

Chapter 6 Pregnancy loss and complexity

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Trauma and loss are experiences that push us to our limits. By definition, trauma overwhelms our usual abilities to cope and adjust, calling into question the most basic assumptions that organize our experience of ourselves, relationships, the world, and the human condition itself

Irene Smith Landsman (2002, p13)

Although the literature is replete with references to birth as sacred, a spiritual journey where a new life is welcomed into the world, this is juxtaposed with the almost exclusively medical focus on birth if something should go wrong. Ultrasound screening for foetal anomalies was first introduced into practice more than thirty years ago, and rapid technological developments have meant that women's experience of pregnancy has changed irrevocably. Whilst science endeavours to come to terms with constantly evolving diagnostic techniques, mass screening of foetal health in pregnancy is blurring the traditional boundaries between health and illness, as normal populations are being screened for a condition that has not manifested itself through the identification of risk factors. Acceptance of routine ultrasound in low risk pregnancy has led to the modality developing a social meaning, one that for many women has come to dominate its medical use (Lalor 2007a). Attending for a routine second trimester ultrasound examination is perceived as an opportunity to meet the baby, as visualisation of the foetus not only enhances parental attachment; the recorded images also facilitate a sharing of the experience with friends and families (Lalor 2007a).

There is little doubt that one of the most profound inequities for parents eagerly awaiting the birth of their child is to have their hopes and dreams shattered by the diagnosis of a severe or lethal abnormality. The evidence is unequivocal in that women have demonstrated that a threat to foetal health represents a major traumatic event (Lalor, Devane, and Begley 2007)

one in which their assumptions and beliefs about the world are violated. So why is an adverse diagnosis so traumatic?

I have spent many years as a clinician imparting a diagnosis to couples, followed by many more listening to their stories as a researcher. My work in this field has been exclusively within the Republic of Ireland, a country with a complicated history of religious involvement in State affairs, where the influence of Church doctrine on social policy is well documented (Inglis 1998). Smyth (2005) suggests that our political and national identity is constructed in traditional, patriarchal, familial and orthodoxly catholic terms. In Ireland, Church and State have been intertwined for many decades and the integration of catholic philosophy and state policy is well documented (Oaks 1999, 2003). Catholic doctrine is interwoven into the Constitution that sets out how Ireland is to be governed (Government of Ireland 1999). For example, Article 40.3.3 offers constitutional protection to the unborn, stating that the unborn has an equal right to life to the mother, clearly indicating that Ireland has a national identity that is unambiguously pro-life. Consequently, women who are pregnant in Ireland are aware that termination of pregnancy remains out of the State remit, leaving women with a feeling that choosing not to continue the pregnancy is inherently wrong (Lalor, 2013). Therefore it is unsurprising to find many women continue the pregnancy in order to have family support or because they simply do not have the wherewithal to access services outside of the State (Lalor, 2007a). For those that choose to travel, they do so in a context of secrecy and lies (Lalor, 2013). In this chapter I will use women's stories that participated in my doctoral and postdoctoral work to illustrate the psychological burden associated with a diagnosis of foetal anomaly in pregnancy and how a belief in God (or other higher power) influenced their ability to cope.

I have found the theoretical construct of the Assumptive World conceived by Colin Murray Parkes to be indispensable in my efforts to understand the psychosocial process experienced by those affected. Colin Murray Parkes (1971) defines the assumptive world in terms of

the only world we know and it includes everything we know or think we know. It includes our interpretation of the past and our own expectation of the future, our plans and our prejudices. Any or all of these may need to change as a result of changes in the life space (Murray Parkes, p102).

Without exception, receiving an adverse prenatal diagnosis constitutes a change in one's expectations and plans for a pregnancy. Seldom are accounts available from those affected by prenatal diagnosis. In this chapter I explore whether spirituality and faith are evident in the narratives of those who hope to adapt to an unforeseen and at times unpredictable future, as previously unquestioned beliefs of normality are replaced with shattered assumptions (Parkes 1971).

