

Stigma and silence: Oral histories of tuberculosis

by Susan Kelly

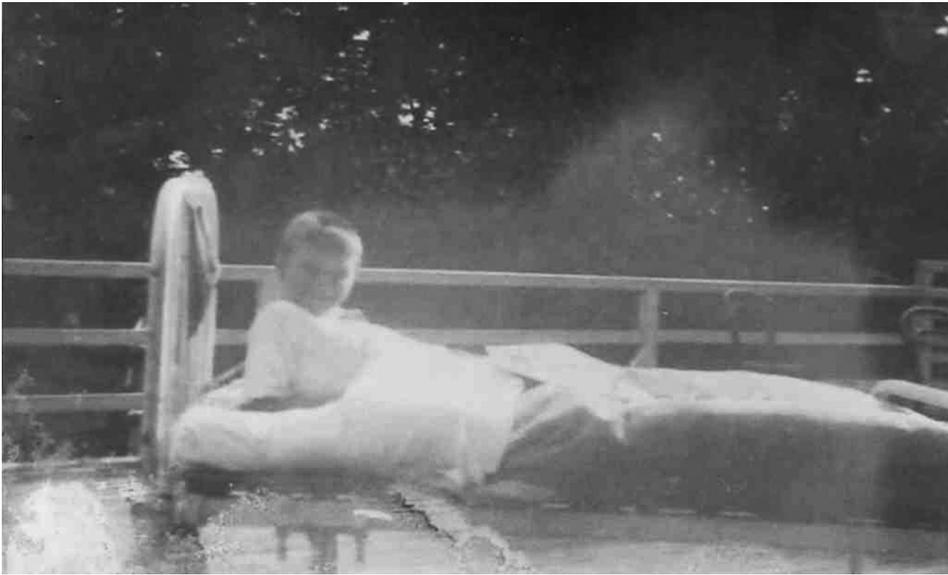
Abstract: In Ireland the tuberculosis death rate was still increasing in 1900, thirty years after it had begun to decline in England and remained higher until the 1950s. Tuberculosis sufferers and their families often felt stigmatised and many people chose to keep quiet about their disease. In time the silence became a habit. This article is based on thirty-three interviews with adults who suffered tuberculosis as children in Northern Ireland. The interviewees experienced the onset of the disease between 1926 and 1962 and many of them had never spoken of their experiences before. This paper examines why some chose to speak now and why others were still reluctant to respond.

Keywords: tuberculosis, stigma, silence, illness narratives, Northern Ireland

Ireland's children were said, in 1907, to be in the 'jaws of the devouring dragon' of tuberculosis.¹ The 'dragon' rampaged through the country creating one of the worst tuberculosis death rates in Europe. Its association with poverty led sufferers to feel shame, and the widely-held belief that it was hereditary meant that often whole families entered a conspiracy of silence. People were afraid of the disease but also of how the community would react if they knew there was tuberculosis in the family. In 1912 Dr Woodcock of the National Association for the Prevention of Tuberculosis wrote 'Tubercle is in truth a coarse common disease, bred in foul breath, in dirt, in squalor... The beautiful and rich receive it from the unbeautiful poor... tubercle attacks failures'.² This rhetoric from an educated man working in the field of tuberculosis is an indicator of how the public at large felt. As one man said on receiving his diagnosis, 'overnight I had joined the ghetto of tuberculosis lepers in Irish life'.³ A survey as late as the 1950s showed that many people still believed

the disease to be hereditary.⁴ A degree of stigma persists to the present day influencing men and women about whether to talk about their tuberculous past.

