Agree Disagree Strongly Disagree	N/A

4.9	In later weeks after my loss, if people said or did things that made me feel bad, I was able to ask them to stop	Strongly Agree Agree Disagree Strongly Disagree	Strongly Agree Agree Disagree Strongly Disagree
4.10	In later weeks after my loss, if something happened that I did not like, I was usually able to resolve the problem	Strongly Agree Agree Disagree Strongly Disagree	Strongly Agree Agree Disagree Strongly Disagree
4.11	During and after my perinatal loss, I was satisfied with the way my loss experience was unfolded, given that I had to go through it	Strongly Agree Agree Disagree Strongly Disagree	Strongly Agree Agree Disagree Strongly Disagree
4.12	During and after my perinatal loss, I was satisfied with my interactions with my family	Strongly Agree Agree Disagree Strongly Disagree	Strongly Agree Agree Disagree Strongly Disagree
4.13	During and after my perinatal loss, I was satisfied with my interactions with my friends	Strongly Agree Agree Disagree Strongly Disagree	Strongly Agree Agree Disagree Strongly Disagree
4.14	During and after my perinatal loss, I was satisfied with my interactions with my nurses	Strongly Agree Agree Disagree Strongly Disagree	Strongly Agree Agree Disagree Strongly Disagree

Appendix 11 – Debriefing Script

Thank you for your participation in the research study. It is hoped that the results of this study will help us to better bridge the gap between gestnatal grief experiences, school experiences, adolescent grief, educational impact (if any) and how schools, policy makers, medical professionals, counsellors, parents and peers can better understand and support the issues affecting these young people.

I would just like to discuss with you in more detail the study you just participated in to explain more comprehensively what we are trying to better understand.

Studies sometimes require that research participants are not given full information about the research until after the study is completed. Although we cannot always tell you everything before you begin your participation, we do want to tell you everything when the study is completed.

We don't always tell people everything at the beginning of a study because we do not want to influence your responses. If we tell people what the purpose of the study is and what we predict their responses will be, then their reactions may be influenced by that information.

Following the quantitative results of the first phase of this study, the results suggest that educational outcome following a gestnatal loss in adolescence may be affected in a variety of ways depending on the individual, however most go on to study further education at a later age. We also found that some participants reported that as adults they were not affected emotionally by a gestnatal death in the long term but they may have been impacted in the short term, and vice versa. We also found that some form of loss response was present in all of the girls within the first six months of the event. Our results also show that a lack of support and information

provided to the girls was perceived and that schools and medical professionals could do more. Our aim with this research is to present these findings to contribute to understanding and the provision of better understanding and resources to teenage girls when these events happen.

If other people knew the true purpose of the study, it might affect how they behave/answer questions, so we are asking you not to share the information we just discussed.

If you have any questions at a later date, please feel free to contact me at lloydca@tcd.ie.

Thank you again for your participation.
Caroline Lloyd

Appendix 12 – Support Organisations Information Sheet

Support for Bereaved Parents

www.pregnancylossdirectory.com

This website signposts to support organisations across most of the United States, Canada, New Zealand, Australia and Portugal following a miscarriage, infertility, termination, stillbirth or infant death.

United Kingdom

Cruse Bereavement Care are a national charity supporting bereaved people across the United Kingdom. They have online resources, free professional grief counselling, free support groups and a helpline that will signpost to reputable specialised bereavement organisations e.g. SANDS (Stillbirth and Neonatal Death Charity). Colin Murray Parkes OBE is the Life President and is highly regarded as a grief expert worldwide.

Contact: www.cruse.org.uk

Telephone: 0808 808 1677

Email: areasupport@cruse.org.uk

Ireland

A Little Lifetime

A Little Lifetime Foundation is the voice for bereaved parents and their families across Ireland, our aim is to promote healthy grieving and bring

understanding and hope when a baby dies at any stage of pregnancy, during or after birth.

Contact: www.alittlelifetime.ie

Telephone: 01 8829030

Email: info@alittlelifetime.ie

Anam Cara

Anam Cara Parent Bereavement understands we don't live in an ideal world, we live in a world after our precious children have died before their time. Bereaved parents have set up this organisation to help themselves and all bereaved parents cope with their grief and loss and journey on.

Contact: www.anamcara.ie

Telephone: 01 4045378

Email: info@anamcara.ie

Feileacain

Feileacain is a new not for profit organisation that aims to provide support to anyone affected by the death of a baby during pregnancy or shortly after. We ourselves are a group of bereaved parents who came together to offer hope and support to others who may need our help in the future.

Contact: www.feileacain.ie

Telephone: (085) 249 6464

Email: admin@feileacain.ie

The Miscarriage Association of Ireland

The Miscarriage Association of Ireland is a charitable body set up by, and with the support of women and men who themselves have been experienced the loss of a baby through miscarriage.

Contact: www.miscarriage.ie

Telephone: 087 9239217

Email: mailto:info@miscarriage.ie

Professional Counselling Services

United States

American Psychological Association

APA is the leading scientific and professional organization representing psychology in the United States, with more than 115,700 researchers, educators, clinicians, consultants and students as its members. There are online resources and a referral page to local psychologists in your area.

Contact: www.apa.org

United Kingdom

Cruse Bereavement Care are a national charity supporting bereaved people across the United Kingdom. They have online resources, free professional grief counselling, free support groups and a helpline that will signpost to reputable specialised bereavement organisations e.g. SANDS (Stillbirth and Neonatal Death Charity). Colin Murray Parkes OBE is the Life President and is highly regarded as a grief expert worldwide.

Contact: www.cruse.org.uk

Telephone: 0808 808 1677

Email: areasupport@cruse.org.uk

<u>Ireland</u>

ICP (Irish Council for Psychotherapy)

The Irish Council for Psychotherapy represents eleven organisations and over 1,500 psychotherapists and is the National Awarding Organisation (NAO) of the European Certificate of Psychotherapy

(ECP). Contact:

www.psychotherapycouncil.ie

Telephone: 01 9058698

Email: hello@psychotherapycouncil.ie

PSI (Psychological Society of Ireland)

The Psychological Society of Ireland (PSI) is the learned and professional body for psychology and psychologists in the Republic of Ireland. The PSI is committed to maintaining the high standards of practice in psychology that have been set by its members since the founding of the Society and also to exploring new and innovative ways of furthering psychology as a real and applied science.

Contact: www.psychologicalsociety.ie

Telephone: 01 4720105

IACP (Irish Association for Counselling and Psychotherapy)

Our Association was established in 1981, to identify, develop and maintain professional standards of excellence in counselling and psychotherapy. Our work promotes best practice and the development of the profession as well as safeguard the public. As a registered Charity (CHY 6615) representing over 4,200 members, we are the largest Counselling and Psychotherapy Association in Ireland.

Contact: www.iacp.ie

Telephone: 01 2303536

Email: iacp@iacp.ie

Appendix 13 – Ethical Approval Received from the School of Education

ET7259-A-Y-201819 (RESEARCH ETHICS)

Order by:

- All
- Marked
- Upcoming
- Submitted

ITEM

LAST ACTIVITY

MARK

Application Status
05-Mar-2019 19:40MARKED

Approved

8-2-2019 Ethics Submissions and Resubmissions
DUE: 08-FEB-2019
Assignment
05-Mar-2019 15:00MARKED

Approved

Appendix 14 – Social Media Processes and Safeguards Document

The researcher acknowledges the necessity for social media processes and safeguards to ensure that any potential ethical dilemmas are considered.

Introduction

Advertisements and posts on websites are commonly used to recruit research participants, with Facebook and email the most commonly used internet technologies. Blogs, forums, discussion boards and other social media sites are also used. (Hokke et al, 2018). The rise in internet utilisation can be attributed to efficiency; its ease of use, availability, common application and the ability to reach more people worldwide. With this research study, it is anticipated that finding participants may be particularly problematic due to the perception of the area of teenage pregnancy and gestational/neonatal death in Ireland perhaps still considered 'taboo' topics. The internet, particularly social media sites, may enable us to reach more adults who experienced a gestnatal bereavement whilst in secondary school more efficiently. The internet also provides a "safe distance" for potential participants to read about the study, ruminate and then decide if they would like to take part either remotely via online questionnaire, paper questionnaire which can be emailed or mailed, or by attending a semi-structured interview either remotely or in person. Twitter may also be an effective way to recruit participants through the use of hashtags.

Hokke et al, 2018 searched the academic literature and found the following ethical concerns regarding recruitment and participation in research via the internet. These are detailed, and proposed safeguards are suggested below:

- *Age verification*. This research study is designed to elicit information from adults regarding their experiences as adolescents. With the quantitative element; whilst age prompts have been inserted into the questionnaire, there will also be a pre-screening box that has to be ticked to confirm that the participant is over 18 prior to accessing the questionnaire. However, it is acknowledged that anyone with access to the internet can complete this and lie about their age. As the questionnaires will be anonymous, we cannot guarantee that someone under the age of 18 will not complete one, and we acknowledge that this is a risk. With the qualitative element; verifying age can be confirmed prior to the interview.
- *Participant vulnerability*. With the quantitative element; the priorities are to obtain informed consent, assure anonymity and provide signposting for those that may wish to avail of specialised support. The questionnaire can be rejected at any point, participants are not compelled to complete it, and they may do so at any time if they are feeling vulnerable or experience any other negative emotion. With the qualitative element; the same principles apply, obtaining informed consent and ensuring that participants understand the nature of the study and what they are consenting to. Ensuring the interview participants are dealt with sensitively and with respect throughout the whole process will be ensured. An information sheet detailing support organisations will be provided to all participants.

- *Participant privacy, confidentiality and anonymity.* As stated in Hokke et al, 2018 "…confidentiality may be breached by participants inadvertently revealing their association with a study by writing on a comment board, 'liking' a study page, or adding a link to a study site on their own profile." Safeguards will be implemented by informing interview participants orally and both interview and questionnaire participants in writing to be mindful of unintended sharing of their research involvement online. We can ensure that our social media, online and offline information and data remain anonymous at all times, however we acknowledge that there is a risk that someone may disclose their participant status. We will add a note to inform potential participants that they may disclose their participation inadvertently within our online promotion of the study and advise ways on how to avoid this.
- *Informed consent.* The consent form has been refined to incorporate the suggestions and answer the queries following the initial ethics committee review. The online draft consent questions also incorporate all the relevant suggestions. Participants engaging with the face to face or telephone interviews can be quizzed by the researcher to ensure full comprehension of what they are consenting to. However, with the online questionnaires this is not possible, so a phased consent approach will be used as per Sharkey et. al 2011. The consent form will be used prior to registration and participants will be required to agree online by electronic assent, as they would be signature in person, this will then lead them on through

registration. Consent will be required for participation through another ‘checkpoint’ and again at the end for the use of any quotes if the participant has added any dialogue.

- *Incentives.* No incentives will be offered.
- *Risks to researchers.* It is acknowledged that study will be advertised globally via the internet. The only personal information that will be given is the researcher’s TCD email address, this sits within the suggested protocol to safeguard the researcher as suggested by Hokke et al 2018.

