

# Systemic Lupus Erythematosus and Pregnancy in Ireland: Complex yet Manageable

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## Abstract

**Background:** Systemic lupus erythematosus (SLE) is a chronic multisystem autoimmune disease that predominately affects women (90%) during their child-bearing years. Pregnancy complications in women with SLE exceed that of the general population. Women with systemic lupus erythematosus (SLE) have fewer children on average than other women. This research aimed to analyse the perspectives of individuals with SLE in Ireland towards pregnancy.

**Methods:** The research involved 23 semi-structured interviews with participants from Lupus groups in Ireland using multiple case study analysis.

**Results:** Two key findings emerged in the qualitative interviews: reluctance towards becoming pregnant, and not conceiving again post-diagnosis.

**Conclusions:** This paper through analysis of qualitative findings highlights the need for psychosocial education and awareness in the clinical management of SLE and pregnancy. Patient counselling should be available for all possible issues that may arise both for the individual with SLE (risk of disease flares and pregnancy complications) and the foetus (risk of neonatal lupus syndromes and learning difficulties). There is a necessity for education on optimal disease control with safe medications during pregnancy.

**Keywords:** SLE; Pregnancy; Self-management; Decision-making; Medicotheology; Psychosocial education; Multidisciplinary care

## Highlights

Perspectives of women with SLE in Ireland on pregnancy.

Women contemplating a fear of the unknown towards pregnancy and pregnancy outcomes.

Choices being made with a lack of awareness and patient counselling in optimal disease control with safe medications during pregnancy.

The need for psychosocial education and awareness in the clinical management of pregnancy.

## Introduction

Systemic lupus erythematosus (SLE) is a chronic multisystem autoimmune disease that predominately affects women (90%) during their child-bearing years. When an individual has SLE although fertility rates are similar to the general population, fertility rates can be affected by renal failure and high steroid dosage [1,2]. Pregnancy can both trigger and cause SLE flares [1-3]. There is a two-to-three-fold increase in SLE disease activity during pregnancy [4]. Common symptoms of flares include rashes, arthritis, and fatigue, and can often be easily treated [5]. Fatigue is reported by 80% of individuals with SLE independent of pregnancy [3]. Approximately 15-30% of women with SLE, who flare will have severe disease manifestations, with the involvement of the kidneys and other internal organs [2]. Certain complications during pregnancy have a higher frequency in those with SLE than those who do not have lupus including; pre-gestational diabetes mellitus, hypertension, pulmonary hypertension, renal failure, thrombophilia, stroke, pulmonary embolus, deep vein thrombosis, major infections, bleeding and thrombocytopenia [6]. American statistics have shown that during pregnancy pre-eclampsia occurred in 22.5% of women with SLE as against 7.6% in the general population [7]. However, although there are risk factors associated with pregnancy and SLE (disease flares, miscarriage, the safety of drugs), there is now better disease control, pre-pregnancy counselling, and understanding [8].

Several key issues are common in the management of SLE in pregnancy including; the treatment of SLE activity during pregnancy, the ascertainment of lupus nephritis, treatment of antiphospholipid antibodies, treatment of hypertension, and laboratory monitoring. Pregnancy complications in women with SLE still exceed that of the general population [9]. Although being pregnant with SLE is high risk, strategies to

control disease activity displayed a 90% success rate in targeting clinical remission [10]. Overall, the medical profession have altered their direction from avoidance [11] to the realisation that pregnancy is possible under careful management. Timing a pregnancy to overlap with a period of SLE dormancy for at least six months strongly increases the chances for a healthy and uneventful pregnancy for both mother and baby [12]. Maternal anxiety has been seen to have an effect on the developing baby, where through identifying anxiety symptoms early in pregnancy caregivers can provide counselling or treatment to decrease the anxiety [13]. Having SLE and being pregnant is complex and can be stressful, which can affect decision-making. Individuals with SLE have fewer children than their normal counterparts [14]. This is potentially influenced by the pressure of performance and challenges in the role of motherhood. Planning a conception and controlling the symptoms of SLE during and post-pregnancy need continuous monitoring and management for both the health of the baby and the mother [15].

