

School of Nursing & Health Studies

## SYMPHYSIOTOMY IN IRELAND: A QUALITATIVE STUDY

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### **1.** INTRODUCTION

Symphysiotomy is a surgical procedure used in the arrest of descent during the second stage of labor in order to increase the diameter of a woman's pelvis and allow for a vaginal birth. Initiated in France in the 18<sup>th</sup> century, this procedure involves severing the cartilage that connects the symphysis pubis with a scalpel under local anesthesia followed by unhinging of the pelvic bones to the extent needed for delivery. (Bergström, Lublin, & Molin, 1994).) A related procedure, pubiotomy, which was sometimes mislabeled in medical records as symphysiotomy (O'Connor, 2011), involves the cutting of the pubic bone to obtain the pelvic enlargement.

### History

First performed in 1777, the high maternal and fetal mortality rates for the procedure limited its use until the advent of aseptic procedures in the late 19<sup>th</sup> century. By the early 20<sup>th</sup> century, both symphysiotomy and publotomy saw resurgence, although publotomy soon fell out of favor due to continued high mortality and morbidity. Modifications to the symphysiotomy procedure and the use of local rather than general anesthesia led to acceptance of the procedure in some parts of Europe and South America (Björklund, 2002). Maternal and fetal mortality associated with symphysiotomy in the early 20<sup>th</sup> century was much lower than that associated with other options for obstructed birth, such as caesarian section, forceps delivery, or embryotomy (Grebbie, 1982). With the introduction of the antibiotics sulphanomides and penicillin in the mid-20<sup>th</sup> century, caesarian section became safer and its use was promoted over symphysiotomy in western medicine.

Due to the traumatic invasion of tissue and physically denaturing effects, symphysiotomy has all but disappeared in western medicine, although there are some who have called for its revival in very rare emergencies for shoulder dystocia or breech birth when the head is trapped (Goodwin, Banks, Millar, & Phelan, 1997; Menticoglou, 2009). Symphysiotomies are recommended for use in developing countries only in emergency situations when delivery by cesarean section is not a viable option and only with appropriate post-delivery management. (Wykes, Johnston, Paterson-Brown, & Johanson, 2003)

### The Case of Ireland

In the mid-20<sup>th</sup> century, at a time when the rest of Europe and North America had abandoned the practice of symphysiotomy, its use was championed by some Irish doctors (Barry, 1952; Spain, 1949). While acknowledging that the use of antibiotics and improved Caesarean Section (C-section) techniques made C-section a preferred technique when problems with delivery were anticipated before labor had advanced, both Barry and Spain noted a particular advantage to symphysiotomy for Roman Catholics—from their perspective, it facilitated future vaginal deliveries.

Ireland was also differentiated from other European countries in the mid-20<sup>th</sup> century by family size and the number of pregnancies and deliveries individual women underwent (Fahy, 2001). Walsh (2012) notes that women experiencing their 8<sup>th</sup> delivery in Ireland during this period were fairly common. She continues: "In addition to live births, women could furthermore expect to

suffer miscarriage, stillbirth, and post-partum difficulties including incontinence, uterine prolapse, diabetes insipidus, and perineal problems" (p. 18). Walsh suggests the lack of options to control fertility as one of the key reasons for the return to symphysiotomy in mid-20<sup>th</sup> century Ireland.

There are few records available for most hospitals in Ireland during this time, making thorough documentation of the use of symphysiotomy difficult. In four hospitals-three in Dublin and Our Lady of Lourdes in Drogheda, there are reports documenting the use of symphysiotomy from 1944 to 1984, with the most frequent usage from the late 1940s to through the 1960s. It should be noted that even in the hospitals with the heaviest reliance on symphysiotomy, the procedure remained quite rare, accounting for an estimated 0.05 percent of all deliveries (Walsh, 2012). The highest prevalence recorded was in 1956 in Coombe Hospital, Dublin, at 1% of all births. In comparison, C-section prevalence averaged just under 2% of all births in 1944, rising to a little over 4% in 1984 (Walsh, 2012). The low prevalence, combined with available published case histories, suggests that symphysiotomy was rarely used and generally only in emergency situations. Nevertheless, records show that prophylactic use of symphysiotomy was also undertaken during this time at some hospitals, a use that was not in accordance with the recommendations of experts at the time (Walsh, 2012). Cases of symphysiotomies performed after a caesarian section while the woman was still under anesthesia were reported at several hospitals in Ireland. The reason given was that the permanent widening of the pelvis would facilitate future vaginal births. Symphysiotomy in this situation has been roundly condemned and was controversial even at the time (Barry, 1952).

Although formal standards of care, including indications for use, techniques, and post-surgical care, did not exist for symphysiotomy, or for other medical and obstetric procedures, at the time, there were frequent discussions of these issues at medical conferences and in the medical literature. In fact, symphysiotomy was one of the most debated subjects during the 1950s in the "Transactions" of the Dublin hospital (Walsh, 2012). There was general agreement that the procedure should be done only in cases of pelvic contraction resulting in obstructed labor and in cases of unusual presentation in which repositioning of the child is unsuccessful (Barry, 1952). Spain (1949) argued for expanding use of the procedure to before labor began or early in labor for women with seriously small or malformed pelvises, but this prophylactic use was quite controversial. Barry (1952) described how symphysiotomy should be performed. Although he indicated that no special nursing aftercare was required, he did indicate that a "symphysiotomy belt" (p. 53) should be used for support of the pelvis for at least four to five days and up to 11 days, that pain medicine could be administered, that a girdle or pelvic support should be used if the patient felt it necessary, and that heavy lifting should be avoided for three months. These recommendations are quite similar to those made in the 1970s and 1980s when symphysiotomy became prevalent in developing countries, although the later standards of care recommend that walking be delayed until the woman felt ready and that supports such as walkers be used in the beginning (Grebbie, 1974; Hofmeyr, 1961).

There is much controversy over the justification of symphysiotomies performed in Ireland between 1944 and 1984. In fact, the procedure was often carried out without a woman's understanding or her consent. Most of the estimated 1,500 or more Irish women on whom symphysiotomies had been performed, and who were alive in 1999, learned, for the first time in

that year that the procedure had been performed on them, as a result of a newspaper article based on a doctoral thesis. Due to the damaging impact this procedure reportedly has had on women and families, it is important to investigate the contributing factors that allowed symphysiotomies to take place in Ireland at a time when cesarean sections were the norm in developed countries, where symphysiotomies had scarcely been used since the early 1900s.

The purposes of this study, carried out from August 2011-September 2012, inclusive of data collection, analysis and report preparation, were: 1) to explore the factors that contributed to the use of symphysiotomy as a delivery intervention in Ireland from 1944 through 1984; and 2) to explore the impact of symphysiotomy on the women on whom it was performed.

## 2. METHODS

### 2.1 Research Questions

The research questions are:

- 1. What are the factors that contributed to the use of symphysiotomy as a delivery intervention in Ireland from 1944 through 1984?
- 2. What has been the impact on the women on whom symphysiotomies were performed?