References

Hokke, S., Hackworth, N. J., Quin, N., Bennetts, S. K., Win, H. Y., Nicholson, J. M., ... & Crawford, S. B. (2018). Ethical issues in using the internet to engage participants in family and child research: A scoping review. *PloS one*, *13*(9), e0204572.

Sharkey, S., Jones, R., Smithson, J., Hewis, E., Emmens, T., Ford, T., & Owens, C. (2011). Ethical practice in internet research involving vulnerable people: lessons from a self-harm discussion forum study (SharpTalk). *Journal of medical ethics*, medethics-2011.

Appendix 15 – General Data Protection Regulations Procedural Document

GDPR came into effect on 25 May 2018. The aim of the GDPR is to give people back control of their personal data by giving them:

- The right to be informed
- The right of access
- The right to rectification
- The right to erasure
- The right to restrict processing
- The right to data portability
- The right to object
- Rights in relation to automated decision making and profiling.

What is personal data?

The normal test is whether a living individual can be identified from the data. Even without an individual's name, data can still be considered personal data if it identifies an individual e.g. 'the tall man living at no 4 Rose Drive, who drives a blue Ford Focus'.

It includes information such as home address, ID number, contact details e.g. phone, social media, email etc.

What is the responsibility of the researchers in complying with GDPR?

In addition to our obligations under the rights above, the researcher has a duty to process personal data fairly and to keep it secure. This can only be achieved if the researcher takes responsibility for the personal data held.

1. **Fair Processing of Personal Data**

The personal data held will only be used to carry out the activity for which the personal data was given e.g. for the research thesis.

The personal data must not be used or processed for any other purpose unless the data subject has given explicit consent. Where consent is given verbally it must be documented.

2. Security of Personal Data

The researcher must ensure it is treated as confidential and kept secure at all times.

In circumstances where the personal data is stored on an electronic device it must be kept confidential and secure by ensuring the device is password protected.

In circumstances where the personal data is held as a paper record it must be kept confidential and secure by:

- ensuring the personal data is kept in a locked drawer, cabinet, security box etc. and that access is not available to other occupants of the property.
- ensure that data relating to participants is anonymised e.g. a client's name and address cannot be linked easily to details of their research participation.

Personal data will only be disclosed to another party if required to by law or in circumstances where there is a safeguarding concern.

3. Data retention periods

It is important that data (either in paper or electronic format) is kept for no longer than is necessary for fair processing. The retention periods are set out in the table below.

Information Where Retention period

Participant records and notes from interviews	In a secure password protected online document or in a secure, locked place	To be destroyed by shredding no longer than one year following graduation
Questionnaires	In a secure password protected document online, or in a secure, locked place	To be destroyed by shredding no longer than one year following graduation

4. Data Breaches

GDPR places an obligation on the researchers to report data breaches to the ICO within **72 hours**.

A personal data breach means a breach of security leading to the accidental or unlawful destruction, loss, alteration, unauthorised disclosure of, or

access to, personal data. This includes breaches that are the result of both accidental and deliberate causes. It also means that a breach is more than just about losing personal data.

Personal data breaches can include:

- access by an unauthorised third party;
- deliberate or accidental action (or inaction) by a controller or processor;
- sending personal data to an incorrect recipient;
- computing devices containing personal data being lost or stolen;
- loss of availability of personal data;
- attempts (failed or successful) to gain unauthorised access to information or IT system(s);
- unauthorised disclosure of sensitive / confidential data;
- alteration of personal data without permission.

How the researchers meet the rights of individuals under GDPR
The right to be informed

The right to be informed encompasses an obligation to provide individuals with information on how their personal data is used and how it is kept secure.

The right of access

Individuals will have the right to obtain:

- confirmation that their personal data is being processed;
- access to their personal data.

The right to rectification

Individuals are entitled to have personal data rectified if it is inaccurate or incomplete.

If personal data in question has been disclosed to third parties, we have a duty to inform them of the rectification where possible. We must also inform the individuals about the third parties to whom the data has been disclosed.

The right to erasure

The right to erasure is also known as ‘the right to be forgotten’. The broad principle

underpinning this right is to enable an individual to request the deletion or removal of personal data where there is no compelling reason for its continued processing.

If the personal data in question has been disclosed to third parties, we must inform them about the erasure of the personal data, unless it is impossible or involves disproportionate effort to do so.

The right to restrict processing

Under the Data Protection Act, individuals have a right to ‘block’ or suppress processing of personal data. The restriction of processing under the GDPR is similar.

When processing is restricted, you are permitted to store the personal data, but not further process it. You can retain just enough information about the individual to ensure that the restriction is respected in future.

The right to data portability

The right to data portability allows individuals to obtain and reuse their personal data for their own purposes across different services. It allows them to move, copy or transfer personal data easily from one IT environment to another in a safe and secure way, without hindrance to usability.

The right to object

Individuals have the right to object to: processing based on legitimate interests or the performance of a task in the public interest/exercise of official authority (including profiling); direct marketing (including profiling); and processing for purposes of scientific/historical research and statistics.

Rights related to automated decision making and profiling

The GDPR provides safeguards for individuals against the risk that a potentially damaging decision is taken without human intervention. These rights work in a similar way to existing rights under the DPA. Identify

whether any of your processing operations constitute automated decision making and consider whether you need to update your procedures to deal with the requirements of the GDPR.

The researchers will not process data for automated decision making.

Appendix 16 – Mapping of the Research Instruments to the MTB

MTB Context		**Survey Question Numbers**
Individual	**Biological**	
Nature: pre-deterministic	Sex	1.1
Genotype: complete heritable genetic identity	Ethnicity	1.2
Phenotype: a description of actual physical characteristics	Age now	1.3
	Age at time of death	1.31
	Physical characteristics/health	
Individual	**Behavioural**	
	Contraceptive use	1.24
	Gender	1.1
	Pupil behaviour	1.13
	Attitude to education at that time	1.28
	Perception of effect on education (reflective)	1.29
	Perception of overall affect (reflexive)	1.39

	Living children	1.35
	Religiosity	1.2
	Type of death	1.30
	Mental health state	1.36
	Identity: 'bereaved parent'	57
	PGIS (below)	
	External Mediators	
Microsystem	**Parents**	1.23
Activities, roles, relations in a defined setting where the individual interacts directly with others. These are face to face relationships within the home environment	**Friends**	3.14
	Siblings	
	Other significant bereavements in childhood	1.37
	Other family members	

	Teachers	1.27
	Work	1.15
	Techno-subsystem	1.38
PGIS	Pregnancy didn't seem real (1st 6 months)	2.1a
	Pregnancy didn't seem real (after 6 months)	2.1b
	I did not think of the baby as a person (1st 6 months)	2.2a
	I did not think of the baby as a person (after 6 months)	2.2.b
	I did not think of the baby having a personality (1st 6 months)	2.3a
	I did not think of the baby having a personality (after 6 months)	2.3b
	I felt I'd lost a son/daughter not just a pregnancy (1st 6 months)	2.4a
	I felt I'd lost a son/daughter not just a pregnancy (after 6 months)	2.4b
	Both my pregnancy and baby seemed real to me (1st 6 months)	2.5a

	Both my pregnancy and baby seemed real to me (after 6 months)	2.5b
	It seemed more like the loss of a pregnancy than a baby (1st 6 months)	2.6a
	It seemed more like the loss of a pregnancy than a baby (after 6 months)	2.6b
	Shortly after the loss I was able to ask people to stop if they did/said something that made me feel bad (1st 6 months)	2.7a
	Shortly after the loss I was able to ask people to stop if they did/said something that made me feel bad (after 6 months)	2.7b
	If something happened that I did not like, I was usually able to resolve the problem (1st 6 months)	2.8a
	If something happened that I did not like, I was usually able to resolve the problem (after 6 months)	2.8b
	In later weeks if people said/did things that made me feel bad I was able to ask them to stop (1st 6 months)	2.9a
	In later weeks if people said/did things that made me feel bad I was able to ask them to stop (after 6 months)	2.9b

	In later weeks after my loss, if something happened that I did not like I was able to resolve the problem (1st 6 months)	2.10a
	In later weeks after my loss, if something happened that I did not like I was able to resolve the problem (after 6 months)	2.10b
	During and after the loss, I was satisfied with the way my loss experience was unfolded, given that I had to go through it (1st 6 months)	2.11a
	During and after the loss, I was satisfied with the way my loss experience was unfolded, given that I had to go through it (1st 6 months)	2.11b
	During and after I was satisfied with my interactions with my family (1st 6 months)	2.12a
	During and after I was satisfied with my interactions with my family (after 6 months)	2.12b
	During and after I was satisfied with my interactions with my friends (1st 6 months)	2.13a
	During and after I was satisfied with my interactions with my friends (after 6 months)	2.13b
	During and after I was satisfied with my interactions with my nurses (1st 6 months)	2.14a

	During and after I was satisfied with my interactions with my nurses (after 6 months)	2.14b
Mesosystem		
Interconnections between two or more Microsystems; face to face relationships outside of the home in the locality	Medical services	1.32
	Medical service signposting	1.33
	Medical service signposting to what?	1.34
	Church group	
	School	1.27
	Work	
	Stigmatic death	
	Social support	
	Cultural environment	
	Religion	1.16
Macrosystem	Macro politics	
Include norms and values of cultures and subcultures	Socioeconomic status	

	Internet/smartphones helped?	1.38
	Stigmatic death	
	Media	
	Social welfare/support services	
	Sex education classes in school (curriculum)	1.21
	School bereavement policy	1.25
	Educational attainment	1.14
	Educational attainment	1.13
	Legal environment	
Chronosystem	Sociohistorical conditions	
Digisystem		

Appendix 17 – Phase one - Online AAA Qualtrics Survey

The Experience of Gestnatal Death in Adolescence

Start of Block: General Questions

1.1 **Study Information**

1.2 **This research is exploring the experiences of adults who became pregnant whilst attending secondary school and subsequently experienced the death of the embryo/foetus/baby. These losses can include miscarriage, stillbirth, neonatal death, abortion, therapeutic termination, or ectopic pregnancy.**
You are being invited to take part in this study. Before you decide, it is important for you to understand why the study is being done and what participation will involve.
This Participant Information sheet will tell you about the purpose, benefits and risks of this study. If you agree to take part, you will be asked to sign a Consent Form. If there is anything you are unclear about, we are happy to explain it to you. Please take as much time as you need to read this.
You should only consent to take part in this study when you feel that you understand what is being asked of you, and you have had enough time to make your decision. Thank you for reading this.
WHO I AM AND WHAT THIS STUDY IS ABOUT
My name is Caroline Lloyd and I am a Ph.D. researcher in the School of Education, Trinity College Dublin. I am undertaking this study because we would like to understand how girls in secondary school are affected when they get pregnant but the baby dies due to miscarriage, stillbirth, neonatal death or abortion/therapeutic termination.
The overall aim of the study is to:1. Better understand the impact of these types of losses to the adolescents.2. Better understand the school responses to these girls and their experience.3. Better understand if the girls' education and future prospects are affected in the longer term. **WHAT WILL TAKING PART INVOLVE?**
The study has two components and you may choose to participate in either component or both. The components comprise of:
1. Completion of this questionnaire electronically which should take no longer than 15 minutes to complete. Your responses will remain anonymous and your data will be stored in protected electronic files and locked filing cabinets.
2. An interview with the researcher that may last up to an hour, in a

location agreed by both parties. This interview would be recorded and transcribed, and all data will remain anonymous. Your data will be stored in protected electronic files and locked filing cabinets. If you are willing to be interviewed ether remotely or in person please email me separately at; lloydca@tcd.ie Further information will be provided on the study, and a list of support organisations will be included at the end of both the questionnaire and the interview.