## Methodology

The analysis was part of a broader investigation into the lived experience of SLE. Individuals with SLE were recruited through advertisement and word of mouth within the two SLE support groups in Ireland: the Irish Lupus Support Group and Lupus Group Ireland. Using an interview guide, in-depth interviews were conducted that exposed the participant's perspectives on pregnancy and becoming a parent. A case study design was considered in exploratory and instrumental analysis, with the cases playing a supportive role in providing insight and to gain an understanding of pregnancy and SLE [16]. It is suggested that for designing and implementing a case study that additional components be considered:

Propositions (which may or may not be present)

The application of a conceptual framework

Development of the research questions (generally 'how' and/or 'why' questions)

The logic linking data to propositions

The criteria for interpreting findings

Within the semi-structured qualitative interviews, the topic of pregnancy naturally arose in the narratives of everyday living. Participants described symptoms originating during pregnancy, fatigue and work commitments that led to the emerging themes. Propositions were not present in the research. The conceptual framework identified who should participate in the study. The 23 female participants varied by age (19 to 59 years) and came from different socio-demographic areas across Ireland. The age range gave the perspectives of participants examining their options in the future regarding becoming pregnant and those who had chosen not to become pregnant. The participants were given pseudonyms to maintain their anonymity. The framework developed as the study progressed, analysing the experiences and themes that emerged from the data analysis. Interviews were transcribed verbatim from the Dictaphone recording and

analysed. Using N-Vivo software, the transcripts were reviewed over multiple sessions and refined thematic codes in a systemic and inductive manner. A comparative method was used for reporting these case studies with the same case study of pregnancy being described by different perspectives [17,18]. This research was approved by the University College Dublin Human Research Ethics Committee (Humanities). Participants signed informed consent forms and gave permission for the use of their case studies in research and publications.

## Results

Two key findings emerged in the qualitative interviews; reluctance towards becoming pregnant, and not conceiving again post-diagnosis. Five participants aged between 21-35 who were not yet in serious relationships told of their reluctance towards becoming pregnant in the future due to the risks associated with SLE in pregnancy. The participants over the age of 35 who already had children had not conceived again since their diagnosis of SLE. There were numerous factors attributing to this; lack of knowledge, fatigue impacting parental ability, and fear of risk to self and the foetus. Participants who had children spoke of how their SLE impeded their functioning so that they could no longer work and be a parent; other family members and friends were relied upon (such as bringing and collecting their children from school), and husbands taking on both the 'breadwinner' role and the 'domestic' role.

This paper divides the findings into two sections. Firstly, the findings look at an experience of SLE during pregnancy and how it was managed. Secondly, the findings examine participants who are reluctant to become pregnant due to the complications not just to themselves but also to the unborn child.

## An Experience of SLE during a Pregnancy

Emer had one miscarriage in between her pregnancies, with a seven-year age gap between her two children. During her second pregnancy, she had been 'extremely tired from day one' which she saw as a different type of fatigue that she could not fully explain. Emer had wondered if it was related to being 'that bit older', but at 26 weeks she had a stroke. Emer's slurred speech had been noticed the previous week. She had a dead arm and had lost the feeling down the right-hand side of her body which she attributed to the baby lying on a nerve. It was only when she was in the hospital for tests that she realized she could not sign her name:

*"I was like 'oh my God, so there is something really wrong here'. So I had the CAT scan and they wanted to do an ultrasound and I was absolutely terrified and thought that's it, because the baby had actually stopped moving, and I thought that's it, you know a miscarriage or whatever. So I couldn't look at the screen, really couldn't, and I was in floods of tears; I*

*was inconsolable. He popped up on the screen. So, once he was okay I thought 'grand; we'll deal with the rest of it'.*