Although women universally accept routine ultrasound in pregnancy, understanding the meaning of an adverse diagnosis requires some exploration of the context. In many countries where routine ultrasound is available, there is a high incidence of spiritual and religious beliefs in the population being screened. In the 2011 Census in Ireland, although a surge in the number of people that describe themselves as non-religious was evident at 5.6%, just over 84% described themselves as Catholic, and the remaining 10% as affiliated to other religious groupings. Although figures vary internationally, there remain higher proportions of the population who indicate religious association, as over 76% of citizens in North America and 59.3% in the United Kingdom are affiliated to Christian faiths, with many others describing

themselves as non-religious. In considering these census figures, it is important not to confuse spirituality and religion as not everyone who considers himself or herself religious consider themselves spiritual and vice versa (see chapter one). The supposition that society is fast becoming a secular one is highly contested, as there seems to be little correlation between attendance at church and belief in God. Consequently statistical patterns indicating a decline in membership or attendance in traditional religious practices does not necessarily indicate a non-belief in the existence of God or a higher power. Therefore it is important to consider the distinction between religion and spirituality as many who describe themselves as non-religious may engage in spiritual coping activities such as prayer or pleading with God in time of stress.

For the purpose of this chapter, spirituality will be conceived as an attempt to seek meaning and purpose in life in relation to a higher power, a universal force or God. The word spirituality is derived from the Latin word *spirale*, to blow or to breathe, thus denoting giving breath or hope to individuals, families or communities. Religion on the other hand refers to a form of social institution, an agreed set of beliefs with accompanying practices and rituals, and can play a significant role in helping individuals to cope with stressful life events (Janoff-Bulman 1992).

The positions outlined below have evolved over the course of my professional career, in the capacities of clinician, academic and researcher, as I have had occasion to work with many couples traumatised by an unexpected diagnosis of a serious or lethal foetal anomaly in pregnancy. In my doctoral and postdoctoral work I used a grounded theory approach to explore women's experiences of an adverse prenatal diagnosis. Over 60 women were interviewed on up to three occasions from the diagnosis up to and beyond the birth.

Narratives from these interviews will be used as exemplars of how women whose lives are disrupted by a profound loss seek to make sense of this ostensibly meaningless event.

Diagnosis of foetal anomaly- a violation of the assumptive world

Regularising second trimester ultrasound has created an environment where women attend to seek reassurance of presumed foetal well-being rather than the exclusion or confirmation of foetal abnormality. Although most infants are born well, approximately 1:50 will be born with a structural abnormality and 1:700 with a chromosomal or serious genetic disorder. As the presence of a foetal anomaly is relatively uncommon, women are not prepared for such a diagnosis, in particular when the pregnancy has been without complication up to that point. Consequently, when the expectation of normality was devastated through an adverse diagnosis, some mothers were not only incredulous but also questioned how they could have been visited by such an injustice. Several systematic reviews have found that the use of religious and spiritual coping efforts are associated with better emotional outcomes (Frankl 1963). In my doctoral and postdoctoral work I sought to explore not just the initial response to the diagnosis but how women made decisions regarding the outcome of the pregnancy, and in particular, how they adapted to this traumatic and unexpected news. All of the narrative quotes are excerpts from interviews I undertook with women during the course of my work (Lalor 2007b, Lalor 2013, Lalor, Devane, and Begley 2007, Lalor and Begley 2005, 2006). For some women the initial response to the news may be disbelief, as some resorted to prayer (Janoff-Bulman 1992), hoping that it is all a terrible mistake. Sian said

I mean it happens to people [conceiving a baby with an abnormality], like you think it will never happen, but like I mean these things do happen and then you have to think

about them. If I was to think about why it would seriously drag me down through the pregnancy if I was to, sort of get hung up on it like. ... I lost my child for about four days [after the diagnosis] and it was like a big black cloud and you wake up in the morning and you think I can't get out of this.... So I thank God, I just hand it over to the Lord, like and say well, you know, God give me the grace or the strength, or please God the baby will be perfect (Lalor 2007a, 129).