WHY HAVE YOU BEEN INVITED TO TAKE PART?

Anyone who has experienced a teenage pregnancy and subsequent gestational (from conception to birth) or neonatal (up to 28 days post birth) death whilst attending secondary school is invited to take part in this study. These losses can include miscarriage, stillbirth, neonatal death, abortion, therapeutic termination or ectopic pregnancy. To minimise any potential risks to participants you should not have experienced a significant (someone very close to you) bereavement in the two years prior to participation.

DO YOU HAVE TO TAKE PART?

Participation in this study is voluntary and you may refuse to answer any question or exit out of the questionnaire at any time without any consequence whatsoever. Once your questionnaire has been submitted, due to it being anonymous, the researcher will not be able to identify your data so it will not be possible to request to withdraw it after that time.

WHAT ARE THE POSSIBLE RISKS AND BENEFITS OF TAKING PART?

Talking about personal experiences may be difficult for some people and may lead to a range of emotional responses from mild discomfort to significant psychological distress. However, despite these potential difficulties, participants in sensitive research studies often report cathartic effects; they are often grateful for the opportunity to tell their story and may find increased self-awareness, empowerment, emotional relief and a sense of healing. If you choose to be interviewed, all interviews will be conducted at a time and location that is comfortable for you so as to ensure that you feel safe. You may answer as many questions in this questionnaire or during an interview as you feel able to, you may refuse to answer questions and may take a break or stop the questionnaire or interview at any time.

An information sheet will be provided at the end of the questionnaire to ensure signposting to counselling professionals and reputable organisations that support bereaved parents should you feel the need to avail of these services.

WILL TAKING PART BE CONFIDENTIAL?

The questionnaire replies are completely anonymous. All data will be stored and protected within the remit of the GDPR regulations and all Trinity College, Dublin ethics procedures will be adhered to. All data will be stored in password protected files or locked filing cabinets. Non-anonymised data in the form of signed consent forms and audio recordings will be collected and retained as part of the research process but will be protected and anonymised. Access to any data is restricted to the researcher and the researcher's supervisor; any publications or summaries will be completely anonymised.

HOW WILL INFORMATION YOU PROVIDE BE RECORDED,

STORED AND PROTECTED?
All interviews will be audio recorded, transcribed by the researcher and stored in password protected files within a password protected computer or in locked filing cabinets within secure Trinity College Dublin premises. All data will be anonymised and identifiable by numeric code only. Access to the signed consent forms and original audio recordings will only be available to the researcher and the researcher's supervisor and both sets of data will be kept separately. The questionnaires and interview transcripts will be retained securely until the thesis has been published and then will be destroyed by shredding within one year of commencement.

WHAT WILL HAPPEN TO THE RESULTS OF THE STUDY?
All anonymised data provided both from the questionnaires and the interviews will be summarised and detailed in the final PhD thesis. There is a possibility that this anonymised information will be published in academic, professional, or other publications to provide information to professionals and academics, to help raise awareness and knowledge on how best to support adolescents experiencing these types of deaths.

CONTACT DETAILS RESEARCHER: Caroline Lloyd lloydca@tcd.ie
SUPERVISOR: Professor Conor Mc Guckin conor.mcguckin@tcd.ie

○ I HAVE READ AND UNDERSTAND THIS STUDY INFORMATION SHEET (1)

1.2 CONSENT FORM FOR ONLINE QUESTIONNAIRE

The researcher requests your consent for participation in a study about the experiences of teenagers (from aged 12 to 19) who lose a baby whilst in school. This consent form asks you to allow the researcher to store and view the questionnaire answers and to use any comments that you make to enhance understanding of the topic.

Participation in this study is completely voluntary. If you decide not to participate there will not be any negative consequences. Please be aware

that if you decide to participate, you may stop participating at any time and you may decide not to answer any specific question.

The researcher will maintain the anonymity of the research records or data, and all data will be destroyed in accordance with the regulatory requirements of Trinity College, Dublin.

By submitting this form you are indicating that you have read the description of the study, are over the age of 18, and that you agree to the terms as described. The researcher also requests participation in interviews, whether you complete this questionnaire or not. If you would like to receive information on the interviews and what that might entail please email Caroline Lloyd at Lloydca@tcd.ie and full details will be provided. Please note that this questionnaire is anonymous and any email enquirers will not assume that you have participated in this online study.

If you have any questions on the study, the questionnaire, or would like a copy of this consent letter, please contact me at Lloydca@tcd.ie
If during your participation in this study you feel that the information and guidelines that you were given have been neglected or disregarded in any way, or if you are unhappy about the process, please contact Professor Conor Mc Guckin, School of Education, Trinity College, Dublin at +353 1896 2175 or conor.mcguckin@tcd.ie Please be assured that your concerns will be dealt with in a sensitive manner.

Thank you in advance for your participation.

Caroline Lloyd

○ I HAVE READ AND UNDERSTAND THE CONSENT FORM FOR ONLINE QUESTIONNAIRE (1)

1.3 I understand the purpose and nature of this study and I am participating voluntarily

○ I AGREE (1)

1.4 I understand that I can withdraw from the study at any time before the answers are submitted at the end, without any penalty or consequences

○ I AGREE (1)

1.5 I grant permission for the data generated from this interview to be used in the researcher's publications on this topic

○ I AGREE (1)

1.6 I grant permission for the questionnaire to be securely stored for purpose of review by the researcher and researcher’s supervisor.

○ I AGREE (1)

1.7 I am aware my data will be kept anonymous, within the regulations of the GDPR, and will be securely shredded at a future date

○ I AGREE (1)

1.8 I am fully aware that there is a risk that responding to this questionnaire may lead to a range of emotional responses. I confirm that I am aware that signposting to suitable reputable support organisations will be provided at the end of the questionnaire

○ I AGREE (1)

1.9 I understand that once the questionnaire has been submitted I cannot request that it be withdrawn. The reason for this is that the data is anonymous and the researcher will not know which questionnaire is yours

○ I AGREE (1)

1.10 Sex of Respondent

○ FEMALE (1)

○ MALE (2)

○ NON BINARY (3)

1.11 How would you describe your ethnicity?

○ WHITE (1)

○ BLACK (2)

○ ASIAN (3)

○ OTHER (Please Specify (4) ____

1.12 How old were you at your last birthday?

○ CURRENT AGE (1) ____

1.13 What is the highest level of schooling you have completed?

- ◯ PRIMARY (1)
- ◯ SECONDARY (2)
- ◯ COLLEGE (3)
- ◯ UNIVERSITY (4)
- ◯ POSTGRADUATE (5)

1.14 Are you currently attending school, college or university?

- ◯ YES FULL TIME (Please state whether school, college or university) (1) ____________________
- ◯ YES PART TIME (Please state whether school, college or university) (2) ____________________
- ◯ NO (3)

1.15 If you are not currently studying; how old were you when you left school, college or university?

- ◯ Age when you left education (1) ____________________

1.16 Was your school associated with a particular religion or religious group?

- ◯ YES (Please state religion/religious group) (1) ____________________
- ◯ NO (2)

1.17 Have you ever worked for pay?

- ○ YES (1)
- ○ NO (2)

1.18 How old were you when you started working for pay?

- ○ Age started working for pay (1) ____

1.19 Are you currently working for pay?

- ○ YES - FULL TIME (1)
- ○ YES - PART TIME (2)
- ○ NO (3)

1.20 Do you associate with a religion or religious/spiritual group?

- ○ YES (Please specify) (1) ____
- ○ NO (2)

1.21 Did you receive classes on puberty, sexual or reproductive health, and/or relationships in school?

- ○ YES - I ATTENDED ONE OR MORE (1)
- ○ YES - BUT I DID NOT ATTEND (Please give reason for non attendance) (2) ____
- ○ NO (3)

1.22 Where did you receive your most important source of sex education from?

- ◯ SCHOOL (1)
- ◯ MOTHER (2)
- ◯ FATHER (3)
- ◯ BROTHER (4)
- ◯ SISTER (5)
- ◯ OTHER FAMILY MEMBER (6)
- ◯ FRIENDS (7)
- ◯ MEDICAL PROFESSIONAL (8)
- ◯ BOOKS/MAGAZINES (9)
- ◯ ONLINE; EITHER ON THE INTERNET OR A SMARTPHONE (10)
- ◯ OTHER (Please specify) (11)

1.23 Whilst in secondary school, did you ever discuss sex-related matters with either your mother or father?

- ◯ OFTEN (1)
- ◯ OCCASIONALLY (2)
- ◯ NEVER (3)

1.24 Were you using any form of contraception when you got pregnant as a teenager?

◯ YES (1)

◯ NO (Please state why not) (2) ____

1.25 Did your secondary school have a bereavement policy?

◯ YES (1)

◯ UNSURE (2)

◯ NO (3)

Display This Question:

If Did your secondary school have a bereavement policy? = YES

1.26 If your secondary school had a bereavement policy (that you knew of), did they follow the policy after your gestnatal loss?

◯ YES (1)

◯ SOMEWHAT (2)

◯ NO (3)

1.27 Is there anything that your school or teachers could have done better to support you after your gestnatal loss?

◯ NO (1)

◯ YES (Please provide details) (2) ____

1.28 Did your experience of gestnatal loss whilst in secondary school affect your attitude towards education at that time?

- ◯ YES (Please provide details) (1) ____
- ◯ NO (2)

1.29 As an adult, do you think your gestnatal loss affected your education in any way?

- ◯ YES - IN A POSITIVE WAY (1)
- ◯ YES - IN A NEGATIVE WAY (2)
- ◯ NO (3)

1.30 What happened to your pregnancy/baby whilst you were in secondary school?

- ◯ ABORTION (1)
- ◯ MISCARRIAGE (2)
- ◯ STILLBIRTH (3)
- ◯ NEONATAL DEATH (from birth to 28 days old) (4)
- ◯ OTHER (Please specify) (5) ____

1.31 How old were you when you experienced your gestnatal loss in secondary school?

- 12 (1)
- 13 (2)
- 14 (3)
- 15 (4)
- 16 (5)
- 17 (6)
- 18 (7)
- 19 (8)

1.32 Did you seek medical services during or following your gestnatal loss?

- YES (1)
- NO (2)

Display This Question:

If Did you seek medical services during or following your gestnatal loss? = YES

1.33 If you sought medical services during or following your gestnatal loss, were you given any advice, support information or signposting to helpful organisations?