In 1983, Ireland became the first country in the world to constitutionalise foetal rights. The 8th Amendment (Article 40.3.3) introduced constitutional protection for 'the right to life of the unborn', which was deemed 'equal' to the right to life of the mother [19]. Since 1861, abortion has been criminalised with Ireland viewed as having some of the most restrictive abortion laws in the world [20]. The passage of the 8th Amendment introducing 'the right to life of the unborn' allowed the 'political system to systematically abdicate responsibility for the responsible regulation of reproductive freedom in Ireland' [21]. This Amendment is seen to have contributed to the ill-health and deaths of unknown numbers of women and, potentially, children [22]. It has faced political and legal protest due to cases involving child rape resulting in pregnancy, a death due to septicaemia and *E.coli* during a protracted miscarriage, subsection of unwanted Caesarean section, and maintenance of organ function of a deceased woman to prolong her pregnancy [23]. In 2013, the Protection of Life during Pregnancy Act outlined the circumstances for which abortion is lawful when there is a threat to the life of the woman [24]. However, abortions in circumstances where the health of the woman is at risk, where the foetus suffers from a fatal foetal abnormality incompatible with life outside the womb, or where the pregnancy results from rape all remain unlawful in Ireland [25]. The Act has limited references to choice, dignity or reproductive rights [26]. In terms of ethics, equality means treating both the mother and the foetus with equal value and respect. The aspect of equal rights for mother and the unborn was seen within Emer's medical care.

*"Funnily enough, when you're actually pregnant and something goes wrong, they've to spend as much time on the mother as the baby. They need to make sure that the pregnancy is continuing, and it's basically a case of treat the two separate individuals but at the same time, so that's how it sort of proceeded".*

During this time SLE was not detected, and the medics were 'baffled', with tests showing multiple clots on the left side of the brain. The next phase was of regaining functioning ability. However, with the pregnancy came limitation as the medics wanted her to rest between the stroke and giving birth because of her brain injury.

*"So I was like in 14 weeks I'll have to be able to give birth and look after a baby and function in some way myself. So there was a bit of urgency about it".*

The link with SLE was not identified initially but in retrospect, it seemed to have emerged after her first pregnancy. Emer noted there was no pattern to 'join up the dots' in between pregnancies. Symptoms included headaches, joint pains, sore muscles, fainting, nausea and low haemoglobin levels. The stereotypical association of tiredness and being a new mother may have shaded the actual SLE symptoms. Then, only a week after giving birth to her son, Emer had another minor stroke.

*"They would take the babies into the nursery, for the first two nights to give the mother a sort of rest. The nurse pushed him back in at 6 am and I thought 'right, I'll just get up now to move'. I couldn't move. So I was thinking 'Oh God I've a terrible headache', I know what this is, so I managed to wriggle and wriggle and got the bell".*

Emer asked the nurse to feed him, to which the nurse questioned why after the baby had been in the nursery all night. Emer then mentioned that she had a 'slight problem'.

*"I can't feel the right side of my body, now don't panic, this has happened before, but I think I've had another stroke'. She flies off and comes back with about ten others, and I'm there 'no, it'll be okay, but can you feed him, he's waking up there, he's due his feed. I was more concerned that [the baby] would get fed than anything else".*

Emer's situation represents the overall concern that the participants' predominant concerns were for the risk to and care for the child. Emer noted that since her pregnancy and diagnosis, one significant change was the Antiphospholipid syndrome (APS). Antiphospholipid antibodies have been found to be increased in pregnant women who have had miscarriages. The combination of thrombotic problems, miscarriages, and/or a low platelet count is referred to as APS. This identifies the importance for doctors to check for these antibodies in the event of an individual having a stroke, heart attack, or miscarriage for no known reason. APS provokes blood clots in arteries and veins, as well as pregnancy-related complications such as miscarriage and severe pre-eclampsia [27].

*The one thing that has changed is the APS, which is the blood clotting which I presented with first. I believe now that if you present with 3 or more miscarriages in pregnancy they will automatically test for APS because there is now a confirmed link to miscarriages, and there is a risk of APS, there but there's still not looking at the Lupus part. They're only focusing on APS. Initially, it was considered the entire one. But say, for example, I presented with primary APS, now at that stage I wasn't SLE, I've only been SLE since 2006. It was primary APS, secondary SLE. But it seems it was inevitable that it would always go that way, but there was a chance that it wouldn't so the two can exist completely separately. You could just have APS and never develop SLE.*

Emer's narrative displays confusion around the prognosis of APS and the implications. Emer's second son has since developed Juvenile Idiopathic Arthritis, which some participants view the impact of maternal SLE on the foetus as a reason they are reluctant to becoming pregnant.