Tuberculosis is an infectious bacterial disease spread when the bacillus mycobacterium tuberculosis is inhaled or swallowed. In adults the disease predominantly settles at the point of entry to the body, so when it is inhaled this is the lungs. In children the disease can spread around the body infecting any organ. One of the most common sites for children was tuberculosis of the bone, particularly after drinking infected milk. Tuberculin tests in 1947 showed that in some parts of Ireland over half of the school children had been exposed to tuberculosis.⁵ With the partition of Ireland in 1921 political action against tuberculosis diverged between the North and South meaning that the experience of the tuberculous was different both sides of the border. In the North, where all of the interviews for this article were conducted, the Northern Ireland Tuberculosis Authority (NITA) was



**TB Patient at
Graymount Hospital,
1938. Source:
author's collection.
Permission given by
family of patient.**

formed in 1946. For example in 1921 175 deaths per 100,000 of the population in Northern Ireland were from tuberculosis as compared with 150 in Eire, 120 in Scotland and 110 in England and Wales. By 1941 Eire had the top place with 120 deaths, NI was next with 100, Scotland had eighty-five and England and Wales seventy.⁶ By 1954 the rate of the disease in Northern Ireland fell below that in the rest of the British Isles.

Until the discovery of streptomycin in 1946 there was no successful pharmacological treatment for tuberculosis. The only 'cure' that the medical profession could offer was fresh-air, rest and good food. Public health officials believed the best place to provide this was in a purpose built sanatorium, which would also have the benefit of isolating the diseased and preventing the spread of infection. By the 1940s, increased attention was being given to the disease in Northern Ireland. Tuberculin testing and mass radiography were introduced for early detection and BCG vaccination was reducing the morbidity rate. Increased money invested to tackle the problem resulted in more sanatorium beds. In Northern Ireland the infrastructure put into place by NITA meant that, once streptomycin became available, those that needed it could be identified efficiently and treatment initiated relatively quickly. Whilst action by NITA influenced the mortality and morbidity of tuberculosis, however, it had little impact on the fear of the disease that remained.⁷ With the fear came stigma and silence which continues to the present day.

Personal testimony

The history of tuberculosis in Ireland (North and South) has been written but the very different experience of children has not been

published.⁸ The different physical impact of the disease meant that children often had to spend much longer in sanatoria than adults. Their institutional experience was frequently more traumatic psychologically due to the impact that separation from family has on the young and the increased vulnerability of youth. Whilst many government sources are available, such as the Registrar General (Ireland) mortality figures and the Chief Tuberculosis Officer of Belfast's Annual Reports there is very little in the way of personal testimony from the people who had suffered from the disease. Daniel J Wilson writing about polio in the USA was able to draw on many 'pathographies'.⁹ I found that these were unusual in the field of childhood tuberculosis.

Illness, biography and narrative have a complex relationship. Illness impacts on patients' biography and sense of self and narratives can be used to give meaning and voice to suffering.¹⁰ Michael Bury describes illness as causing biographical disruption both by its physical assault and by attacking a person's sense of self-worth.¹¹ In 1988 Bury distinguished two types of meaning from chronic illness: consequences and significance. *Consequences* for the individual were caused by the disruption of symptoms and treatment and the *significance* of the illness changed how individuals saw themselves and believed others now viewed them.¹² Simon Williams felt it was also important to take timing into account when considering biographical disruption, for example, some illness in old age is seen as inevitable.¹³ I believe timing was important in the case of many of my interviewees also, as they were young children at the onset of their tuberculosis and did not have a clear idea of who they were or a planned path in life. They had, to a certain extent, 'biographical

uncertainty' and as such did not have a fixed biographical narrative to be disrupted.

Catherine Kohler Riessman states in *Narrative Methods for the Human Sciences*, that in the illness narrative individuals attempt 'to reconstruct a sense of order from the fragmentation produced by chronic illness'.¹⁴ This attempt to establish order is apparent in what Arthur B Frank describes as the 'restitution narrative'. In his book *The Wounded Storyteller* Frank describes three types of illness narrative, the 'restitution', the 'chaos' and the 'quest' narrative and the interviews used for this paper represent all these categories.¹⁵ In the restitution narrative illness is seen as a temporary deviance alleviated by medical treatment. This is the most common form of written illness narratives though elements of the 'quest' and 'chaos' can also appear in the same story. In the quest narrative the writer uses the illness as a voyage of self-discovery looking for meaning in the challenge of adversity. The chaos narrative is rarely the focus of a first person narrative as, while it is 'truly being lived it cannot be articulated'.¹⁶ It can instead be seen as 'anti-narrative; [as] it indicates troubles so deep they cannot be fully verbalised'. Therefore when 'chaos' is part of the story the events themselves have passed but the memory of it can be articulated.