Sian's ultrasound had indicated the possibility of duodenal atresia and Sian was given a 1:3 risk that her baby had Down Syndrome. Although it has been shown that spiritual beliefs can interfere with medical help seeking behaviours, in the context of prenatal diagnosis this behaviour manifested most often in a refusal to undergo invasive testing, such as amniocentesis. Refusing further testing was seen as a way to keep the hope of a healthy baby alive. Sian refused amniocentesis as she needed to keep the hope that the baby did not have Down syndrome in order to cope on a day-to-day basis until the birth.

I said no it [amniocentesis result] it could put a totally different outlook on the last few months of your pregnancy, we prefer to think that the baby will be normal.... I feel what we have to focus on is getting our head around it, keep going with the ordinary everyday things. We hope to cope, hope that the baby will feed and sleep....that we will become normal (Lalor 2007a, 186).

In the field of positive psychology it has been recognised that negative orientations toward the future are associated with hopelessness and pessimism. Therefore in order to maintain hope, positive expectations and the cognitive capacity to direct one's thoughts towards a future goal, (in Sian's case a healthy baby) is central to an individual's ability to manage

successfully that which was unforeseen. Although Sian had a strong belief in God and engaged in spiritually based activities such as attending mass and praying for strength and support, others used their faith as a way of coming to terms with the fact that they might never find a reason for why this has happened. Emma said

You know, I am not a religious person but I do talk to God and that...and I do say well you wouldn't want me to go through this would you? Maybe He [God] wants me to go through this. Just telling yourself, maybe this is to be, and just get on with it (Lalor 2007a, 151)

Some even viewed the diagnosis as a wakeup call to live a better life (Becker et al. 2007, Gall et al. 2005), such as taking this event as a signal to eat more healthily, avoid risk taking behaviours, reduce alcohol intake or to stop smoking. I was prompted to search further as to why some women believed that this unforeseen event could be attributable to their own actions. It was a quote from Emma about the unfairness of the diagnosis that led me to Lerner's theory of 'belief in a just world' (Lerner 1980). Lerner's (1980) just-world hypothesis is based on the assumption that a person's actions are inherently inclined to bring just and fitting consequences. Evidence of this belief in the vernacular in Ireland (and likely elsewhere) include common parlance such as 'you reap what you sow', 'what goes around comes around' and 'your chickens have come home to roost'.

Therefore in the case of very negative events, people may often find it easier to attribute blame rather than accept the randomness or unjustness of the experience. Although uncommon, some women chose to blame themselves. Fiona had two healthy children and had just received a diagnosis of hydrocephaly in her third pregnancy.

I would blame a lot of it on the wine. There is a difference between liking wine and loving wine, I love wine...I would drink a bottle no problem. I wouldn't have a problem with it in the world. But like you see on my first pregnancy I couldn't drink. But then when I had [second baby], I didn't drink on that pregnancy, I drank beer or whatever but I went to wine then, you know [in this pregnancy]. But I blame it on me, and then I try to blame it on like loads of things, but mainly me (Lalor 2007a, p148).

Hayley, a single mother with a two year old son described how she discovered she was pregnant follow her return from a holiday with her family.

I blamed myself. I was in New York with my best friend and my Mam and my aunt and I was out on the batter every night. I was getting drunk. I was a week over there and I found out I was pregnant (Lalor 2007a, 149).

One aspect of constructing meaning is to seek significance in the event, to re-prioritise, and to learn lessons for the future. Both Fiona and Hayley attributed the diagnosis to their alcohol intake in early pregnancy. Each indicated that in attributing causality to their behaviour they could protect themselves in future pregnancies by doing things differently. Lerner (cited in Miller and Kelley 2005) suggests that in order to maintain an illusion of control over a random event it is tempting to attribute blame as this keeps the 'belief in a just world' intact, restoring one's sense of control, and avoiding the significant cognitive task of revising one's assumptions about the world. However, some women, who did not blame themselves for the diagnosis, felt, on occasion, that their friends were attributing them with causal responsibility for the anomaly through actions that they may have taken or failed to take earlier in the

pregnancy. Ava, whose baby was diagnosed with a lethal abdominal wall defect, commented on how friends were keen to get to the root of the problem.