- YES (1)
- NO (2)

1.34 Following your gestnatal loss, what would you have liked information on?

- [ ] BEREAVEMENT INFORMATION/SUPPORT (1)
- [ ] CONTRACEPTION (2)
- [ ] OTHER (Please specify) (3) ________________

1.35 Do you have any living children?

- ○ 0 (1)
- ○ 1 (2)
- ○ 2 (3)
- ○ 3+ (4)

1.36 I had mental health problems prior to getting pregnant as a teenager in secondary school

- ○ Strongly agree (1)
- ○ Somewhat agree (2)
- ○ Neither agree nor disagree (3)
- ○ Somewhat disagree (4)
- ○ Strongly disagree (5)

1.37 Did you have any other significant bereavements as a child or teenager prior to your gestnatal loss?

○ NO (1)

○ YES (please give details of relationship and your age at time of death) (2) ________________

1.38 Online/smartphone resources (websites, blog posts, social media, WhatsApp etc.) helped me during and/or after my gestnatal loss

○ Strongly agree (1)

○ Somewhat agree (2)

○ Neither agree nor disagree (3)

○ Somewhat disagree (4)

○ Strongly disagree (5)

1.39 As an adult looking back, how do you think your gestnatal loss as a teenager in secondary school affected you?

○ It had a bad effect on me and it still affects me today (1)

○ It was an event in my life that has had neither a bad or good effect in my life overall (2)

○ It was a traumatic experience that has enabled me to change my life in a significantly positive way; I wouldn't be the person I am today if it hadn't happened (3)

End of Block: General Questions

Start of Block: Perinatal Grief Intensity Scale

2.1 The pregnancy did not seem real to me

	Strongly agree (1)	Somewhat agree (2)	Neither agree nor disagree (3)	Somewhat disagree (4)	Strongly disagree (5)
Within the first six months following the loss (1)	○	○	○	○	○
Six months or more following the loss (2)	○	○	○	○	○

2.2 I did not think of the baby as a person

	Strongly agree (1)	Somewhat agree (2)	Neither agree nor disagree (3)	Somewhat disagree (4)	Strongly disagree (5)
⊗Within the first six months following the loss (1)	○	○	○	○	○
⊗Six months or more following the loss (2)	○	○	○	○	○

2.3 I did not think of the baby as having a specific personality yet

	Strongly agree (1)	Somewhat agree (2)	Neither agree nor disagree (3)	Somewhat disagree (4)	Strongly disagree (5)
⊗Within the first six months following the loss (1)	○	○	○	○	○
⊗Six months or more following the loss (2)	○	○	○	○	○

2.4 I felt I had lost my son or daughter, not just my pregnancy

	Strongly agree (1)	Somewhat agree (2)	Neither agree nor disagree (3)	Somewhat disagree (4)	Strongly disagree (5)
⊗Within the first six months following the loss (1)	○	○	○	○	○
⊗Six months or more following the loss (2)	○	○	○	○	○

2.5 Both my pregnancy and baby seemed real to me

	Strongly agree (1)	Somewhat agree (2)	Neither agree nor disagree (3)	Somewhat disagree (4)	Strongly disagree (5)
⊗Within the first six months following the loss (1)	○	○	○	○	○
⊗Six months or more following the loss (2)	○	○	○	○	○

2.6 It seemed more like the loss of a pregnancy than the loss of a baby

	Strongly agree (1)	Somewhat agree (2)	Neither agree nor disagree (3)	Somewhat disagree (4)	Strongly disagree (5)
⊗Within the first six months following the loss (1)	○	○	○	○	○
⊗Six months or more following the loss (2)	○	○	○	○	○

2.7 In the first hours and days after my loss, if people said or did things that made me feel bad, I was able to ask them to stop

	Strongly agree (1)	Somewhat agree (2)	Neither agree nor disagree (3)	Somewhat disagree (4)	Strongly disagree (5)
⊗Within the first six months following the loss (1)	○	○	○	○	○
⊗Six months or more following the loss (2)	○	○	○	○	○

2.8 In the first hours and days after my loss, if something happened that I did not like, I was usually able to resolve the problem

	Strongly agree (1)	Somewhat agree (2)	Neither agree nor disagree (3)	Somewhat disagree (4)	Strongly disagree (5)
⊗Within the first six months following the loss (1)	○	○	○	○	○
⊗Six months or more following the loss (2)	○	○	○	○	○

2.9 In later weeks after my loss, if people said or did things that made me feel bad, I was able to ask them to stop

	Strongly agree (1)	Somewhat agree (2)	Neither agree nor disagree (3)	Somewhat disagree (4)	Strongly disagree (5)
⊗Within the first six months (1)	○	○	○	○	○
⊗Six months or more following the loss (2)	○	○	○	○	○

2.10 In later weeks after my loss, if something happened that I did not like, I was usually able to resolve the problem

	Strongly agree (1)	Somewhat agree (2)	Neither agree nor disagree (3)	Somewhat disagree (4)	Strongly disagree (5)
⊗Within the first six months (1)	○	○	○	○	○
⊗Six months or more following the loss (2)	○	○	○	○	○

2.11 During and after my gestnatal loss, I was satisfied with the way my loss experience was unfolded, given that I had to go through it

	Strongly agree (1)	Somewhat agree (2)	Neither agree nor disagree (3)	Somewhat disagree (4)	Strongly disagree (5)
⊗Within the first six months (1)	○	○	○	○	○
⊗Six months or more following the loss (2)	○	○	○	○	○

2.12 During and after my gestnatal loss, I was satisfied with my interactions with my family

	Strongly agree (1)	Somewhat agree (2)	Neither agree nor disagree (3)	Somewhat disagree (4)	Strongly disagree (5)
⊗Within the first six months (1)	○	○	○	○	○
⊗Six months or more following the loss (2)	○	○	○	○	○

2.13 During and after my gestnatal loss, I was satisfied with my interactions with my friends

	Strongly agree (1)	Somewhat agree (2)	Neither agree nor disagree (3)	Somewhat disagree (4)	Strongly disagree (5)
⊗Within the first six months (1)	○	○	○	○	○
⊗Six months or more following the loss (2)	○	○	○	○	○

2.14 During and after my gestnatal loss, I was satisfied with my interactions with my nurses

	Strongly agree (1)	Somewhat agree (2)	Neither agree nor disagree (3)	Somewhat disagree (4)	Strongly disagree (5)
⊗Within the first six months (1)	○	○	○	○	○
⊗Six months or more following the loss (2)	○	○	○	○	○

Page Break

Q57 Following my loss whilst in secondary school, I would describe myself as a 'bereaved parent'

- Strongly agree (1)
- Somewhat agree (2)
- Neither agree nor disagree (3)
- Somewhat disagree (4)
- Strongly disagree (5)

2.15 If you have any further comments please write them here

- Yes I'd like to add a comment (1) ________________

2.16 Thank you for your participation in the research study. It is hoped that the results of this study will help us to better bridge the gap between gestnatal grief experiences, school experiences, adolescent grief, educational impact (if any) and how schools, policy makers, medical professionals, counsellors, parents and peers can better understand and support the issues affecting these young people.
A list of support organisations that support bereaved parents and professional therapeutic organisations will follow on the next page should you feel the need to avail of these services.
If you have any questions please feel free to contact me at lloydca@tcd.ie Now that the study has been explained more fully, by submitting this questionnaire you are giving permission for the researcher to use the data collected from your participation.
Thank you again.

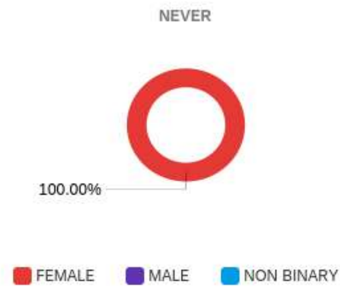
End of Block: Perinatal Grief Intensity Scale

Appendix 18 – Phase one – AAA Questionnaire Responses

The Experience of Gestnatal Death in Adolescence

April 25th 2022, 3:24 pm BST

1.10 - Sex of Respondent

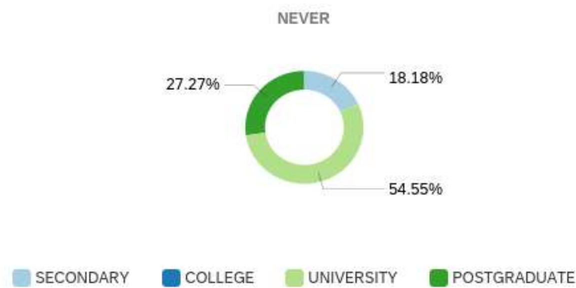


1.11 –

1.10 - How would you describe your ethnicity?

#	Question	Total
1	WHITE	22
2	BLACK	1
3	ASIAN	0
4	OTHER (Please Specify	0

1.13 - What is the highest level of schooling you have completed?



1.14 - Are you currently attending school, college or university?

#	Question	Total
1	YES FULL TIME (Please state whether school, college or university)	3
2	YES PART TIME (Please state whether school, college or university)	4
3	NO	16

1.15 - If you are not currently studying; how old were you when you left school, college or university?

Age when you left education - Text
23
27
25
25
21
23
21
39
Left school at 17, attended uni as a mature student age 42

Age when you left education - Text
25
16
18
45
21
30 after PG 21 after undergraduate
24

1.16 - Was your school associated with a particular religion or religious group?

#	Question	Total
1	YES (Please state religion/religious group)	6
2	NO	16

YES (Please state religion/religious group) - Text
Catholic
Catholic
Christian

YES (Please state religion/religious group) - Text
Catholic
Roman Catholic
Catholic

1.17 - Have you ever worked for pay?

#	Question	Total
1	YES	23
2	NO	0

1.18 - How old were you when you started working for pay?

Q11_1_TEXT - Age started working for pay - OFTEN

Age started working for pay - Text
18
16
14
16
24
18
16
13
16
16
11
17

Age started working for pay - Text
16
17
15
17
17
21
16
15
15
17

1.19 - Are you currently working for pay?

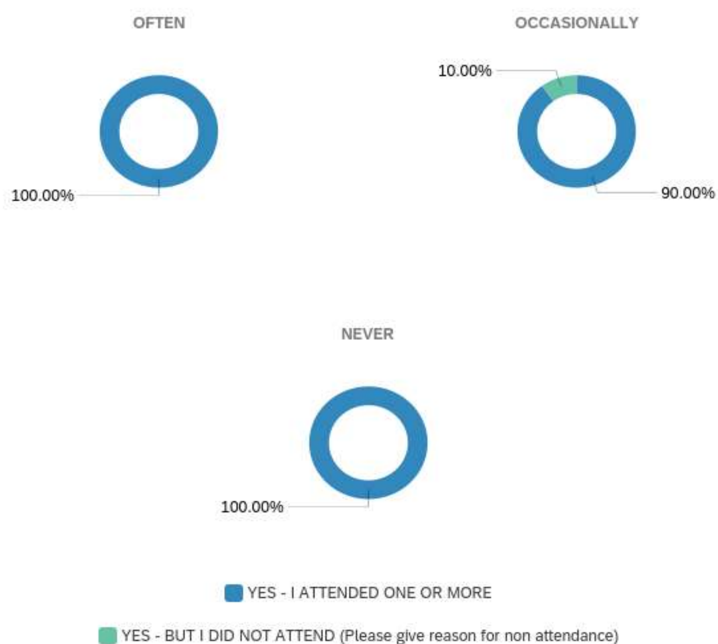
#	Question	Total
1	YES - FULL TIME	19
2	YES - PART TIME	2
3	NO	2

1.20 - Do you associate with a religion or religious/spiritual group?