Flowers of the Fairest by Rosemary Conry, about an Irish child with tuberculosis, is an illness narrative in the 'restitution' tradition described by Frank.¹⁷ Conry was a patient at the Cappagh hospital in North Dublin with tuberculosis of the bone. The book describes her friendships, fears and treatments and ends with her guided 'towards the open doors of the ambulance' for her journey home 'to [her] great reward'. To find a first-hand account centered on the experience of childhood tuberculosis in Ireland is unusual.

The experience of tuberculous children can be compared with those with polio, another disease that caused immobilised limbs and long hospitalisation. In Northern Ireland polio patients often occupied the orthopaedic beds vacated by children with tuberculosis of the bone, after the administration of streptomycin had begun to reduce their numbers.¹⁸ Whilst the impact of tuberculosis on the community in Ireland is well remembered, on an individual level it is still neglected. There are polio societies North and South of the border in Ireland whereas those who suffered from tuberculosis in the past have no such forum. Polio also appears a much more popular subject for an illness narrative, possibly because it was not associated with the shame of poverty and was often seen as a middle class disease.¹⁹ Polio had a dramatic onset and the battle towards recovery lends itself to the format of the restitution narrative. Tuberculosis as discussed was tinged with

shame and since the disclosure of the illness could impact on the lives of the whole family the habit of silence developed.

This reticence is explained by Harlan Hahn who writes that, 'Few autobiographies are written by persons who consider themselves a failure in life'.²⁰ Wilson when collecting polio narratives found that oral history interviewees came from a different background to those who had written illness narratives. Most of the writers of illness narratives were 'at least middle class in terms of their economic and social positions at the time of writing', whilst this was less true of the oral histories and internet sources he collected where the background was 'distinctly limited in its pre-polio economic status and social aspiration'.²¹ It would appear oral history interviews are ideally suited to encompass the interviewee whose story includes the 'chaos' narrative, who possibly even regards his life as a failure. This means that instead of pathographies featuring childhood tuberculosis, when the disease does appear in written works it is often as part of an autobiography rather than concentrating on the disease narrative exclusively. Two autobiographies that feature tuberculosis are *Angela's Ashes* by Frank McCourt, and *Against the Tide* by Noel Browne. In the first we hear of Mickey Spellacy's family dropping one by one of the 'galloping consumption'.²² McCourt and Browne both describe teachers with 'consumption' coughing over the front rows of school children.²³ Browne also describes how he lost both parents and two siblings to the disease and suffered from it himself at the age of twenty-five. Even these are, however, not typical autobiographies. McCourt aimed to highlight the poverty and social injustice of his Ireland as he remembered it and Browne, as Minister of Health for Southern Ireland (Saorstát Éireann), made the eradication of tuberculosis his political goal and therefore was always very open about the disease. It seems highly likely that other autobiographies not formed by the particular viewpoint of McCourt or Browne drew a veil over the tuberculosis in their family past.

On the whole accounts of illness tend to be written by adults about illnesses suffered as an adult. Private diaries written by mothers, however, sometimes recount their children's experience of tuberculosis. This is the case in an unpublished diary written in 1941 about a child's stay at a sanatorium in Belfast.²⁴ Two others that the author is aware of relate to the pain of separation; one tuberculous mother, from London, separated from her baby and another from Seattle, Washington separated from her children.²⁵

The dearth of pathographies regarding tuberculosis emphasises the importance of oral history in recovering memories from hitherto silent groups. This process has recently begun in