## Reluctance to becoming Pregnant

Heather is a 22-year-old childminder who developed SLE when she hit puberty. Her symptoms are multi-system including; joint pain, chest pain, anaemia, migraines, exhaustion, and stage five kidney damage.

*It makes me think about having children when I'm older because I'm only 22. I don't want to have children. I'm minding*

*them at the moment – there's more than one. But because I'm on the immunosuppressant even if I wanted to have a child now I wouldn't be able to because there's way too many complications, with deformities and things like that. And when I do eventually get pregnant - fingers crossed that will happen when I want it to – I'm a high-risk pregnancy, a higher chance of miscarriage, higher chance of far more complications and things like that. And when I'm older I want to be able to do the things my mum's done. I want to be able to go away. I want to be able to do whatever I want. I don't want to have to be sick at home, not being able to look after my children or whatever. So it does make me think about that.*

Heather gives two different perspectives about having children. Overall is a dominant reluctance to having children as she worries about the high chance of miscarriage and complications. Due to the 8th Amendment, if there are complications, there is awareness of the limitations surrounding choice, dignity and reproductive rights. However, she briefly mentions the dream of a 'fingers crossed' pregnancy but counteracts that by questioning the ability to have a good quality of life with her child. Heather's concern that her immunosuppressants would cause 'deformities' leads to reviewing neonatal lupus erythematosus (NLE). NLE is a 'clinical spectrum of cutaneous, cardiac, and systemic abnormalities observed in newborn infants whose mothers have autoantibodies against Ro/SSA and La/SSB' [28]. When only skin lesions are present children with SLE, have an excellent long-term outcome. Cardiac involvement due to NLE is associated with a 20 to 30% morbidity rate in the neonatal period [29]. Mothers with anti-Ro/SSA and/or anti-La/SSB antibodies and infants with congenital heart block have a 17-25% risk of recurrence in subsequent offspring [30,31]. Research has indicated the importance of careful monitoring and multidisciplinary team involvement [32]. Women with SLE should be treated with drugs that are effective and safe for the foetus, to help diminish or reduce NLE conditions; these can include some immunosuppressive medicines and corticosteroids [33]. Findings have indicated a link with learning difficulties, but no differences in intelligence have been seen compared with the general population [34].

Fiona is a 30-year-old unemployed health and safety officer who displayed SLE symptoms since puberty but attributed the triggering in 2009 when she had a severe reaction to her wisdom teeth being removed. Her symptoms have included depression, grittiness sensation in her eyes, rashes, inflammation, hair loss, and fatigue.

*It just makes me worry that I'll end up on my own and that I want to have kids. I'd love to have kids. Could I have kids? Between my lupus and my chronological problems, it's very unlikely. But do you go for someone who does not want kids, but I do want kids? And there is a small chance you could have kids. Do you take someone else's chance in a way by saying, 'I want kids with you, but I probably can't have them', which means you would have them if you stay with me? It's very complicated.*

To represent concern of parenting ability, one of the participants, Sandra, a teacher in her 40s with two sons (a

teenager and an 8-year-old) has had SLE symptoms for over two years which she describes as 'completely debilitating'. She requires assistance such as 'getting from chair to chair'. Sandra identified the effect of her SLE on her children:

*It's very hard on the 8-year-old. The teenager kind of carries on with his life, but the 8-year-old is constantly asking me what kind of day I'm having and am I any better and will I get better. You know, when he asks for something to eat, and he'll say: 'Only if it's possible. Only if you can', He walks slowly next to me. He allows for my pace. He's doing great, but the fact that my husband has had to take over everything in the house and the shopping and all of the [chores]. He's really become a househusband. He works full time, but he has to do everything. So everyone's affected.*