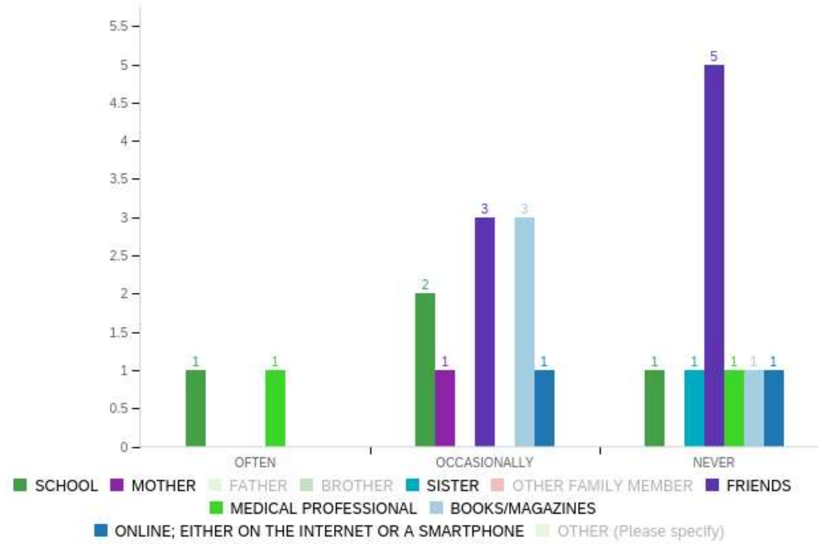
#	Question	Total
1	YES (Please specify)	6
2	NO	17

YES (Please specify) - Text
Goddess-centred Paganism
Christian
Roman catholic
Jesus follower
Asatru

1.21 - Did you receive classes on puberty, sexual or reproductive health, and/or relationships in school?

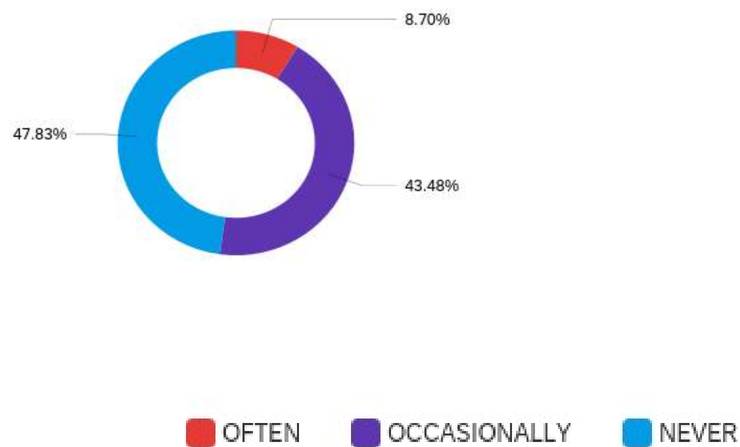


1.22 - Where did you receive your most important source of sex education from?

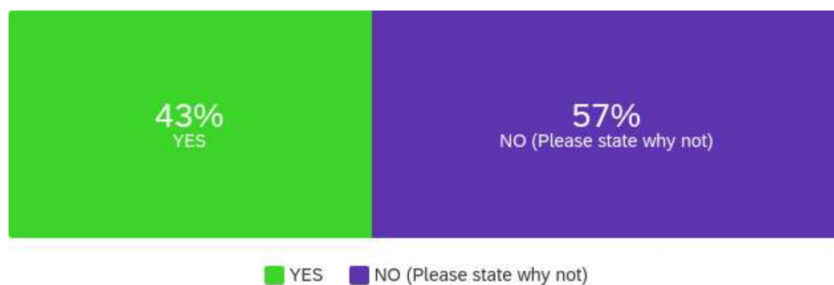


#	Question	Total
1	SCHOOL	4
2	MOTHER	1
3	FATHER	0
4	BROTHER	0
5	SISTER	1
6	OTHER FAMILY MEMBER	0
7	FRIENDS	8
8	MEDICAL PROFESSIONAL	2
9	BOOKS/MAGAZINES	4
10	ONLINE; EITHER ON THE INTERNET OR A SMARTPHONE	2
11	OTHER (Please specify)	1

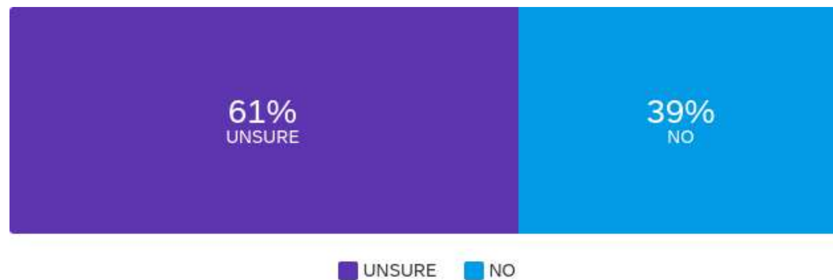
1.23 - Whilst in secondary school, did you ever discuss sex-related matters with either your mother or father?



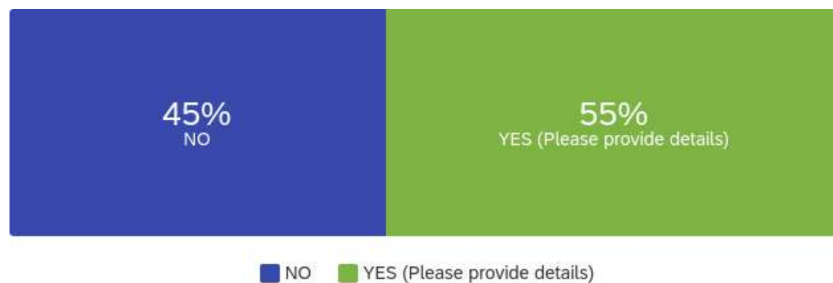
1.24 - Were you using any form of contraception when you got pregnant as a teenager?



1.25 - Did your secondary school have a bereavement policy?



1.27 - Is there anything that your school or teachers could have done better to support you after your gestnatal loss?



YES (Please provide details) - Text
Was never refereed to councillors and was made attend classes like normal so a bit of leeway and help would be needed

YES (Please provide details) - Text
Support, counselling, drop in sessions
I didn't inform the school.
I didn't actually tell any adults but I was also never educated about terminations. Further, because it was never talked about at school, no one was ever highlighted as the support person to go to, should you need support. I feared being shamed for being irresponsible. Education on the topic, as well as on relationships and what our rights are would have helped me to know that I

should have asked for support and that I would have been treated with respect and sensitivity.

Hard to answer - I had a termination over 35 years ago so I may not be the candidate you're looking for. There was no help in school for anyone who got pregnant- you left school and that was that.

Been more neutral and explained my options better

YES (Please provide details) - Text

They did nothing

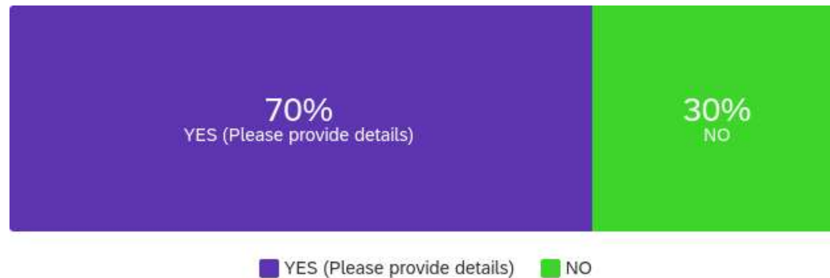
Probably, but I kept this very private, I did not tell my parents or anyone

I was bullied due to pregnancy/ termination and guidance teacher informed me was all my own fault and I brought the bullying on myself. I needed support and when I reached out for it, it started a downward spiral of depression.

I chose not to tell any adults of my termination. This was because it had only ever been talked about in a negative light. I don't ever remember school talking about termination whilst empowering young women/ teens. I chose not to talk to any adults as I was afraid of the judgement that would be passed. It felt easier to pretend to be okay

Acknowledged it

1.28 - Did your experience of gestnatal loss whilst in secondary school affect your attitude towards education at that time?



YES (Please provide details) - Text
Stop caring about my exams and became detached
Lost interest

YES (Please provide details) - Text
Yes - I felt very isolated and it affected me very badly. Hated school and there was no one to discuss it with or help me.
Initially, I felt as though I had to get really good grades. I think this was because I was being really hard on myself and was struggling with processing a death I didn't really (and perhaps still don't) fully understand. I felt as though I needed to get perfect grades!
Didn’t want to attend. Felt I had gone through something that changed me and was no longer an adolescent
Others convinced me that having a child would be damaging to my education so it made me more aware of long term consequences of my actions
I got into Uni through Clearing whereas I hadn’t planned to go
I closed down mentally
I dropped out

YES (Please provide details) - Text
interestingly, it made me feel as though I HAD to achieve. I experienced many negative feelings about myself and therefore felt I had to achieve academically in order to feel accepted
Everything felt pointless
I had always been a bright student but I rebelled and took less interest in school
Did not care about school

1.29 - As an adult, do you think your gestnatal loss affected your education in any way?

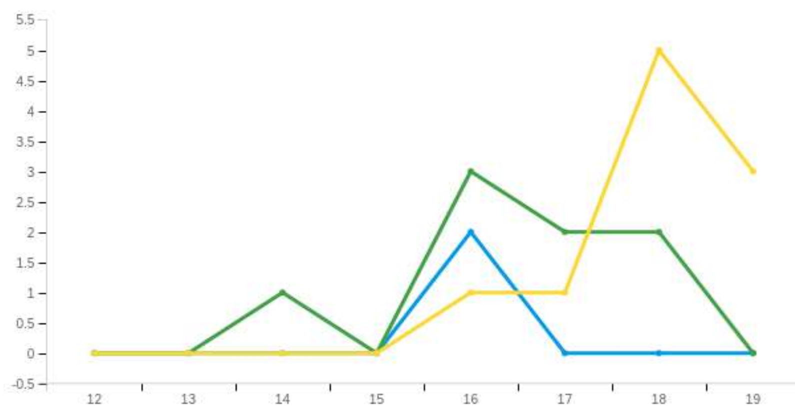
#	Question	Total
1	YES - IN A POSITIVE WAY	4
2	YES - IN A NEGATIVE WAY	11
3	NO	4

1.30 - What happened to your pregnancy/baby whilst you were in secondary school?