That was Christmas day, a friend of mine called, I mean she is genuine no more than anybody else has been about the whole thing and she was saying to me, so they just don't know why it's happening? I mean we have asked this question ourselves and they [foetal medicine specialists] just don't know why it would happen, and it's just sporadic. So I just said nothing to her, I just let it go. But she turned around and said to me I know it makes no difference but did you check if you were pregnant say when we went to [a friend's party] and you had a couple of glasses of wine and maybe you didn't know you were pregnant? I am looking at her thinking I know it has nothing to do with that but even suggesting that there is any element of blame... we haven't spoken since (Lalor 2007a, 149).

Lerner (1980) suggests that just as we believe in a just world so do others around us. Therefore if Ava was not to blame for the diagnosis this may have threatened her friend's security around conceiving a normal baby. However, for others the sense of injustice and distress caused them to turn away from their religious beliefs and forsake their beliefs, temporarily if not permanently.

Keeping the faith in an unjust world - it's more than a spiritual struggle

Rotter (1980) proposed that individuals have an internal locus of control - a belief that what happens to us is a consequence of our actions. However, when the trauma experienced does not fit with this assumption, the individual becomes an 'innocent victim' and may become overwhelmed by the objectively uncontrollable nature of the crisis. Molly prepared

assiduously for her first pregnancy, refraining from taking alcohol, altering her diet and taking pre-conceptual folic acid, yet Molly received a diagnosis of anencephaly.

So I don't know, part of me thinks like I did everything so right and yet it went so wrong. It's weird. Maybe if ... there is something about doing everything so correct, you know, I know it would have anyway but it is a thought that goes through my mind like when you are so adamantly balancing your food and things and it still happened. The same for folic acid I am just almost, I feel so let down, you are let down by everything, you are let down by God, you're let down by your body (Lalor 2007a, 186).

Other elements of the assumptive world such as 'I am a good person, things are meant to be a certain way, God is good, having a vision of the future' also emerged during women's reconstruction of their experience. This is similar to the premise outlined in Lerner's (1980) theory of 'belief in a just world' such as 'bad things happen to bad people'.

Emma's diagnosis in the context of having prepared for pregnancy violated her belief that she could have some control over future outcomes.

They [the staff] said just go out and get a bit of a breather, I got a bit angry then, you know. I know it's terrible, I am not a bad person but I was coming down the steps in the main building, coming down the steps and going out and watching all the girls either going off with their babies, husbands coming in, partners coming in with the carry cot to bring the baby home, and there was one girl parked outside. I always looked towards that day when I would be bringing my baby home... and young girls were going in for their appointments... Here they are going in no problem, getting

everything handed to them, perfect babies probably. Because I had felt I had done everything by the book. You know, I don't smoke and very rarely drink, look after myself as much as I can, you know, as you do, well I always do try and eat well and whatever. I think I tried to do everything right in life, you know, not do anything wrong on anybody or you know, and was thinking this is unfair like for us... it should be them' (Lalor 2007a, 132).

Emma's experience shakes her beliefs and provides her with evidence that supports the fact that the world may not be just. Making sense of loss requires a search for meaning, and one of the first steps in this journey was for women to seek answers to the 'Why me?' question through gaining information to clarify and assess the consequences of the diagnosis for the pregnancy/baby. Meaning is an explanation for an event that renders it consistent with one's assumptions or understanding of the nature of the social world. That is, an event "makes sense" or "has meaning" when it does not contradict fundamental beliefs about justice, order, and the distribution of outcomes (1966). Some of the most common questions asked as women seek meaning in the immediate aftershock of the diagnosis are 'Why did this happen? Why me? Will it be ok? What caused this?'