### **Research Design and Protection of Human Subjects**

The study was cross-sectional and descriptive; it entailed the use of qualitative methods, including individual interviews and structured review of existing documents.

As is the case with all research involving human subjects conducted by Georgetown University faculty and/or staff, this study received approval from the Institutional Review Board (IRB) prior to any data being collected. Indeed, because of the particularly sensitive nature of the study, this process was lengthy and quite rigorous. All required aspects of protection of human subjects was assured and implemented, including but not limited to: all researchers' completion of the National Institutes of Health required online course; use of informed consent with all of those interviewed; diligent maintenance of the confidentiality of data and information. IRB approval was received on July 12, 2011; the IRB number is 2011-332. The interviews were conducted over a six-week period in July-August 2011.

### 2.2 Sample

The sample of women and their husbands was selected using the snowball method with women who are survivors of symphysiotomy and whose names had been reported in Irish media being asked to participate in the study and being asked to assist in contacting other women who are survivors of the procedure. These women in turn made contact with others to obtain permission for the authors to interview them. This ensured that the women had an opportunity to determine if they wished to participate in the interview prior to the visit by the researcher. They were also asked to suggest the most appropriate location for the interview. When the researcher met each woman or husband, but prior to conducting the interview, she gave each interviewee a hard copy of the informed consent script and also read it allowed to the interviewee. The researcher also asked the woman permission to review her medical records that pertain to the symphysiotomy and to which the woman had access. There estimated to be less than 180 survivors of symphysiotomy; 35 women were asked to participate in the interviews (nearly one-fifth) and 29 agreed to do so. All of the eight husbands who were asked to be interviewed agreed to do so. The authors recognize that this is a self-selected sample, but maintain that this is acceptable for the purposes of a qualitative study designed to yield descriptions of the women's experiences with the procedure. There is also no intent to generalize the experiences of the women participating in the study to others who had the same experience.

In order to help ensure that the widest possible perspectives of the practice of symphysiotomy in Ireland during the period of interest would be obtained, many attempts were made to interview physicians and midwives who performed the procedure or cared for the women after the procedure. Unfortunately, none was possible.

### 2.3 Data Collection Instruments

Two types of data collection instruments were used in the study: 1) a structured review form to review public documents and peer-reviewed-articles; and 2) individual interview guides. These are described below.

To help ensure that the relevant data and information were extracted from the public documents and peer-reviewed literature, the researchers used structured review form designed for this purpose. The form was developed to ensure that, insofar as possible, the variables related to the study were recorded. A form also was developed for use in extraction of key information from the patient files of the women who agreed to be interviewed and who provide permission to review the medical files related solely to the symphysiotomy procedure. The researchers were trained in use of these forms. The proposed structured review form is shown as Appendix 2.

The individual interview guide was modular in form; that is, there was a base set of questions for all categories of respondents and specific questions for each category. The guide used for the women included 22 items and three categories: 1) demographics; 2) child-bearing; and 3) experience with symphysiotomy. In the latter category, the respondents were asked to describe their personal experience and its impact on them and their families. The guide used for the husbands included 17 items and two categories: 1) demographics; and 2) experience with symphysiotomy. The interview guide was semi-structured, with a focus on open-ended questions so that respondents had an opportunity to "tell their story." The guide was designed such that the interview was planned to last 30-45 minutes. However, given the nature of the topic and the research questions, many of the interviews lasted for one and a half to two hours. Each of the women and husbands interviewed simply wanted to tell her or his personal story. Three experts in labor and delivery and two health researchers reviewed the individual interview guide.

### 2.4 Data Collection Methods

The data collection methods included review of public documents and published research articles; individual interviews; and review of patient records related to the symphysiotomy procedure.

Beginning in the first month of the study and continuing for twelve months, the research team collected available: 1) public documents related to symphysiotomy in Ireland from 1944-1984; 2) peer-reviewed articles related to symphysiotomy in general and to its use in Ireland during that time period; and 3) mass media materials including newspaper and magazine articles and television reports/documentaries. The research team used the structured form to review the each of the documents. During the data collection, the researchers tried to access additional documents that were available; these also were reviewed using the structured form and the results included in the synthesis. The synthesis of findings of the literature is included in this report.

Research team members from Georgetown University School of Nursing and Health Studies conducted the individual interviews. Most of the interviews took place in the home of the individual(s) interviewed. In the case of the exceptions, the interviews took place, as indicated previously, in a location of the woman's choosing or, in case of an interview with a husband, of his choosing. All of the interviews were audio-recorded with the permission of the interviewee. The researchers kept these audio-recordings and notes in a portable locked file that they carried with them on the interviews.

The symphysiotomy procedure\_medical records of the women who have participated in the interviews were obtained from three women interviewed and reviewed by the researchers at the location of the interview. The researcher then extracted the data that related to the research question. No identifying information of any type was recorded on the form. Nonetheless, the researchers kept the Record Extraction Form in the portable locked file that they carried with them on the interviews.

### 2.5 Data Analysis

The audio-recorded interviews were transcribed verbatim over a four-month period. This was a much more lengthy process than anticipated for three reasons: 1) availability of the researchers who conducted the interviews, all of whom were either in school or working fulltime and who were volunteering to conduct the study; 2) the quality of some of the audio-recordings, which at times necessitated multiple occasions of listening to the recording to ensure accuracy; and 3) the nature of the discussion, which made it difficult for those transcribing the recordings to do so for more than two hours at a time.

The responses were then entered onto a Word spreadsheet sorted by question item. The researchers analyzed the data using the Glaser and Strauss grounded theory method (Glaser and Strauss, 1967) and specifically the editing analysis style. At least two researchers identified key words or phrases in each of the responses to each of the questions. At this point, they also initially identified potential (anonymous) quotations that could be used in the report of findings.

The research team then met to discuss the key words and reach agreement on them. At least two researchers then independently identified categories of responses; the Principal Investigator then selected the final categories and, together with two researchers, identified crosscutting themes. The researchers then used these categories to review the transcriptions and synthesize the findings by categories.

### 3. FINDINGS

### 3.1 Who are These Women, These Survivors?

Participants in this research study ranged from 56-86 years of age at the time of the interview, with the majority of participants between 60-80 years of age. Two-thirds were married at the time of the interview; 28% were widowed. While most participants currently live in County Louth, Ireland (n=22, 76%), other participants live in counties Cork, Dublin, Galway, and Meath. Similarly, the majority of symphysiotomies were performed in County Louth (n=23, 79%). Most women and their husbands interviewed in the study had completed primary (n=9, 31%) or secondary (n=9, 31%) education. However, a few reported completing a college degree (3) and/or technical schooling (4).

The participant's living situation at the time of her symphysiotomy was used as an indicator for economic status. Most participants (8, or 28%) lived with their family; six owned their own home or flat and, six rented their flat or home.