This background of living with SLE highlights potentially why the participants in this research did not conceive again after SLE diagnosis or made other choices instead of pregnancy. The 8th Amendment does not legislate for children dependent on mothers who are potentially at risk; it seeks life existence itself rather than life outcome. An illness impacts not just on the mother, but also on their children and if they have a partner. Physical symptoms such as fatigue and nausea, and hospital visits (creating separation) were seen as particularly disrupting to mothering roles in the face of illness [35]. The impact of an illness and its treatment can, in turn, lead to changes in both roles and relationships, where a dependent child someone else will need to fulfil these roles and relationships [35]. Two of the participants over 40 years old discussed the life choice of work over family life, indicating that doing both was not seen as possible. The findings indicate that multidisciplinary care is lacking as none of the interviewees indicated pre-conception assessment or counselling (advice giving, information sharing and therapeutic work) prior to pregnancy or suggested in advance of that situation, or indeed post-pregnancy.

## Discussion

Pregnancy and SLE remains a high-risk situation, where multidisciplinary care with close monitoring is essential for good outcomes [36]. The importance of counselling on contraception is a priority, as a planned pregnancy is associated with fewer complications and successful outcomes, however, research has identified that this is a 'forgotten duty' [37,38]. Counselling in Ireland emerged in the 1960s under the auspices of the Catholic Church, with a belief in the sanctity of life [39]. However, the role of the Catholic Church in Ireland has changed dramatically in the last several decades from 'devotional loyalty, political influence, and institutional power' to reform and renewal to a 'more humble, prophetic, and creative presence in Irish life' [40]. Religion guides and defines cultures and medicine, and is largely influenced by such beliefs [41]. But religion is morals not ethics; 'ethics in medicine would refer to a rational, holistic consequentialism' [41]. The church versus medicine battle is 'a subcategory of the Church versus state battle whereby the Church often sees itself as above the state and above medicine' [41]. Furthermore, Irish hospitals provide pastoral counselling. Pastoral counselling



approaches by Catholic priests found a lack of awareness of counselling skills, techniques, models of helping, with a need to establish barriers. There is no formal supervision, and the counselling sessions were usually a single session with a problem-solving approach to reach rapid solutions [42]. Catholic bioethics focuses on social justice, the right to healthcare, ethics of human reproduction and end-of-life decisions, and the duty to preserve life – the belief in the sanctity of life [43]. In Ireland, the Health Service Executive provides free public maternity care under the Maternity and Infant Care Scheme to 'ordinary residents' living in the country for over a year. This includes six antenatal GP visits and six antenatal hospital visits, where the hospital appointment is scheduled for the 12<sup>th</sup> and 20<sup>th</sup> week of pregnancy. Conditions, illnesses or injuries that are not related to the pregnancy are excluded from the Scheme and the usual healthcare costs apply. This highlights a lack of respect and care for individuals with SLE facing potential complications during pregnancy that differ from the typical pregnancy. Counselling in Ireland remains unaffordable for many and is unregulated on a statutory basis [44].

These factors potentially create issues around access and barriers to care. The findings call for the strategic management of pregnancy in patients with SLE to give security in decision-making and preventative care.

These case studies can be conceptualized from a psychosocial perspective, which call for integrative measures of care. The invisibility of SLE is seen through the symptoms that can be invisible and also typically immeasurable subjective experiences [45]. Furthermore, there is 'no predictable path from warning signs to recovery' rather the individual with SLE lives with 'a baseline of un-wellness that is interrupted by periods of exacerbation and remission, relapse, and remission' [46]. Fatigue was a dominant symptom experienced by all the participants. Fatigue has no predictable paths where they may be reliant on others. Additionally, the hidden symptoms such as joint pain impede the individual's quality of life and functioning ability. This inevitably impinges on the decision-making process of conception and pregnancy. Corcoran noted that although survival rates in Ireland have improved, quality of life has been left unaddressed [47]. The everyday fluctuating symptoms can lead to isolation and fatigue, which subsequently only accentuates the impediments of this chronic illness. It is known for women with SLE to be at risk of psychological distress, such as depression and anxiety; eliciting symptoms. Recurrent miscarriages are linked with SLE [48]. Miscarriages lead to higher levels of pregnancy-related fear and state anxiety, resulting in a negative impact on the course of the pregnancy and delivery [49].