When solace in prayers or an acceptance of God's will does not give sufficient explanation to the event, some experienced a type of spiritual struggle, in particular, if God was viewed as punitive or failing to respond to pleas for help. Lori was pregnant with her second baby and was a mother to a healthy two-year old daughter. The ultrasound detected a serious cardiac defect and Lori, unlike Sian, accepted the offer of amniocentesis to confirm or exclude a diagnosis of Down syndrome, as she described not knowing as 'torture'.

The day mm...I got the results she has Downs there is this big church there beside [hospital] and I went in and I walked back out. This is not for me; I know my faith is gone now (Lalor 2007a, 151).

When asked if Lori practiced her faith before the diagnosis she replied:

Yes, I was brought up Catholic and maybe I prayed at night. I haven't been to mass for a while though. Oh I was very angry, very, very angry. I mean I am sure I was saying what did I do to deserve this? I have no faith now. I had to sit in mass one day, I wanted to go for my granny's anniversary but just listening to the priest standing up there, you know the way they talk and lecture us, and I was so angry. My baby might die and the way I am looking at it is and here is my faith coming again that if she died God is after taking her away... why take her back? (Lalor 2007a, 151).

Irrespective of whether women mentioned a belief in God or not, they all said that they had to have hope (in something) to cope. This may have been simply that when the baby had a lethal anomaly they hoped that the baby could be born alive in order to be baptized. Laoise said

I hope that he is born alive and really hope for as long as possible he will live. The longer time I can get with him the better, but I need to bond now, while he is alive, just in case [he is stillborn]. It's hard to let go. I mean just, like I really want to bond with him and have him for as long as possible (Lalor 2007a, 152).

Heather whose baby had been diagnosed with a lethal cloacal abnormality said

I have asked for a section so she can be born alive, she can't be baptized if she is stillborn (Lalor 2007a, 124).

For others the prospect of caring for a child with significant challenges was the worst possible outcome, and in these cases women often prayed for the best possible outcome, and for some death before birth was the preferred ending. Niamh said

I have heard it over and over again, yes I know I shouldn't be wanting it to be over and I really do still want to think the best for the baby but dear God I am thinking how in God's name am I going to get through the next few weeks, I am hoping things wont be half as bad as what I expect. But from the day you get pregnant you hope your baby will be fine now I hope it will be the least bad problem (Lalor 2007a, 180).

Doireann on the other hand was fearful that she might not be able to cope with caring for a child with complex needs.

I'm hoping they'll say the heartbeat is fading away. My biggest fear is that the baby will survive and I'll be left with a seriously handicapped baby... How will I cope? (Lalor 2007a, 110).

When women described themselves in negative self-deprecating terms such as '*I deserve this* or *this is my punishment*' feelings akin to unworthiness or worthlessness emerged.

I am sick of hearing God sent you this child...then I met a lovely priest yesterday just out of blue walking down the street, like I felt dirty and I suddenly felt this is my punishment and like he doesn't know me or what is going on (that my baby is abnormal and I don't want him),.... I am not even Catholic and I still feel dirty (Lalor 2007a, 176).

Regan understood that termination of pregnancy was not available in Ireland and was clearly views as immoral; however, as she had been sharing care with her GP she chose to inform her out of courtesy of her decision to travel.

I found her incredibly good till I told her I had a baby with anencephaly and I was planning on going to England... and I just didn't like her reaction.... You see I understand as well that they can't give any information, they can't give their opinion, they can't but... But she could be humane I sort of feel that she thought I should have gone to term... she told me how dare I say such a thing and asked me to leave (Lalor 2007a, 172).

Although women are aware of the legal context, they assume medical professionals will put their personal beliefs aside in the context of a consultation. To be faced with such opprobrium by a health professional adds to the guilt and shame women are made to feel that they would even consider such a heinous act. For those that continued the pregnancy, some women were so overwhelmed by the news and an inability to see a future in which they could cope, that they used avoidant coping strategies, sometimes not leaving the house for days.