#	Question	Total
1	ABORTION	11
2	MISCARRIAGE	8
3	STILLBIRTH	0
4	NEONATAL DEATH (from birth to 28 days old)	0
5	OTHER (Please specify)	1

OTHER (Please specify) - Text
Forced abortion

1.31 - How old were you when you experienced your gestnatal loss in secondary school?



#	Question	Total
1	12	0
2	13	0
3	14	1
4	15	0
5	16	6
6	17	3
7	18	7
8	19	3

1.32 - Did you seek medical services during or following your gestnatal loss?

#	Question	Total
1	YES	16
2	NO	4

1.33 - If you sought medical services during or following your gestnatal loss, were you given any advice, support information or signposting to helpful organisations?

#	Question	Total
1	YES	6
2	NO	10

1.34 - Following your gestnatal loss, what would you have liked information on?

#	Question	Total
1	BEREAVEMENT INFORMATION/SUPPORT	14
2	CONTRACEPTION	3
3	OTHER (Please specify)	7

OTHER (Please specify) - Text
In response to the question regarding being signposted, I was asked on one occasion 'would you like access to our free therapy service' but I was too embarrassed and proud to feel as though I needed support. I also didn't understand the impact of the situation and how it might affect me. I feel that a meeting with a nurturing person who talked to me about the situation and helped me to identify it as a bereavement would have been really useful. I definitely didn't identify the abortion being a bereavement at the time. Later therapy, roughly 5 years after helped me to work through this.
The potential impact of the medical procedure
Practical advice or signposting on housing and benefits etc

OTHER (Please specify) - Text
I remember being called be someone who said ‘would you like to access our free counselling service to support you with this?’ I was embarrassed and very quickly refused support. I didn’t place any value on the importance of my experience. In retrospect, someone offering support with ‘how to talk to my family,’ or ‘how to respond to a controlling partner,’ would have benefitted me hugely. In response to whether this affected my education, initially it had a negative response. I was lucky enough to embark on a journey to become a therapist which involved a lot of self exploration. I then used my experiences to benefit my studies (post grad) in a positive way. I do however feel that my a-levels and degree were negatively impacted upon.
therapy

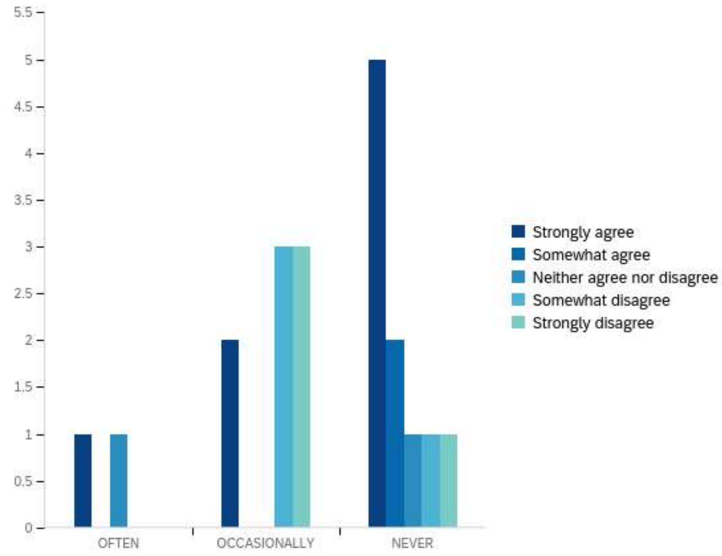
My surgery declined my enquiries for a termination, I was told it was because the surgery was Catholic. I had to go to another gp surgery to be referred for a termination. I just would have liked more support.

Decades later, I attended a Deeper Still retreat, very healing on many levels. I don't know if I would've been receptive to such help at the time .

1.35 - Do you have any living children?

#	Question	Total
1	0	6
2	1	5
3	2	8
4	3+	1

1.36 - I had mental health problems prior to getting pregnant as a teenager in secondary school



#	Question	Total
1	Strongly agree	8
2	Somewhat agree	2
3	Neither agree nor disagree	2
4	Somewhat disagree	4
5	Strongly disagree	4

1.37 - Did you have any other significant bereavements as a child or teenager prior to your gestnatal loss?

#	Question	Total
1	NO	14
2	YES (please give details of relationship and your age at time of death)	6

YES (please give details of relationship and your age at time of death) - Text
Best friend at 13
A grandparent passed away and also pets, however, these were bereavements that felt more natural and a part of life.
My parents had a nasty divorce and my Father did not want to see us
Grandparents! However I classify this as ‘expected’ and therefore felt able to accept these bereavements.
Father 11
Loss of grandparents, no unusual “trauma”.

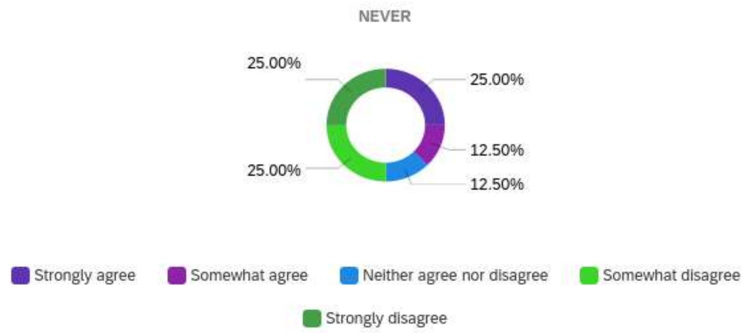
1.38 - Online/smartphone resources (websites, blog posts, social media, WhatsApp etc.) helped me during and/or after my gestnatal loss

#	Question	Total
1	Strongly agree	0
2	Somewhat agree	4
3	Neither agree nor disagree	4
4	Somewhat disagree	0
5	Strongly disagree	11

1.39 - As an adult looking back, how do you think your gestnatal loss as a teenager in secondary school affected you?

#	Question	Total
1	It had a bad effect on me and it still affects me today	5
2	It was an event in my life that has had neither a bad or good effect in my life overall	4
3	It was a traumatic experience that has enabled me to change my life in a significantly positive way; I wouldn't be the person I am today if it hadn't happened	9

Q57 - Following my loss whilst in secondary school, I would describe myself as a 'bereaved parent'



#	Question	Total
1	Strongly agree	4
2	Somewhat agree	2
3	Neither agree nor disagree	2
4	Somewhat disagree	4
5	Strongly disagree	5

The Perinatal Grief Intensity submissions that were embedded within the AAA on Qualtrics™ are detailed separately in Appendices 20 and 21

2.15 - If you have any further comments please write them here

Yes I'd like to add a comment - Text
in my experience, i didn't feel empowered to speak out. I had been told not to and not to 'cause a fuss.' It felt easier to appear okay. Behaving in this way is partially a response based on previous life experiences, however, I fell that if someone was there to support me in expressing my pain and vulnerability, I might have been less likely to develop an eating disorder at a later date. I feel a large part of this mental health condition enabled me to get the support and attention from my mum that I craved at the time of having an abortion. Further, I had control of what went in and out of my body. It also numbed many difficult feelings. i had never been educated about early pregnancy. I had been taught to be ashamed of it and taught that if you fell pregnant early, you were irresponsible. Retrospectively, I wish I had been less compliant and more able to speak out as I am now!
The abortion was not pleasant and i was embarrassed both at my stupidity and the pain i caused to family members. I have spoken to people about it but it is still something I tend to keep to myself. I don't feel it defined me but it was a steep learning experience. For a few years i did reckon up how old the child would be often with incredulity that i could have been a parent rather than who i was. It was a situation which i should have avoided but i didn't. It hasn't defined me though.
This was before the internet and research was limited. All the advice I received (including from my GP and nurse) was biased and religious
I was pregnant after rape and have never told my family about it.
I feel lack of support from health care practitioners, my school, parents and friends let me down, I do still carry some guilt. I am now a nurse and the experience has helped me care for others going through difficulties in their lives.
It was a traumatising experience amplified by the silence of no one speaking about it. When others did say things they felt at the time like like callous and cruel statements. Today they seem thoughtless and hurtful.
Initially, I'll thoughts and feelings were married, and I went on with my life as if nothing had happened . Decades later, I can see how the whole experience affected not only me and my partner, but our subsequent children and families . #DeeperStill
Abortion was a very positive experience and pregnancy was a very negative one. There was no grief involved.

Appendix 19 – Phase one – Perinatal Grief Intensity Scoring Sheet

Perinatal Grief Intensity Scale

Marianne H. Hutti, PhD, WHNP-BC, FAANP

University of Louisville

DEFINITIONS:

Perinatal losses include:

1. **Early pregnancy losses** such as **miscarriage** or **ectopic pregnancy** (pregnancy loss before 20 weeks gestation), and
2. **Later losses in pregnancy or soon after birth** such as **stillbirth** (death of a baby after 20 weeks gestation but before birth), **or death of a baby soon after birth** (such as newborn death-death of a live-born baby in the first 28 days after birth).

This scale helps doctors and nurses better identify parents who are likely to have intense grief after an early or late pregnancy loss or death of an infant.

DIRECTIONS: On a scale from "strongly disagree" to "strongly agree," place a circle around the answer that is closest to how you have felt about your perinatal loss.				
I. Reality Subscale				
1. The pregnancy did not seem real to me.	Strongly Disagree	Disagree	Agree	Strongly Agree

	4	3	2	1
2. I did not think of the baby as a person.	Strongly Disagree 4	Disagree 3	Agree 2	Strongly Agree 1
3. I did not think of the baby as having a specific personality yet.	Strongly Disagree 4	Disagree 3	Agree 2	Strongly Agree 1
4. I felt I had lost my son or daughter, not just my pregnancy.	Strongly Disagree 4	Disagree 3	Agree 2	Strongly Agree 1
5. Both my pregnancy and baby seemed real to me.	Strongly Disagree 4	Disagree 3	Agree 2	Strongly Agree 1

6. It seemed more like the loss of a pregnancy than the loss of a baby.	Strongly Disagree 4	Disagree 3	Agree 2	Strongly Agree 1

Subtotal = _______

Perinatal Grief Intensity Scale

(Continued)

II. Confront Others Subscale				
7. In the first hours and days after my loss, if people said or did things that made me feel bad, I was able to ask them to stop.	Strongly Disagree 1	Disagree 2	Agree 3	Strongly Agree 4
8. In the first hours and days after my loss, if something happened that I did not like, I was usually able to resolve	Strongly Disagree	Disagree	Agree	Strongly Agree

the problem.	1	2	3	4
9. In later weeks after my loss, if people said or did things that made me feel bad, I was able to ask them to stop.	Strongly Disagree 1	Disagree 2	Agree 3	Strongly Agree 4
10. In later weeks after my loss, if something happened that I did not like, I was usually able to resolve the problem.	Strongly Disagree 1	Disagree 2	Agree 3	Strongly Agree 4
III. Congruence Subscale		**Subtotal =**	________	
11. During and after my perinatal loss, I was satisfied with the way my loss experience unfolded, given that I had to go through it.	Strongly Disagree 1	Disagree 2	Agree 3	Strongly Agree 4