The women were asked about their pregnancies; most – 13, or 45%-- reported having between four and six pregnancies; seven (24%) reported having between one and three pregnancies. Just three had seven or more pregnancies. Most of the women interviewed reported having children still living.

Characteristic		Number of Participants	% of Participants
	•	(n=29)	
Age (in years)	50-60	6	21%
	60-70	10	34%
	70-80	8	28%
	80-90	4	14%
	No response	1	3%
County of Residence	Cavan	1	3%
	Cork	1	3%
	Dublin	1	3%
	Galway	1	3%
	Louth	22	76%
	Meath	4	14%
County where Symphysiotomy	Cork	2	3%
was Performed	Dublin	1	3%
	Galway	1	3%
	Louth	21	79%
	Meath	4	14%
Level of Education	Primary	9	31%
	Secondary	9	31%
	College	3	10%
	Technical	4	14%
	No Response	4	14%
Marital Status at time of interview	Married	19	66%
	Widowed	8	28%
	No Response	2	7%
Economic Status at time of	Lived with Family	8	28%
Symphysiotomy (indicator: ownership of a home)	Owned a Home	6	21%
	Rented	6	21%
	Other	4	14%
	No Response	5	17%
Number of Pregnancies	1-3	7	24%
	4-6	13	45%
	7+	3	10%
	No Response	6	21%
Number of Pregnancies Carried	1-3	9	31%
to Term	4-6	12	41%
	7+	2	7%
	No Response	6	21%
Number of Children Currently	1-3	10	35%
Living	4-6	11	38%
	7+	1	3%
	No Response	7	24%

## Table 1. Demographics of study participants

# **3.2** Lack of knowledge and consent: what were the women told about Symphysiotomy prior to the procedures?

Lack of consent and lack of information about symphysiotomy were two pervasive themes throughout the interviews. None of the 29 participants reported that she or her husband gave consent for the symphysiotomy procedure. At this time in Ireland, husbands were not particularly involved in childbirth. As one husband explained, "We were shielded from that, childbirth was a woman's area and men didn't have anything, men had no knowledge of it." While some women chose to discuss the procedure with their husbands afterwards, many kept it a secret for years.

Most women reported that they had either never heard of the procedure or didn't know what the procedure was at the time of their delivery. One woman reported that they had her signature for consent but she didn't remember signing it and felt forced into the procedure. Another participant explained she was told she would need an operation, but wasn't told what that operation would entail. Doctors rarely gave an explanation of what they were doing before or during the procedure. As one woman explained,

"Right before they broke the bone the doctor told me I was going to have a symphysiotomy, but I didn't know what it was, or what they would do. But I was in labor at the time, so I wasn't in the questioning mood."

Acceptance of a healthcare provider's word, particularly that of a doctor, was *status quo* in Ireland for most, if not all of the time that symphysiotomies were performed in Ireland. Thus women were unaware of what was occurring at the time of the procedure itself as well as unaware of the accepted practice for post-symphysiotomy care. In spite of the fact that they usually suffered severe pain and discomfort, the majority accepted the procedure as necessary, not questioning the pain they endured.

Even after the procedure women were unaware that a symphysiotomy had been performed on them. Indeed, many women and their husbands reported that they did not know what happened to them until 1999, when the Irish Times (the most popular daily newspaper published in Ireland) carried an article based on Dr. Jacqueline Morrissey's doctoral thesis— and the subsequent television and radio reports. Some did not know until a small group of survivors joined together following the publication of the Irish Times article, formally launching the Survivors of Symphysiotomy (SOS) in the Shellbourne Hotel in Dublin in May 2002. Another organization critical for the survivors has been Patient Focus, one of Ireland's leading national patient advocacy groups, formed in 1999.

### 3.3 The Procedure

Symphysiotomy was an exceedingly painful experience for the women, in both physical and psychological terms, from the initiation of the procedure and for many years thereafter for most of them. In fact, for most, mistreatment began before the start of the actual surgery. Women

recalled negative experiences with medical professionals regarding discussions of their plans of care. In tears, one woman related:

I had four other children at home...[and] wasn't expecting to be admitted to hospital straight away. ... I was trying to say this, and I'll never forget. He just stood up, and he... said, 'Well that's my medical opinion. If you don't wish to come into the hospital, then I will no longer treat you if anything happens.' So I was dumbfounded when I came out, and I remember crying to my husband, because he was waiting, and I said I have to go in straight away.

The doctors and nurses were uninformative. Explained one woman,

He said nothing so then the day went on and it was absolutely horrendous and you know and I didn't get an awful lot of attention; nobody said anything. Nurses were... they were so worked, overworked and I knew they just didn't have time and then eventually it could have been 6, 7 the next evening they said we're bringing you down to theater for Doctor Connolly to help you."

Although the procedure was ostensibly required in order to facilitate delivery, in one case the baby had already been delivered—there was, therefore, no medical justification for the procedure. Indeed, there was a lengthy legal case that was recently decided in the plaintiff's favor, with the presiding judge stating that the reasoning offered for the use of the procedure with this delivery was "almost unfathomable."

The women described the excruciating details of their symphysiotomies, highlighting not only the pain but also the confusion about what was going on and why. Said one, "[all] I heard them saying was 'slice, slice' for a few hours." Another compared the sound of the instrument to that of an electric meat carver. One woman explained, "I had felt he had hammered – to me, it felt like he had hammered a red hot poker through the bottom of me there." Multiple individuals described the physical sensation as "an explosion of pain" and noted periods when they were roaring and screaming. One victim described her experience as follows:

And next I could feel the pelvis caving in, and an awkward sensation that went through my body. I won't ever forget that. I could feel everything get up to my head. It sort of went down then eased away. Everything just seemed to cave in down there. It was a terrible experience. Then I had to push as well for the baby, they were telling me to push. So I did that, anyways I did what I was told.

When describing how she felt immediately following the procedure, one victim stated, "I was in pain all the time, in pain. I couldn't move in the bed. I couldn't move in the bed and there weren't lots of distractions around. And I had to stay in that position, when they did the cut."

### Another recalled:

Eventually I just remember I was being wheeled back I was conscious, fully conscious and I was just screaming and screaming for them to let me go and to let me die. One of the nurses that was holding me down was not at all nice she was not at all nice 'we're

## only trying to help you' I said if you want to help me please just let me die and she said 'and leave your child without a mother?'

The lack of compassion from doctors and nurses only made the situation worse. One woman stated that, during her times of greatest physical turmoil, "there was no niceness about him. He [just said]: 'give her the gas; shut her up." At least one doctor was just as traumatized as his patients. One woman explained, "He came in to me and he said, 'I'll have nightmares about you for the rest of my life." Although many health professionals treated the patients without respect, it is evident that there were others, albeit few, who were empathetic.