Cliona said

I was still tossing at maybe three this morning, I still hadn't closed me eyes, and I know he [partner] only went to sleep at about one, but we weren't, we weren't talking about it. When he went to sleep last night I probably cried for a little while all right..... I haven't been out in days,... I just don't want to see anyone ((Lalor 2007a, 128).

Irrespective of whether women at an individual level describe themselves as religious or not, when faced with the prospect of caring for a baby with significant health needs, or a stillbirth or neonatal death, many consider if they have the strength to cope with continuing the pregnancy. It has been previously identified that religiosity is also significant in women's decision making in terms of whether to continue the pregnancy or not (Lerner 1980). However, given the high levels of religious affiliation and spirituality in the Irish population, these women were asked if their decision to continue or to terminate the pregnancy was influenced by a particular belief system. Laura said

Surprisingly not, I thought it might, you know...but it hasn't for me. I don't feel, I don't feel I am sending the baby to hell or anything (by having a termination); I am not worried about that. I am more worried about it suffering, its physical suffering than its soul suffering. I am not sure if it has a soul, I really am not. I am not sure how conscious it is of what is happening to it and its hard to imagine that, and the God I believe in is not that kind of God [who would punish her for this decision], He is not so merciless I think (Lalor 2007a, 173).

Finding meaning in the aftermath of an adverse prenatal diagnosis

References to God and the belief in a just world were common in women's narratives. Some described trying to come to terms with the diagnosis as a spiritual struggle as they questioned why God was punishing them when they perceived that they were not responsible for the diagnosis. For others, prayer was used as a form of bargaining to seek a better outcome or as a way to find strength to carry their burden. Although women made reference to more frequent conversations with God, none reported an increased involvement with the church, as they did not perceive that this would help them to cope. An overwhelming belief that God could remedy the situation was rare, and references to one's faith been shaken or lost were common. Surprisingly, although references to belief in their God were common in everyday language, only one woman had a faith so strong that she believed that a miracle was possible if she prayed hard enough.

Neimeyer et al (2002) contend that human beings are 'meaning makers' as we seek to interpret our experiences in order to find a purpose and significance in the event. Following a traumatic event such as the diagnosis of a serious or lethal foetal abnormality, basic assumptions about the world, such as, *parents do not outlive their children* and *bad things happen to bad people* are shattered. For many the search for meaning that follows seeks to resolve and restore previously held assumptions. For some, attributions of blame are used as a mechanism to restore assumptions and regain control over the future; by altering our behaviour, we can alter the outcome and regain control of the future. The literature offers

many examples of how individuals in the wake of a traumatic event have used their religious beliefs, faith and spiritual activities as a means of finding meaning and coping.

Although my research did not seek to measure if women of religion coped better with the loss than non-religious women, the findings show that the more demanding searches for meaning are associated with prolonged feelings of injustice, unfairness and loss of control. In this context it is more likely that women will experience a sense of helplessness and hopelessness with little attention focused on the future. Without hope, the pain of the loss can become overwhelming, resulting in self-isolation and potentially despair. Just as some women accommodated the diagnosis easily into their assumptive worlds, some may never find meaning, but other adjustment variables such as somatic effects, negativity levels, future mindedness can be monitored by caregivers and appropriate referrals made if concerns develop, as complicated grief is not a self-limiting process (Zisook and DeVaul 1983). A more recent finding, supported by a growing evidence base, is that complicated grief reactions go together with a sense of pervasive hopelessness.

The term hope has a long history, and according to the pagan Greek myth, hope was the only good force to be contained in Pandora's Box. In the past, the Biblical St Paul exalted Hope as one of the most fundamental Christian virtues, whilst Dante equated the absence of hope with hell (Stroebe, van Son, and Stroebe 2000). In principle, hope has been referred to as a positive expectation, a wish about an issue which has a realistic prospect of coming to pass (Magaletta and Oliver 1999). However a darker side to hope such as blind hope, false hope (Peterson and Seligman 2004) and so on, may exist.¹ Consequently, hope has been presented in binary terms within philosophical debate as both- "a blessing and a curse" (Snyder et al. 2002). In the context of foetal anomaly diagnosis, as the assumption of foetal health is lost,