So, with this distress due to lack of understanding of the individual's subjective experience of SLE, accompanied by slow periods of diagnosis where numerous consultations and tests are needed before any progress is made, how can an individual make the life-changing decision of becoming pregnant when they have an unpredictable and limiting illness? Family and friends are viewed as pivotal in supporting the individual with

SLE to live an active and independent life as well as enhancing security. Eighty percent of individuals with SLE reported that their ability to function in various family roles was negatively affected with SLE. To keep a balanced quality of life other mandatory activities and work were forced to be chosen ahead of family by 60% of individuals. Families help individuals with SLE to maintain independence without a reliance on social services, concluding that SLE along with income, relationships and social services all influenced the experience of quality of life. However, not all individuals have a supportive family, and unforeseen circumstances mean there is no long-term guarantee of family and friends always being there to be dependent on for enhancing independence.

This leads to the reasoning that to enhance successful pregnancy outcomes of individuals SLE education is needed. The case studies call for tertiary care, separate from GP and hospital visits, providing specialized investigative attention, treatment, and information to individuals with SLE. Adapting the concept of Preventative Home Visits (PHV) to reflect similar care for individuals with SLE is proposed. PHV has been seen to lead to positive changes such as; accentuating the participant's human value, bringing a feeling of security, and giving an incentive to action. PHV are carried out by health professionals seeking to increase autonomy through primary, secondary and tertiary prevention activities, differing from home care interventions treating individuals with medical problems focusing on risk factors.

There is a need for personalised care, taking into account individual's characteristics and coping attitudes to self-manage their conditions. Anxiety can result from a lack of knowledge and education which leaves individuals more dependent on health care than necessary while PHV also draw on patient empowerment in coping skills and self-management.

Reflecting on how PHV assists in providing knowledge and education (changes in knowledge, social participation and self-advocacy compared with the normal care group) leads to a model that SLE can be incorporated into. This would result in knowledge on appropriate drugs, risk factors, conception education, managing symptoms and planning ahead, their illness being taken seriously with public awareness, and the individuals participating in decision-making concerning their health. Currently, the public health nurse calls to the house to check that the baby is progressing. However, a SLE model of PHV and tertiary care directed towards equal care for both mother and baby that may potentially provide a level of specific care directed towards SLE.

The tertiary care would result in a level of self-management being taught before, during, and after an individual with SLE considers becoming pregnant. This self-management would create an interactive and daily process aimed at helping the individuals with SLE to maintain a wellness perspective by engaging in the medical and emotional management of tasks.

Pregnancy outcome for women with SLE has improved remarkably, with an 85% increased success rate in recent years seen in international populations with multidisciplinary approaches including pre-pregnancy counselling, risk

assessment and early recognition signs of complication. However, the unfortunate case is that, in general, there is no self-management education for individuals with SLE in Ireland, and all SLE support is provided on a voluntary charitable basis [35-51].

## Conclusion

If individuals were to be educated in maintaining, changing, and creating new life roles and behaviours to deal with the emotional consequences of having SLE, potentially pregnancy would not seem like such a daunting prospect. The effects of the 8th Amendment are felt on a daily basis by women in Ireland with restrictive legislation that impinges on decision-making. Psychosocial education and awareness would provide strategic management of gestation in women with SLE to give security in decision-making, preventative care, and safe treatment options accompanied by multidisciplinary care.

The multiple case studies have provided contrasting results (the birth experience, work life, quality of life and ethics), but for predictable reasons such as fear of complications [51]. Regulated patient counselling should be available for all possible issues that may arise both for the individual with SLE (risk of disease flares and pregnancy complications) and the foetus (risk of neonatal lupus syndromes and learning difficulties). There is a clear necessity to provide an education on the need for optimal disease control with safe medications during pregnancy.

## Conflict of Interests

The author declares that there is no conflict of interests regarding the publication of this paper. They have no competing interests.

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