Notwithstanding the fact that there were known protocols for how to help ensure that women who had a symphysiotomy would heal most effectively and as quickly as possible, these protocols were not usually and not consistently followed. Women were told to use a pillow to splint while coughing, most were not bound, some were told to stay sitting, others to lie down, at least one was forced to walk right away, and one reported being made to walk up and down stairs in the stairwell at the hospital in heels at a follow up visit. In this latter case, the woman was ordered to do so in front of a class of nursing/midwifery and medical students. There was one hospital in particular in which there was virtually no consistency in the post-operative medical intervention process, which has added to some women's perception that they were unwittingly human subjects of experiments or at least training programs for doctors and nurses or midwives.

Regarding the husbands' responses, some husbands expressed gratitude initially, naturally focusing on the positive outcomes as reported by the doctors. These men were thankful to the doctors for successfully delivering their babies (all but one) and for keeping their wives alive in the process. It was not until details were fully disclosed years later, and after their wives had endured years of pain and disability, that they experienced anger and shock.

### 3.4 Outcome of the Procedure

Although all but one of the newborns delivered by symphysiotomy to women interviewed in this study survived, many of the women felt helpless to care for their children immediately post-surgery. They made statements such as "I wasn't able to feed her, I wasn't able to do anything for her." Involvement from mothers, mothers-in-law, sisters, husbands and others in child care, in particular care of the newborn, was often necessary. This caused many of the new moms to feel defeated and often helpless.

The pain of recovery was so severe, reported several of the women, that they were unable to bond with their newborns. Neither were they able to have intercourse with their husbands for some time, both because of the pain and as a result of fear of becoming pregnant again. This in turn was a factor in marital discord and dissolution, although as is reported below, many of the husbands were, and remain, stalwart supporters of their wives. Other impacts, including incontinence, mental health diagnoses and inability to return to work, and therefore to contribute to the household income, were also described by women.

### 3.5 Immediate post-care

Many symphysiotomy victims were not aware, at first, of how significantly they had been disabled by the procedure. Many thought the way they felt was normal following childbirth, especially if they had been told that their baby was large and their pelvis small. One mother explained,

I didn't know what was wrong with me so I was just sore and what's the point in talking about it, because that's probably the way everybody is and you didn't want to seem as if you were complaining about something.

Adding to the trauma was the fact that most of the women were immediately separated from their babies and given vague information about their physical condition. Explained one mother, "I was convinced, you know, that the baby really had died, because now it was five, six days, and I still hadn't seen him." A majority of respondents commented on the extended length of time that passed before they were able to see their babies and the emotional toll it caused them. Given their physical condition following the symphysiotomy, they were understandably concerned about the health of their babies. It did not help their psychological and emotional well being to be left in the dark by the clinicians about their condition.

Initial mother-child bonding was impacted in a number of ways. One woman shared her first breastfeeding experience:

This lovely little nurse who used to put this binder around me said, "Please lay on your back it's for your good; stay on your back try not to move." Of course I was terrified then to move so in comes the baby with another nurse and said "You're breastfeeding your baby" and I said but I can't and she said "You want to be a good mother don't you?"... I felt like screaming; with hindsight I was I think I was in a total panic.

Relearning to stand and walk was another issue: "I remember the first time I stood up out of bed – I just went down. I just fainted. And I think, for the week, the first initial time you were taken out of bed and made to stand and told to hold the chair — I felt so weak... I was very, very weak."

### 3.6 Follow-up care post-discharge

Following the symphysiotomy, most women did not know how to respond to family members' and friends; questions about the procedure and its aftermath such has difficulty walking and incontinence. This is understandable, given that for some time the women did not have a name for the procedure, did not know what had actually happened to them. One mother explained, "I thought for a long, long time that it had to be done to get the baby out, I thought it was necessary. People asked me why I had gotten it done, I thought I had to get it done."

The emotional and psychological impact post-discharge was significant. Shared one mother, "I just couldn't [breastfeed]. I was like a lump the only way I can describe it is that I was like a

lump in the bed not a human being. Just waiting to die. Hoping to die." When she became pregnant again, this mother looked for an out, relief from the pain:

At about seven months I took an overdose... I didn't want to kill the baby inside me I didn't want to leave my other baby I wanted to escape from the pain and that was really stupid and foolish but that's what I wanted to escape.

Few women spoke this openly about attempts to dull the pain and escape their suffering. However, this woman's feelings were likely shared by many of her fellow symphysiotomy victims. Many other women discussed those first few weeks and months at home with their child and the fear they felt as disabled primary caregivers. For example,

I was terrified of going home with this baby not being able to do anything. I said how in the name of God am I going to cope here? What is wrong or what have they done to me? You know then I knew friends of mine who had babies around the same time and they were out wheeling their babies and I didn't even want mine.

Since the husbands were not fully aware of the severity of the situation, the details of the surgery, and the extent of their newfound limitations, these women felt even more alone and helpless. One woman summarized the disappointment and trauma quite simply as: "What should have been a happy time was a dreadful time."

### 3.7 The Pain Endures: Physical Impact of the Symphysiotomy

The physical distress following the symphysiotomy procedure was significant for nearly every woman interviewed. Women consistently reported chronic pain, fatigue, urinary tract infections, incontinence, difficulty walking, limited mobility, and pain during sexual intercourse. Many are confined to wheelchairs and/or have to walk with the assistance of a cane or walker. With regard to incontinence, one woman described continued problems with incontinence, which is both embarrassing and inconvenient. In describing her lack of bowel control, one woman shared, "I had no muscular control…It felt like a herd of elephants had walked all over me body."

Pain pervaded the daily lives of many of the participants, altering the amount they could work and the amount of energy they had to carry out activities of daily living. Back pain was a persistent problem that limited the mobility of many of the women, and continues to do. As one husband described his wife's condition: "She has huge arthritis in her hips and back and pelvic area. She's been to a rheumatologist since not long after that birth where she gets injections into her bones just to keep her mobile to keep her going basically." The physical pain was unforgettable for many, and a number of respondents still take painkillers to endure the continued pain and discomfort.

Many experienced pain or lost interest during sexual intercourse, and as a result, suffered significant relationship problems with their husbands. One participant described the intense pain associated with sexual intercourse – "The intimacy. Having sex. Dreadful, because all the time you can hear the bone rubbing off. Painful. Not very nice." Another participant revealed that since the procedure, she has never been able to enjoy sex.

After the procedure, many women experienced significant difficulty walking and had to go through the pain and frustration of relearning to walk. Several women reported suffering such pain walking, and such difficulty going up and down stairs that they had to "sit" up and down stairs one stair at a time on their bottom; for some, this humiliating, uncomfortable and painful way of getting up and down stairs lasted some for a long period of time. One had to have her house remodeled, at her own expense, in order to ensure that she would not need to use the stairs.

Many still are unable to walk up stairs normally, have limited mobility, and have a limp. As one survivor described, "We walk like ducks. We all thought we were all right. We were not all right." Women frequently reported fear of falling, dropping their baby, and "breaking" themselves. As one husband explained, "But she's afraid, she's afraid if she falls to the floor she'll never get off the floor." Thus, their fragility is a significant physical and mental burden for many of the women.