one strategy utilised by women to reconstruct their assumptive world was to hope for the best possible outcome. For those women who continued the pregnancy, some hoped the outcome would be better than predicted, for others they hoped the foetal would die in utero, and for some wishing to have their baby baptised, the hope the baby would be born alive. For those who travelled outside the State to access termination of pregnancy services, women spoke of how they desperately hoped that one day they could to be open about their decision and their sentiments are reflected in Laura's comment *"I wanted everyone to know something awful had happened to me- not that I did something awful"*.

Finding a responsive other

Of importance to caregivers is the relationship between hope and help. There is evidence in the literature that a person can sustain his or her own hope to a certain degree; however, this cannot continue *ad infinitum* (Snyder, Cheavens, and Michael 1999 p205), as hope seeks for and depends upon external sources for sustenance (Cutcliffe 2004). Within the area of palliative care it has been suggested that nurses have a crucial role as an external source in promoting hope in their patients (DuFault and Martocchio 1985), as hope is seamlessly interlaced with caring (Cutcliffe 1996). When any hope for neonatal survival was untenable, women shifted their goal and welcomed the opportunity to plan a funeral service, to do something practical for their child. Offering pathways to become involved in such endeavours was particularly useful, as it maintained a vision of the future, one where parents could have some influence.

An important change in grief theory development is the recognition of the importance of continuing bonds with the one who is lost. The notion of 'letting go' is being re-evaluated as maintaining a symbolic link with the deceased can be of more help than a hindrance. Many

women spoke of loving the baby they dreamed of, the life they thought their baby would have, and so having a place or symbols of remembrance are important in the grief process. Therefore funerals and remembrance ceremonies can play a significant role. One key benefit of engagement in spiritual coping activities is that adaptive coping is mediated through a greater use of social support such as being heard, feeling loved and valued by others (Cutcliffe 1996, 1995, Cutcliffe and Grant 2001), thus caregivers play a key role at this vulnerable time.

The scope for a dedicated support role to be influential in instilling a higher sense of control in women is boundless. In addition to fostering a sense of benevolence, meaningfulness and self-worth, reassuring women that others have experienced an increase in negative thoughts, and that these thoughts are not only realistic but are extremely common (Janoff-Bulman 1992), reduces the sense of isolation that women experience. However, perhaps the strength of a dedicated support role lies in increasing women's sense of control through accessibility; if women know they have a contact person, someone on their side to speak to, non-judgemental, who can be truly present as they construct their post-trauma narrative. Reciprocity inspires hope, and a significant negative life event such as prenatal diagnosis requires cognitive and emotional re-adjustment as women's desire to contribute to the world by nurturing a capable and caring child are threatened or crushed (Robinson and Fleming 1992), challenging our sense of who we are (Archer 1999).

Planning a pregnancy in the future was a clear indicator that women were making positive progress in rebuilding their assumptive world. Their capacity to revise their beliefs about the world predicated on what the diagnosis meant for them as individuals, and as members of a family and society. Although women are forever changed by this event, many have said they

emerge 'sadder but wiser' but determined to hope for a better future. Kerrie frames it beautifully in the following quote

We have been to hell and back you know. We may never get pregnant again, but if we do I know I have 16-17 weeks of hell...it takes the magic out of it... but you know they say if it doesn't kill you it makes you stronger, so it just makes us appreciate how lucky we are (Lalor 2007a, 189).

The interconnections between traumatic loss and meaning making are undeniable, and an adverse prenatal diagnosis is a profound event that disrupts the life course of those affected. However the relationship between religions and spiritual beliefs and the ability to find meaning in an effort to cope in the aftermath of a prenatal diagnosis requires further investigation.

Notes

¹ Although some women spoke in terms of hoping for a miracle, that the diagnosis would be erroneous or that the baby would die, none were deluded into believing that the particular outcome was possible. Rather it appeared to be a strategy to help the individual to get through the day.

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