12. During and after my perinatal loss, I was satisfied with my interactions with my family.	Strongly Disagree 1	Disagree 2	Agree 3	Strongly Agree 4
13. During and after my perinatal loss, I was satisfied with my interactions with my friends.	Strongly Disagree 1	Disagree 2	Agree 3	Strongly Agree 4
14. During and after my perinatal loss, I was satisfied with my interactions with my nurses.	Strongly Disagree 1	Disagree 2	Agree 3	Strongly Agree 4

Subtotal = _______

PGIS SCORING

SUBSCALES: Reality Subscale: items 1-6 Confront others: items 7-10 Congruence: items 11-14

Scoring Instructions

- First, reverse the scores on items **1, 2, 3, and 6** so that higher scores now reflect more intense grief.
- Add the selected SUBSCALE scores together and divide the total by the number of items in the subscale (REALITY = 6; CONFRONT OTHERS = 4; CONGRUENCE = 4). The range for each subscale will be 1-4.
- Use the following equation to determine the TOTAL score for the PGIS: range of 2.09-4.37. ***The higher the total PGIS score, the more intense grief is predicted to be.***
- **3.08** + (**.41** x Mean Reality Subscale score) – (**0.2** x Mean Confront Others subscale score) – (**.15** x Mean Congruence subscale score) = TOTAL PGIS score **(Bolded numbers are constants in this equation)**

Using the Perinatal Grief Intensity Scale

First, **look at your patient's responses to each item on the PGIS**. This will help you better understand how this person perceives this loss, and will help guide your response to her. It will also help you to provide care that is congruent with her perception of this loss (e.g., whether she sees this as the loss of a baby, loss of a pregnancy, or as heavy bleeding only). As of the date of its release in 2016, the PGIS was developed from statements obtained from women and men after perinatal loss, but as of summer, 2016 has not been tested with men or women from low resource, non-English speaking countries.

During *Hospitalization*, Use the REALITY Subscale ONLY

PGIS REALITY Score of $\leq$ 3.29 = Lower Intensity Grief Responses

- The closer the patient's OVERALL score is to 1, the more likely she is to experience little or no grief related to this loss. As her score gets closer to 3.29, she may experience grief, but her responses indicate generally positive support from her family and friends. She is likely to have a normal grief response.
- Determine how patients perceive their unborn/stillborn baby by examining their responses to items 1-6 on the Reality scale.
- While she may cry and be sad, her response to the loss usually will not require professional counseling or prolonged follow-up.

Interventions: Immediately Post-Loss

- Focus on the woman who has had the loss: If her score is near 1, provide comfort, treat pain, and teach about and provide reassurance regarding vaginal bleeding and cramping.
- Encourage couples to talk with each other, their significant others, and their healthcare provider about how they are feeling. Validating their sadness, if present, is always appropriate.
- These women will often feel a great need to try again to become pregnant as soon as possible, so a discussion of this topic is also helpful.

PGIS REALITY Score of $\geq$ 3.3 = High Intensity Grief Responses

- This patient is likely experience intense grief related to this loss.
- She perceives herself as a parent and this loss as, at a minimum, the loss of a baby – and maximally, the loss of a son or daughter, regardless of gestational age of the fetus.
- Healthcare providers (HCPs) can determine how patients perceive this baby by examining their responses to items 1-6 on the PGIS.

Interventions: Immediately Post-Loss

- HCPs can support bereaved parents by providing care that is congruent with the way parents perceive the loss:
  - Ask if the baby has been named; if so, use the baby's name;
  - Support memory-making activities (if possible) and validate their right to grieve, regardless of the gestational age of their baby;
  - Encourage a funeral or memorial service; begin to teach about grief;
  - Discuss parents' concerns; give them choices about care whenever possible (promotes congruence in the loss experience);
  - Provide guideposts about what to expect of themselves both physically and emotionally until the follow-up visit;
  - Make an appointment for a future follow-up evaluation before the end of today's clinic visit or hospital discharge.

Use the PGIS TOTAL Scale for any *Follow-Up Visits*

PGIS Score of $\leq$ 3.52 = Lower Intensity Grief Responses

- The closer the patient's **TOTAL** score is to 1, the more likely she is to experience little or no grief related to this loss. As her score gets closer to 3.52, she may experience grief, but her responses indicate generally positive support from her family and friends. She is likely to have a normal grief response.
- Determine how patients perceive their unborn/stillborn baby by examining their responses to items 1-6 on the Reality scale.
- While she may cry and be sad, her response to the loss usually will not require professional counseling or prolonged follow-up.

Interventions at Follow-Up:

- If she answers "disagree/strongly disagree" to items 3 or 4, consider referring her to a perinatal grief support group.

PGIS Score of $\geq$ 3.53 = High Intensity Grief Responses

- This patient is likely to experience intense grief related to this loss.

- She perceives herself as a parent and this loss as, at a minimum, the loss of a baby – and maximally, the loss of a son or daughter, regardless of gestational age of the fetus.

<u>Interventions at Follow-Up:</u>

- HCPs can support bereaved parents by providing care that is congruent with the way parents perceive the loss **regardless of the baby's gestational age**: Acknowledge parents' ongoing grief and validate their right to feel this way; continue to teach about the perinatal grief process, especially about grief differences between men and women.
- Look at items 11-14 on the PGIS. If responses indicate a high level of dissatisfaction with interactions with others about the loss, help her to: (1) identify what she would prefer to happen in these interactions and (2) problem-solve issues with her family members and/or friends. **REFER to face-to-face and online support groups and professional counselors/therapists for continued help and support with these issues.**
- These couples may have great anxiety about attempting another pregnancy and may wish to delay attempting to try again for a long period of time. A realistic discussion regarding the risks of another loss is generally appreciated.
- They will often have a greater risk for anxiety, depression, and PTSD during the subsequent healthy pregnancy. Regular screening in the subsequent pregnancy is suggested.
- **Consider having another follow-up visit scheduled so the grief response can be monitored, especially if a referral to a counselor or therapist cannot be accomplished quickly.**

Appendix 20 – Phase one – Respondent PGIS Scores Within the First Six Months

Appendix 21 – Phase one – Respondent PGIS Scores Post Six Months

SIX MONTHS OR MORE																			
The pregnancy did not seem real to me	Somewhat agree	Strongly disagree	Somewhat disagree	Strongly disagree		Strongly disagree	Somewhat disagree		Strongly disagree	Strongly disagree	Strongly agree	Somewhat disagree	Strongly agree		Strongly disagree	Strongly disagree	Somewhat agree	Strongly disagree	Somewhat agree
I did not think of the baby as a person - Six months or more following the loss	Somewhat disagree	Strongly agree	Strongly disagree	Strongly disagree	Somewhat disagree	Somewhat disagree	Strongly disagree		Strongly disagree	Strongly disagree	Strongly disagree	Somewhat disagree	Somewhat disagree	Somewhat disagree	Strongly disagree	Somewhat disagree	Strongly disagree	Strongly disagree	Strongly agree
I did not think of the baby as having a specific personality yet - Six months or more following the loss		Strongly agree	Somewhat disagree	Strongly disagree	Somewhat agree		Somewhat agree	Somewhat disagree	Somewhat agree	Strongly disagree	Strongly disagree	Somewhat agree	Somewhat disagree	Somewhat agree			Strongly agree	Somewhat disagree	Strongly agree
I felt I had lost my son or daughter, not just my pregnancy - Six months or more following the loss	Somewhat agree	Strongly disagree	Strongly agree	Strongly agree		Strongly agree	Strongly agree	Somewhat disagree	Strongly agree	Strongly agree	Strongly agree	Strongly disagree	Strongly agree		Strongly agree	Somewhat disagree	Strongly agree	Strongly agree	Strongly disagree
Both my pregnancy and baby seemed real to me - Six months or more following the loss	Somewhat agree	Strongly agree	Somewhat agree	Strongly agree		Somewhat agree	Strongly agree		Somewhat agree	Strongly agree	Strongly agree	Somewhat agree	Somewhat agree		Strongly agree	Somewhat disagree	Somewhat agree	Strongly agree	Strongly disagree
It seemed more like the loss of a pregnancy than the loss of a baby - Six months or more following the loss	Somewhat disagree		Somewhat disagree		Somewhat disagree	Strongly disagree		Somewhat agree	Somewhat disagree	Strongly disagree	Somewhat disagree	Strongly agree	Strongly agree		Strongly disagree		Somewhat agree	Strongly disagree	Strongly agree
REALITY SUBSCALE	2.60	2.80	2.33	2.20	2.33	2.20	2.80	2.33	2.33	2.00	2.67	2.50	3.17	2.50	2.20	1.75	3.00	2.17	2.83
In the first hours and days after my loss, if people said or did things that made me feel bad, I was able to ask them to stop - Six months or more following the loss	Somewhat disagree				Somewhat agree	Strongly disagree	Somewhat disagree		Strongly disagree	Strongly disagree	Strongly disagree		Strongly disagree	Somewhat disagree	Strongly disagree	Strongly disagree		Somewhat disagree	
In the first hours and days after my loss, if something happened that I did not like, I was usually able to resolve the problem - Six months or more following the loss	Somewhat disagree	Somewhat agree			Somewhat disagree		Somewhat disagree	Somewhat agree	Strongly disagree	Strongly disagree	Strongly disagree	Somewhat agree		Somewhat agree	Strongly disagree	Somewhat agree	Somewhat agree	Strongly disagree	
In later weeks after my loss, if people said or did things that made me feel bad, I was able to ask them to stop - Six months or more following the loss	Somewhat disagree					Strongly disagree	Somewhat disagree	Somewhat agree	Strongly disagree	Somewhat agree	Strongly disagree	Somewhat agree		Strongly agree	Strongly disagree	Somewhat agree	Strongly disagree	Strongly disagree	Somewhat agree
In later weeks after my loss, if something happened that I did not like, I was usually able to resolve the problem - Six months or more following the loss	Somewhat disagree		Somewhat disagree		Somewhat disagree		Somewhat disagree		Strongly disagree	Strongly agree	Somewhat agree	Somewhat agree		Strongly agree	Strongly disagree	Somewhat agree	Strongly disagree	Strongly disagree	Somewhat agree
CONFRONT OTHERS SUBSCALE	2.00	3.00	2.00	0.00	2.33	1.00	2.00	3.00	1.00	2.25	1.50	3.00	1.00	3.25	1.00	2.50	1.67	1.25	3.00
During and after my gestnatal loss, I was satisfied with the way my loss experience was unfolded, given that I had to go through it - Six months or more following the loss	Somewhat disagree	Strongly agree	Somewhat agree	Somewhat disagree	Somewhat disagree	Strongly disagree	Strongly disagree	Somewhat agree	Strongly disagree	Somewhat disagree	Strongly disagree	Somewhat agree		Strongly disagree	Strongly disagree	Strongly disagree	Strongly disagree	Strongly disagree	Somewhat agree
During and after my gestnatal loss, I was satisfied with my interactions with my family - Six months or more following the loss	Somewhat disagree			Strongly disagree	Somewhat disagree		Strongly disagree	Somewhat agree	Strongly disagree	Strongly disagree	Strongly disagree	Somewhat agree	Strongly disagree	Somewhat disagree	Strongly disagree	Strongly disagree	Somewhat disagree	Strongly disagree	Somewhat agree
During and after my gestnatal loss, I was satisfied with my interactions with my friends - Six months or more following the loss	Strongly disagree		Somewhat agree		Somewhat disagree	Somewhat agree	Strongly disagree	Somewhat disagree		Somewhat disagree	Somewhat agree	Somewhat disagree	Strongly disagree	Somewhat disagree	Strongly disagree	Strongly disagree	Somewhat disagree	Somewhat disagree	Somewhat agree
During and after my gestnatal loss, I was satisfied with my interactions with my nurses - Six months or more following the loss			Strongly disagree	Strongly disagree		Strongly agree	Strongly disagree				Strongly disagree	Somewhat agree	Strongly agree			Somewhat disagree	Somewhat agree		Somewhat disagree
CONGRUENCE SUBSCALE	1.67	4.00	2.33	1.33	2.00	2.67	1.00	2.67	1.00	0.00	1.50	2.75	2.00	1.67	1.00	1.25	2.00	1.33	2.75
(Range 2.09-4.37)	**3.50**	**3.03**	**3.29**	**3.78**	**3.27**	**3.38**	**3.68**	**3.04**	**3.69**	**3.45**	**3.65**	**3.09**	**3.88**	**3.21**	**3.63**	**3.11**	**3.68**	**3.52**	**3.23**
	Intensity but grief present	grief but positive	grief but positive	Intensity Grief Response	grief but positive	Intensity but grief present	Intensity Grief Response	grief but positive	Intensity Grief Response	Intensity but grief present	Intensity Grief Response	grief but positive	Intensity Grief Response	grief but positive	Intensity Grief Response	grief but positive	Intensity Grief Response	Intensity but grief present	grief but positive
Change pre and post six months	-0.06	0.00	-0.36	0.41	0.00	0.00	-0.05	0.00	0.10	0.18	0.00	-0.07	0.27	-0.46	0.00	-0.37	-0.11	0.41	
	High grief intensity, normal grief evident, but adjustment is present	Grief but normal adjustment	Grief but normal adjustment	High grief intensity, greater risk for anxiety, depression & PTSD (grief increased over time)	Grief but normal adjustment	Grief is present, no adjustment over time	High grief intensity, greater risk for anxiety, depression & PTSD	Grief but normal adjustment	High grief intensity, greater risk for anxiety, depression & PTSD (increase over time)	Grief present - increase in grief over time	High grief intensity, greater risk for anxiety, depression & PTSD	Grief but normal adjustment	High grief intensity, greater risk for anxiety, depression & PTSD (increase over time)	High grief intensity but normal adjustment	High grief intensity, greater risk for anxiety, depression & PTSD	Grief but normal adjustment	High grief intensity, greater risk for anxiety, depression & PTSD	Grief present - increase in grief over time	