Significant physical trauma therefore called for significant medical and rehabilitative intervention. One woman described part of her treatment

I had so much physiotherapy in the last 36 years and physical therapy and I wore a belt, a pelvic belt. I got my hip replaced last [year] and I asked the consultant would it have anything to do with the symphysiotomy. He said yes, a non-stable pelvis wears down your hip.

A small minority of respondents was lucky enough to suffer minimal physical problems. As one participant explained, "I have to say physically that I came off a lot luckier then most of them [...] thanks to that little nurse that bound me up so tightly [...]" Proper binding was critical to a quicker, less painful recovery. However, most women were not given adequate post-operation follow-up and continue to suffer the consequences today.

### 3.8 Psychological Impact of the Symphysiotomy

While the psychological impact of the symphysiotomy procedure was negligible for some women, the majority of respondents experienced significant emotional and psychological symptoms as a result of the procedure. Psychologically, these women were permanently scarred. In fact, the trauma of the surgery deterred many from having more children. Said one, "[I was] robbed of children, because I was afraid to have any more children." The experience made them fear that birth control would not even be sufficient, scaring them from intimacy, which had a negative impact on their marriages.

Many others commented on the difficulty of bonding with their babies: "I felt I wasn't a good mother for those two to three years." Traumatized by the birth experience and unable to cope with the painful healing process one woman admitted "I use to be so delighted to see my poor child gone. I use to be delighted to see her gone...I couldn't cope, you know I felt so bad."

Unable to bond with their child, women oftentimes reported feeling a strong sense of guilt and remorse after the procedure. Many women were separated from their child after birth for days or

weeks. Respondents felt that they were inadequate mothers, incapable of giving their child the love and nurturing a child deserves. One woman compared her relationship with her son from the symphysiotomy with her relationship with her other two daughters: "I never thought I love him enough, that's the emotion [...] I certainly don't have the relationship with him that I have with the two girls." Another woman felt that the emotional and physical pain post-operation inhibited her from adequately bonding with her child. She explained, "I did not bond with her [daughter] because I had too much to cope with myself, physically [and] mentally. [...] I felt why couldn't you be like every other woman and have a baby normally? [...] How can I tell my husband I had to have this operation because I wasn't normal?"

Not only did atypical motherhood bring these women down, the new focus on their personal health care and rehabilitation efforts took over. Described one respondent: "we spent my life going from healer to healer."

The horrors of the symphysiotomy, coupled with the lack of information and excruciating pain, damaged many women emotionally. This psychological impact manifested itself differently in each of the women. Some explained how frustrated they were. They felt it was unfair that they had to go through the physical and emotional trauma and were thus frustrated by the circumstances. Respondents also reported experiencing a variety of fears after the procedure. Some were uneasy about pregnancy and had nightmares about becoming pregnant. One woman explained how she wanted an abortion when she became pregnant again. Other respondents discussed the immense sadness they felt. "I did not stop crying for twelve months after that." Many experienced emotional breakdowns. As one woman explained "I was working away then I got this terrible feeling I didn't want to be with anybody I just wanted to be on my own." These intense emotions were isolating and overwhelming for many of the respondents.

Several women suffered from varying degrees of depression. "You kind of blame yourself," one woman explained. "You said, 'oh God, I was thirty years of age then'...I thought it was because I was 30." One respondent mentioned that she has been on an anti-depressant for 10-15 years. Other women were given shock treatments to for the depression, although at least one woman reported refusing to have this procedure. In discussing her experience with depression, one woman noted, "He [the doctor] wanted to put me away. He wanted to give me shock treatments." A few of the women, overcome by the physical and emotional handicaps as a result of the symphysiotomy procedure, exhibited suicidal tendencies. One woman stated: "The only way I can describe it is that I was like a lump in the bed not a human being. Just waiting to die. Hoping to die." Similarly, one woman explained how she wanted to escape from the suffering, "I was about seven months and I took an overdose. [...] I didn't want to kill the baby inside me I didn't want to leave my other baby I wanted." The psychological impact was life altering for many of the women.

### 3.9 Role of and Impact on family members, including husbands and other children

### Husbands

Publicly available information about the details of symphysiotomy painted a more detailed and horrific picture than the husbands ever had previously, including immediately after their wives had the symphysiotomy. Perhaps as a consequence, the husbands were further angered when they realized the cause of their wife's pain and disability. Most of the women explained that, while shocked, traumatized, and angered by the condition of their wives after the delivery, their husbands were supportive. One woman said it would have "been a different story if [the husbands] did come in [to the delivery room]. You know, there'd be more questions asked." Even after the procedure, when the women had the physical and psychological repercussions, many of the husbands did not understand the details of what had happened. Moreover, the women tended not to discuss them and the men did not feel it was their place to ask. One respondent explained, "He wouldn't talk about it. Not like now, everything is out, everyone knows. We didn't know, and he just wouldn't say anything." Along the same lines, one of the husbands described an experience he had, which took things too far:

I asked a question about childbirth and an aunt of mine screamed at me and I decided there to never ask a question again... it's amazing that I had been taught this, and still knew absolutely nothing.

Another was grateful that her husband dealt with her prolonged emotional breakdown following the procedure. She shared, "I did not stop crying for twelve months after that. And how that man put up with me I don't know. But then he didn't try to understand he didn't ask any questions but I couldn't answer them because I didn't know." In general, the women's responses suggested that husbands remained faithful and understanding during their period of initial recovery. However, other relationships suffered infidelity, separation, and/or divorce.

Intimacy was impacted due to the physical and emotional trauma and persistent pain. When asked by her husband if she wanted to have sex, one woman stated, "I wouldn't say yes. I wasn't that much into sex." Another respondent described the impact on other relationships, explaining, "because of the sexual restrictions that remain, a lot of men left their wives, you know, and went off philandering with other ladies." It was hard, explained some, for the men to fully grasp what had happened to their wives and to understand the suffering they endured even months or years after the event.

#### Other family members

Because other family typically did not learn of the details of the symphysiotomy until many years after the fact, the news was often more shocking than that experienced by the husbands in some cases, evoking even stronger emotional responses.

Guilt was commonly felt by the children of symphysiotomy victims, for having put their mother through such a traumatic experience. One respondent stated, "our son feels guilty because he's caused so much pain to his mother." The reverse, however, was also true. Many women felt

guilty for not being able to provide for their children fully, as a result of the physical impact of the surgery. One woman reflected,

"I wasn't able to do as much maybe as I should've done, you know. But, I carried on, done my best for them...but you know, when I see other young mothers, and they're racing around with their kids, you know, I wasn't up to - didn't have as much energy as that."

Another respondent had mixed sentiments stating "I couldn't do things with my children that others can do with them. It affected me a lot" also adding "but here I am alive." Learning about the procedure also instilled fear in some of the women's children, especially the girls. For example, "They couldn't get over what happened to me. And they were – when they were wanting to have babies, they were afraid it was going to happen to them." One mother had protected her child for years from knowing that she had had a symphysiotomy in order to try to ensure that she/he would not suffer guilt from causing her pain. One of the children of a victim shared that around her birthday each year, her mother cannot get excited for her. Rather, her mother becomes distant as she recalls the events of the child's birth.

When asked about her sisters' reactions to the surgery, one woman expressed shame. She said, "They do know about it, but they distance themselves from it, because to feel it's such a mediaeval thing that, I should be getting on with my life; I shouldn't be digging up the past. That's what they feel, and that I would be an embarrassment to them, to continue talking about having your pelvis bone broken." Upon revealing the details of what had happened, one woman's sister even recommended that she not tell anyone, further adding to the trauma.

# **3.10** Perceptions of the Women and their Husbands: Why was symphysiotomy performed?

The women offered a number of possible explanations for use of symphysiotomy in lieu of cesarean sections. While some women remained bewildered about the reasons that the procedure had been carried out on them, many blamed the Roman Catholic Church, saying the church strongly encouraged, if not insisted upon, symphysiotomies. The women's perception is that the Church preferred symphysiotomies, which enlarged the pelvis, over C-sections because the position of the leadership in the Catholic Church in Ireland was that symphysiotomies allowed for women to continue to deliver babies vaginally in the future, while C-sections lowered the number of times a woman could carry a child. As one woman described her perception of the role of the Church in Ireland:

"Basically some theory was that it was a Catholic thing you know, if you had a symphysiotomy on your first baby, you wouldn't have to have sections, that this widened your pelvis. It didn't...I still had subsequent caesarians."

One respondent described repeated attempts to obtain some type of rationale from local church leaders, receiving in return only " a one-liner letter stating that they wouldn't be holding a public inquiry."

"There is more to it, more involved in it than just the doctor carrying this procedure. Because when you look around the world today, we say what's happening to the women in other cultures, it all goes down to religion/religious beliefs"..."Back then it was Church and State" that had to be an influence from the Church, but he had no right to interfere or let the Minister of Health tell us what to do. But the two went together: Church and State and they didn't care about what happened to women at the time."

Other women were told, and had come to believe, that the procedure was performed with the baby's best interests in mind, that their pelvises were too small to safely delivery the baby without the surgery. "There were groups of us," one woman explained. "We'd go up to meetings and we often asked, why was it done? And the answer we got was – to save the baby, to bring the baby," she stated further. Another thought back to what she had heard about symphysiotomies amongst the financially-challenged, saying "I think it was done – they use to say the (poor) people in Africa, that there were no hospital facilities or a quick way of getting – of (cutting) sections to get this done." In other words, it did not make sense that the surgery had been performed in a developed country.

Training was another explanation given. The vast majority of symphysiotomies carried out in Ireland were performed at Lourdes Hospital in Drogheda, which one woman explained "was run by the Medical Missionaries of Mary and it was a teaching hospital."

"It was easier to break the pelvic bone and show to the rest of practicing doctors than to do the section. Take it to Africa and India where people were travelling around and couldn't stay in hospitals: they could do it there without needing to stay in the hospital a long time. Something to teach them."

Indeed, symphysiotomies were performed in Lourdes Hospital until at least 1984, and one report indicates that the procedure was performed as late as 1992, long after it had been discontinued elsewhere in Ireland.

Many were unable to provide any explanation for the brutal procedure other than describing it as a horrific form of human experimentation. An indication of the bitterness felt by these women about the procedure being carried out without their consent, for no medically justifiable reason, and possibly for purposes of research and training, is the comparison that one woman made to medical experiments performed in concentration camps: "It was just sort of similar to what was done at Auschwitz. I honestly think that's the bottom thing of it: it was done to experiment on women...I really think it was an abuse of women."

### 3.11 Trust in Providers

Throughout the process, most women put their health as well as that of their child in the hands of the medical professionals. Despite being unsure of what was happening and why, most of these women trusted the decisions of their caregivers. One woman explained, "but we just trusted them and well if it has to be done it has to be done. You didn't say is there an alternative way or

anything...people didn't ask questions of doctors. They were gods. It would have been so unusual to ask questions."

As a result of the traumatic symphysiotomy experience and aftermath, many women described a fear of doctors and of medical procedures in general. "I'm terrified of white coats," one woman explained. "I have the 'white coat syndrome' since I discovered what happened to me. This general fear of hospitals."

Similar fears persisted even when they involved their children and not themselves personally. One woman explained, "I'm...always very (cringy) about everything. You know, when my children were small, going to a doctor ...for a second opinion, I couldn't deal with that." The toll was physical, psychological, and emotional. Said one respondent, "I would – my blood pressure would be so high; it was because of my – you know, I'd sort of panic. And when my next child was – when I was going into labor, I wouldn't get out of the bed at home." Most respondents expressed uneasiness regarding medical professionals.

Not all the responses, however, were negative. The comments of one woman highlight her respect for the medical profession and gratitude for what medicine has done for another family member: "There are some things they would have looked after. Some members of my family...I have to tell the truth, you know, and my granddaughter had epilepsy...and, she was really suffering, you know. And they did a really good operation on her, and it was a wonderful success. So I have to say, tell you truthfully, that for some parts of the health service, I am really grateful." Another woman said she does not distrust doctors, but rather blames the Catholic Church for how they practice.

Others, still, wavered in their trust of medical professionals. The words of one woman portray this inner conflict: "So in one sense, I can say [it did save my life], but I wouldn't wish it on anyone – on my worst enemy. Because [it was a nightmare]."

### 3.12 What do the women want?

When asked what they would like the outcomes of this study to be, only a few different responses came up. Most women said they want an explanation and awareness raised. Some even stressed that it could become an open conversation:

"I would like transparency. I ...would like the truth to come out...I would like the obstetricians to be vindicated, because I feel – I feel that being tagged by a few bad apples in the bag, you know, from the past. I think they're afraid to come out and tell us the truth, but they shouldn't be afraid to come out and tell us the truth. We're willing to meet with them; we're willing to sit down with them."

Most of the women indicated that even a simple apology from anyone involved in the symphysiotomy procedure, or in some way responsible for it from their perspective – the doctors, nurses, midwives, hospital administrators, the government health system, or Church—would have been welcomed by them. They were, and remain, dismayed that none was ever

provided. No one, including those directly involved, ever openly expressed regret to their patients and their families following the tragedy of the surgery.

Monetary compensation was also requested, to cover the money lost by not being able to return to work as well as to cover resultant medical expenses for lifelong disabilities, but this was not the most commonly mentioned outcome, and the women did not focus on it during the discussion.

Most importantly, it was hoped by many that this study, and the previously mentioned study carried out by Dr. Oonagh, would put an end to the practice, so that no one else must suffer the same dire circumstances. One woman stated, "Make sure it is never done ever and ever again. Because it isn't just that time, it is carried throughout your life for the rest of your life. It is a nightmare." One woman "as a curse one would not wish on my worst enemy" described Symphysiotomy.