Appendix 22 – Phase two – Interview Question Themes

Personality

- What was the relationship with the father? (before/during/after?)
- Did she feel adequately educated on sex education?
- What kind of student was she in school pre loss?
- Was the pregnancy planned?
- **Confirmation bias; what was her attitude before on girls who get pregnant in school & did she have a perception of gestnatal loss before she experienced it?**

Bonding/dependency

- What kind of relationship did the girl have with her primary guardian?
- How did the girl feel about being pregnant?
- Did the girl attach to the baby? (future/loss of dreams?)
- Was the loss significant?

Resilience

- Was the loss significant?
- If it was, were they able to adjust to the loss normally over time (PGD?)
- Did she/does she memorialise the baby? (continuing bonds/meaning making?)

Social support

- If the loss was significant to the participant, was the loss recognised? (Disenfranchised?)
- Was information given to the participant on any support organisations or counselling at that time? If so, was it taken up?
- If no information was given on support, did they want it? Did they look for it? Where would they want it from? (parents, peers, school, independent, online, medical??)
- Were their peer relationships affected?
- Were their family relationships affected?
- Was social media/smart phones a factor in any of your gestnatal loss experience?

Cultural Environment

- How did the school respond to the pregnancy and subsequent loss? (supportive/neutral/discriminatory?)
- Are there any recommendations they would have for schools?
- Do they feel their education was affected?
- **Confirmation Bias; did she have a perception of negative social reactions to her?**
- Was there a perception of Stigma towards her?

Sociohistorical conditions

- Would you like to add any further comments on what your gestnatal loss experience was like in an Irish school that we haven't covered?

Appendix 23 – Phase two – Consent Form

Consent Form

In agreeing to participate in this research I understand the following:

Caroline Lloyd is a Ph.D. student in the School of Education, Trinity College Dublin. As part of this work, she is conducting research in the area of adolescent experiences of pregnancy during secondary education which resulted in a gestnatal death (from conception to 28 days post birth). The thesis is investigating the effects of the event (the pregnancy and death) on the adolescent in general, the school response and educational impact. The study is an investigation from an adult retrospective perspective of their experiences when they were in formal education as adolescents. The aim of the research is to inform school personnel, policy makers e.g. governmental officials and school guidance counsellors of these effects so that adolescents can be effectively supported. Caroline can be contacted at lloydca@tcd.ie.

If you agree to take part in this study, you will be asked to complete a questionnaire and to take part in an audio-recorded interview. The questionnaire will take about 20 minutes and the interview will take between 30 minutes to 1 hour. Both will take place at a time of your convenience and may be undertaken separately. Both the interview and the questionnaire will be stored anonymously i.e. your name will not be kept with the data. If you participate in both the questionnaire and the interview, they will be kept separately and not linked together in order to maintain

anonymity. You may choose to only conduct the interview without completing the questionnaire.

I can foresee no risks for your participation in the study beyond those experienced in everyday life, however, should you experience any discomfort or upset, a list of support organisations will be provided to you. The information given by you will be treated with privacy and anonymity and within the GDPR regulations. No information regarding you will be revealed in the research. Information will be stored safely with access only available to the research team and examiners and it will all be destroyed after 10 years. The anonymised results from the study will be included in a thesis and may be discussed at conferences or published in a book or a journal.

Please answer all of the following (tick the appropriate box):

Yes No

- I have read and understood the information sheet. □ □
- I understand what the project is about, and what the results will be used for. □ □
- I am fully aware of all of the procedures involving my participation in the study. □ □
- I am fully aware of any risks and benefits associated with my participation. □ □
- I am fully aware that I may refuse to answer any questions. □ □

- I know that my participation is voluntary and that I can withdraw from the project at any stage (until the data has been anonymised) without giving any reason. □ □
- I am aware that my results will be kept anonymous. □ □
- I am aware that I may ask any questions at any point before, during or after the conclusion of the study. □ □
- I understand that the interview will be carried out in a sensitive and empathic manner and that I may stop or pause the interview at any time. □ □
- I understand that the interview will be audio recorded and transcribed. □ □
- The data will be held within the regulations of the GDPR (copy of guidelines attached). Within this framework, I can ask that all information given by me can be destroyed upon request, at any time, without giving a reason. □ □
- I understand that this research study does not constitute any kind of counselling or medical treatment and that the study will not form any kind of medical or psychological diagnosis. □ □
- I understand that my identity will be protected via a code number □ □
- I understand that my electronic data will be stored in password protected files and my physical data will be stored in locked cabinets □ □
- I have been provided with a list of support organisations should any issues arise as a result of my participation. □ □

- I understand that I will be asked questions of a personal nature that will include whether the pregnancy was planned, the significance of the baby to me, my responses to the loss, what kind of support I received and how I feel the experience affected me. □ □

You do not have to take part in this study if you do not want to and you can withdraw from the study at any time without saying why until the data has been submitted anonymously. Once the questionnaire and/or interview data has been completed and anonymised it will not be possible to withdraw from the study.

Please understand that you are permitted to present concerns, questions, or queries at any point before, during or after the study.

Provision will be made for a proper debriefing of participants following the interview questions. This will ensure that all participants have an opportunity to ask any questions about the interview or the study and ensure that the researcher has identified any issues that may have arisen that would require signposting to support organisations. The researcher will also use the debriefing session to ensure that no participant leaves the interview in an emotional state where they are worse off than when they started the interview. This can be done by talking about positive ways of addressing these issues, including seeing a qualified counsellor or obtaining support from specialised organisation.

Finally, thank you for taking time to read this and thank you for participating in this study if you decide to participate.

If during your participation in this study you feel that the information and guidelines that you were given have been neglected or disregarded in any way, or if you are unhappy about the process, please contact Professor Conor Mc Guckin, School of Education, Trinity College, Dublin at +353 1896 2175 or conor.mcguckin@tcd.ie Please be assured that your concerns will be dealt with in a sensitive manner.

I agree to participate in this study:

Signed & Dated

____ Participant

Signed &

Dated____Researcher

Appendix 24 – Phase two – Thematic Analysis

Cross-case analysis results

Context	Over-arching Theme	Main Theme	Sub-theme
Social environment	1. pregnant adolescent girls are stigmatised	1. girls are to "blame"	1. patriarchal society
Exo, macro, chrono, digi - systems		2. "damaging" males	2. religious dogma influences societal stigma
			3. society blames girls
			4. girls are called names: sluts, whores, "frigid"
			5. there are cultural expectations of girls vs boys
			6. abortion as 'right' decision due to social stigma
			7. social, empathic support is important
School	2. schools should provide relevant information and support	3. pregnant girls are marginalised	8. education is important
Micro-system		4. Sex and relationship education is inadequate	9. pregnant girls drop out of school & "disappear"
			10. teachers contribute to judgemental attitudes
			11. sex education as biological function only or non existe
(meso-system)			12. lack of information and signposting
			13. lack of contraceptive knowledge and use
Home	3. families are complex structures	5. mothers are influential	14. not wanting to let the family "down"
Micro-system		6. Adverse Childhood Experiences are influential	15. ACEs: divorce, sexual, emotional, and physical abuse
			16. secrets and lies within families
			17. mother is influential
Individual	4. female adolescents as vulnerable and voiceless	7. lack of confidence leads to consent "blurring"	18. self stigma, guilt and shame
		8. lack of information and support leads to isolation, self stigma and mental health issues	19. never told anyone
			20. lies, silence & loneliness
			21. scared and overwhelmed
			22. "good" girls and "good" pupils
			23. inability to say 'no'/consent blurring
			24. mental health issues
Individual (Dividual)	5. impact across the lifespan	9. identity creation and reconstruction	25. constructing and reconstructing identity narrative
		10. emotional attachment	26. emotional connection to pregnancy
			27. varying grief reactions over time
			28. self-identifying as "bereaved parent"
			29. challenging the concept of "motherhood"

Appendix 25 – Phase two – The Bio-Psycho-Social Model of Female Experiences of Adolescent Perinatal Death (BELATED)