### 3.13 Additional Comments from the Women

When asked if there was anything the respondents would like to further comment upon, most reflected on the horror and brutality of the procedure, the lack of transparency and explanation from medical professionals and the fact that it should never have taken place and they would not wish it upon anyone. A respondent stated: "One word: evil. Pure evil. It's like a witch doctor participated in the abuse of women's bodies. That's what I feel. There's nothing positive to report on symphysiotomy." The resultant chronic pain was another area of discussion as was the impact of the symphysiotomy on marital closeness. For example, as one woman noted:

When you hear of a symphysiotomy person that the husband left her it doesn't surprise me because your sex life is gone, practically gone. That person in you has actually changed so much and it's in your midyears when you're supposed to be getting very close together.

A number of the respondents also re-stated their discontent with knowing so little about the surgery itself, including its purpose, the details of the procedure, and what the aftermath would be. One woman explained, "doesn't really give details it should give details about the labor for example to, to say why it was done but it doesn't really give details about the labor it just says 'symphysiotomy'. And though previously discussed, the role of the Church in symphysiotomy was revisited, as well: "the overriding factor there was the Catholic ethos that was there that was the driving force behind all of that.

On a positive note, however, one respondent described the energy of his wife and her desire to rehabilitate to the best of her ability, despite all she had suffered. He said, "she had great spirits: she was going to do that. And to this day now she's very disappointed if she doesn't get on that bicycle once or twice a week." Another actually expressed gratitude that she was a candidate for the surgery, saying, "I count myself very lucky. The baby was alright, because it was just touch and go, and because he was able to do the symphysiotomy at that stage." Though their lives were changed forever, these women want to live life as best they can: "I just want to be able to keep going for the rest of my life: to do things by myself for the rest of my life."

### 3.14 The Husbands' Perspective

Eight husbands were interviewed, offering their insight on the symphysiotomy and its aftermath. As with the women, most of the men were told the procedure was routine. Recalled one, "He [the doctor] just said it would be a slight operation." Another husband explained the extent of his understanding about the surgery and childbirth in general:

I still didn't realize there was anything; I didn't know, I didn't because I wouldn't know anything about childbirth. It was my first experience of it and so just as it looked it appeared to me now, I had nothing to measure it against.

Regarding consent, one woman's spouse stated that permission for the surgery was never given. He said, "No, because she wasn't told they were going to do that you know she probably had an epidural so she didn't know what was going on down there." This husband continued on, describing the pain his wife suffered shortly after the surgery:

She had difficulty walking and at the time in the hospital I didn't notice so much you know but just brought her for a little walk up the corridor and back but when she came home it was evident that she was having difficulty walking and she had a lot of discomfort and she was incontinent for a good while after that birth then came alright again and various times she'd get bouts of incontinence various times on and off and always kind of sore there.

When asked why he believed the surgery took place, one father stated firmly that it was because of Catholic Church teachings. He explained further:

I actually probably blame the nuns because they were in control at the hospital. [...] You didn't question the doctors, priests or bishops or anything like that years ago. If you asked them anything, they would brush you aside, they wouldn't give you an answer. Things happened and you just had to accept it.

In sharing more about the symphysiotomy experience from his perspective, this father explained how he was called and told about an impending cesarean section, but because he was not present to sign, his wife did. After the symphysiotomy, he recalls bringing his wife to see their baby together: "I had to push her down in a wheel chair to see the baby but [...] That was the first she's seen the child, probably over a day old."

Another husband went into detail about his confusion regarding the physical state of his wife post-delivery, saying:

When [my wife] came out she couldn't walk. I couldn't understand what was wrong. I couldn't understand about having a baby and you cant walk. You know? I thought that was crazy. What did they do to you? She didn't know what hit her. She's ignorant as well.

The lack of information provided to husbands and their lack of awareness and understanding regarding what was to be expected post-delivery caused many husbands to brush off their initial concerns about their wives' apparent physical distress. Another husband recounted:

The next thing I knew that okay she was having the baby and then in collecting her when she was coming out of that she was very kind of lame or hardly able to walk but I took it as this was part of the system if you know what I mean... that went on for a fair while then I knew she had the operation and I put this down to getting over the effects of the operation.

The husbands also commented on the persisting physical trauma suffered by their wives. One explained,

Before that you had the energy of ten, the power to do it because her limbs were allowing her. There's nothing wrong with the mind, but she'd have to sit down and relax for three or four hours. To me that was the biggest there were plenty of other minor ones. but the incontinence would be one and you used to have for a couple of years after eight years.

The psychological impact on men should not be minimized. They too, had plans for a growing family and were upset when those plans were halted and their questions left unanswered. Explained one husband of his own situation:

We would've liked to have more children but we didn't have a hand. We own, we built our own home, buy the plot of land, built our own home. But there again it's just life, you know. You accept it at the time and didn't ask questions, but there was no one to tell us. When our own GP didn't know.

Most of the husbands who responded were also aware of the psychological toll on their wives. Stated one, "she felt that that particular thing shouldn't have happened that she shouldn't have gone through what she went through like you know." Others expressed a degree of guilt. For example, one shared "I mean my wife was the person who had to stick the pain. I wasn't what you call a great husband. I got to work I got the bread in; I made sure the kids were okay. The kids looked after their mother." Fathers commented on the psychological impact of the news on their children as well. In one instance, a father described his son's depression and substance abuse, which he associated with the problems faced by his mother as a result of the symphysiotomy.

With regard to intimacy, "when we were intimate we had to be very careful you know so that was always a problem." All the men who commented on this stated respect for their wives and their wives' bodies. They understood the need to rest and take a break from intimacy during periods of healing.

In terms of what they would like to come from the symphysiotomy study, one male respondent mentioned many of the same sentiments, as did the women and the other fathers:

Possibly that it would never happen to anybody again. And I know never is a long time. I see some of the people now I only met them that once in Dublin I went to that meeting

and I just was very very sorry for the people it happened to. Possibly everyone that it happened to doesn't feel the same but there were a few programs on television and they were horrific. There's no doubt about it.

Another husband expressed a desire to spread messages about the complications and severe impact of symphysiotomy as far and wide as he could, but came to realize that was not what his wife wanted. He explained:

It very slowly dawned on me that she didn't want to complain. Her sole concern was [son's name's] health and when [he] was all right she, like I said to you earlier, would've gladly given up her life for him to be all right. And that is, I think, our consolation. I wanted to speak, there was a program on television, and I would've liked to have spoken and said what I thought, but she didn't want me to. She said, "Look [son] is fine and he turned out actually very intelligent, he's a very bright child." And that's all that mattered to her. She would've gladly have sacrificed her life, and did, for him.

Some husbands had put the symphysiotomy behind them and were moving forward with their lives with their families. One explained,

I feel that it's over and done with from my point of view but my wife there again she was the one that was concerned and I know she'd like to follow it up I think I feel it probably might make a difference to her that's my feeling that we won out after all these years. Maybe she will, maybe she won't. Between myself and myself well between me it doesn't make any difference.

## 4. Discussion and Recommendations

A number of themes are clearly evidenced as a result of these in-depth interviews with the women who are survivors of symphysiotomy in Ireland and with their husbands. Perhaps an underlying one is the culture of secrecy and of avoiding taboo topics, including pregnancy and childbirth that pervaded Ireland at the time – and that in some respects still pertains. The dominance of the Roman Catholic Church and the authoritarian nature of Irish society, which resulted in most of the population feeling subservient to clergy and doctors, also played a role in the ability of the physicians to carry out the procedure without engaging the women and their husbands in the decision-making process. As one husband noted, "There were three types of people who controlled our lives: the priests, the doctors and the guarda. It is probably important that, when telephones were installed in Ireland, they were the first three to have them."

The lack of information provided by the doctors and nurses to the women and their husbands before and immediately after the procedure was, in the opinion of the authors, a violation of the Hippocratic oath and also of the standard of care in practice since at least the mid-1960s. That, and the lack of information regarding symphysiotomy provided by clinicians involved as well as by health system leaders since the publication of the Irish Times article in 1995, caused a significant diminishing of trust on the part of the women and their families in clinicians and the health care system. The lack of support from the health care system and the government for

physical and psychological care to address the impact of the symphysiotomy procedure, and the length of time it has taken for the government to assume any responsibility for the care of the women, few of whom survive, has further diminished their trust in governmental systems generally.

With respect to "informed consent," some have suggested that there was no legal requirement at the time that most of these procedures were performed. That is arguable, but what should not be in dispute is that physicians and nurses both take oaths to preserve and protect the health and rights of their patients and have done so for some time. The "healing" professions have long had a duty to their patients and an imperative to ensure that they understand what is being done to them. Most of these procedures were not carried out under "emergency" circumstances. Indeed, for many prior arrangements were made for hospitalization and in some cases the physicians implied to the women that a C-section would be performed. There is simply no rationale for the women and their husbands not to have been informed either prior to or after the procedure of the reason for the symphysiotomy and its likely outcomes, which were known at the time.

Given the lack of care demonstrated by most of the clinicians at the time of the symphysiotomy, and indeed subsequently, support from families, especially husbands, was invaluable to the women. This was a consistent refrain in the interviews: the support from husbands and family members immediately following the procedure enabled the women to care for their newborns and, as applicable, other children. Their support over the time since they were aware of the procedure that had been performed on them, in their efforts to seek justice, also has been invaluable.

During the course of the interviews, the researchers were dismayed that few of the women and husbands recounted positive examples of caring on the part of the doctors and nurses; quite the contrary. There were, ultimately, two stories of "goodness" told by two different women. One mentioned that one of the nurses went to her after the procedure, apologized for it, and began to take special care of her. The doctor had not adequately bound the woman immediately after the procedure in order to limit the damage to her skeletal structure, so the nurse visited her late at night each day, tenderly re-binding her and praying with her. There should not, of course, be only two examples of caring recalled by these women and their husbands.

This brings us to our recommendation. There is currently the Ministry of Health-mandated study that is being carried out by Dr. OonaghWalsh, which is expected to be completed in early 2013. This study should be used as a basis for a decision by the government to provide redress for the surviving women. Less than 200 women are survivors of this procedure. Most continue to live in physical and emotional pain; all continue to have no satisfactory response from authorities. Most of those who were responsible for this procedure – from Bishop McQuaid and other Church officials, to the Masters of the hospitals in which they were performed, to the physicians and nurses who took part in them— are deceased. The current government must ensure that, to the extent possible, these women achieve the rights which they are due and which they have sought for more than ten years.

These women deserve an unreserved apology from the hospitals in which the procedure was performed, by any clinicians who were involved in the procedure – including physicians, nurses

and midwives. Moreover, the Irish Government should establish a Redress Board comparable to the Neary Inquiry. This Board would pay compensation to each of the women who underwent this procedure for the consequences of the symphysiotomy carried out while they were under the care of the State. The case of symphysiotomy in Ireland over a half-century, and the lack of acceptance of responsibility on the part of those involved, make this a quintessential example of "justice delayed is justice denied." This is simply unacceptable. With each passing year, the number of survivors, to whom justice is due, decreases. There is simply no more time to wait, or to waste.

### References

- Barry, A. P. (1952). Symphisiotomy or Pubiotomy. Why? When? and How? *Irish Journal of Medical Science*(314), 49-73.
- Bergström, S., Lublin, H., & Molin, A. (1994). Value of Symphisiotomy in Obstructed Labour and Follow-Up of 31 Cases. *Gynecol Obstet Invest, 38*, 31-35.
- Björklund, K. (2002). Minimally invasive surgery for obstructed labour: a review of symphysiotomy during the twentieth century (including 5000 cases). *British Journal of Obstetrics and Gynaecology*, 109, 236-248.
- Fahy, T. (2001). Trends in Irish fertility in comparative perspective. *The Economic and Social Review*, *32*(2), 153-180.
- Glaser, Barney G & Strauss, Anselm L. (1967) The Discovery of Grounded Theory: Strategies for Qualitative Research. Chicago: Aldine Publishing Company
- Goodwin, T. M., Banks, E., Millar, L. K., & Phelan, J. P. (1997). Catastrophic shoulder dystocia and emergency symphysiotomy. *American Journal of Obstetrics and Gynecology*, 177, 463-464.
- Grebbie, D. (1974). Symphysiotomy. Tropical Doctor, 2, 69-75.
- Grebbie, D. (1982). Symphisiotomy. Clinics in Obstretrics and Gynaecology, 9(3), 663-683.
- Greisen, G. (1985). Three-Year Follow-Up of Eight Patients Delivered by Symphyseotomy. International Journal of Gynaecology and Obstetrics, 23, 203-205.
- Hofmeyr, J. A. (1961). Symphysiotomy: A Re-Appraisal. South African Medical Journal, 35(47), 981-983.
- Menticoglou, S. M. (2009). Is there a role for symphysiotomy in developed countries? *Journal of Obstetrics and Gynaecology*, 29(4), 272-277.
- O'Connor, M. (2011). *Symphisiotomy and Pubiotomy in Ireland, 1944-1992*. Cnoc Sceichín, Leac an Anfa, Cathair na Mart, Co. Mhaigh Eo, Éire: Evertype.
- Royal Academy of Medicine in Ireland: (1963) Discussion of the Maternity Hospitals Reports for 1962. Meeting held on 8<sup>th</sup> November, 1963
- Spain, A. W. (1949). Symphysiotomy and Pubiotomy: An Apologia based on the study of 41 cases. *Journal of Obstetrics and Gynaecology of the British Empire*, *56*, 576-585.
- Walsh, O. (2012?). Draft Report on Symphysiotomy in Ireland, 1944-1984.
- Wykes, C. B., Johnston, T. A., Paterson-Brown, S., & Johanson, R. B. (2003). Symphysiotomy: a lifesaving procedure. *British Journal of Obstetrics and Gynaecology*, *110*, 219-221.