Ireland. Two collections were made around the time of my own, both relating to the Republic of Ireland. In one, interviews were recorded for the RTE radio documentary 'On the White Death Trail' broadcast on 21 July 2004.²⁶ Also in 2004 Simon Guest looked at 'Cure, Superstition and Reaction: Tuberculosis in Ireland 1932-1957', interviewing those with experience of tuberculosis both as adults and children.²⁷ Running simultaneously was the Welsh Craig-y-nos project, led by Dr Carole Reeves, an outreach historian from the Wellcome Trust.²⁸ I decided to create an oral history archive that concentrated on the experience of children with tuberculosis in the North of Ireland. Whilst these projects have concentrated on one specific area such as cures or sanatorium life, the interviews for my own research were wide-ranging. They covered all areas of the tuberculous experience for children, such as stigma, education, cures, sanatorium life in the various institutions around Northern Ireland and treatment. Northern Ireland was selected as childhood tuberculosis had not been studied in this area. It also had the high tuberculosis rate of Ireland but a different political system, which affected the health policy. It was only once the interview process started that it became apparent that many of the interviewees had not spoken to anyone about their tuberculosis in the intervening years. Thus the idea for this paper was born.

Collecting the interviews

The interviewees were found by a combination of methods: word of mouth, approaching a day care centre for the elderly and by placing a letter in newspapers with a circulation covering Northern Ireland. The letter asked for people to make contact who had suffered from childhood tuberculosis, and who were willing to talk of their experience to a researcher. Confidentiality was promised. Fifty-four interviews were recorded. The accounts relate to the decades from 1910 to 1965, with the majority concerning the 1940s (thirty-eight per cent) and 1950s (thirty-two per cent). This meant that forty-three per cent of the interviews related to pre-streptomycin days and fifty-seven per cent to the post streptomycin period. Sixty-eight per cent of the interviewees were born in Belfast and the remaining thirty-two per cent outside the city.

The oral history interviews, therefore, give a reasonably wide perspective of the experience over time, place and treatment regime. The majority of the interviews were recorded in the interviewee's own home in a free form style.²⁹ The aim of the interview was to establish what memories would emerge from a spontaneous retelling of their tuberculosis experience. Therefore the first question was simply, 'What do you remember about the effect tuberculosis had on

your childhood?' The interviewer asked brief questions throughout to draw out further information or clarify points. In the final stage of the interview interviewees were questioned about issues that they had not mentioned. Therefore all interviewees would by the end have covered their experience of tuberculosis in their family, school, sanatorium and community.

Some of the interviewees were health professionals, teachers or family members who had had close contact with tuberculosis. Thirty-three of the interviewees had personally suffered from tuberculosis and these are the cases that are studied for this paper.³⁰ Since the majority of the interviewees actively sought out the interview by responding to a media request it could be hypothesised that their experience or disposition could, in some way, be different from the many people who did not respond to the letter. Guest suggests with regard to his interviews that 'people who were least stigmatised by tuberculosis are most likely to speak of their experiences'.³¹ This, however, was not found to be the case in the interviews I recorded. Among the group the stigma against tuberculosis was felt by about half of the interviewees. Similarly about half of the group had had a very bad emotional experience during hospitalisation, caused by staff relationships or separation from their family. It would seem therefore that stigma or remembered trauma were not direct indicators of who contacted the interviewer. There was also no apparent difference in levels of stigma or trauma between the group who responded to the newspaper letter and the group who were approached through personal contact or through the elderly care centre.

If the interviews are assessed as illness narratives using Frank's categories of restitution, quest and chaos we can see that, although the interviewees do not have the opportunity to structure the story as perhaps they might if writing, many did end their initial story as they left the sanatorium or with a phrase such as 'and I had no further trouble for the rest of my life'.³² Only one would fit into the 'quest' narrative where the interviewee had gone on to use his experience to counsel others. Many of the interviews however give a glimpse into the chaos that affected the lives of the children involved. As one man commented regarding leaving hospital after his second bout of tuberculosis:

I came out of there [the sanatorium] and I felt great coming out of there and in about a month I started drinking. Crazy. I just couldn't help it again, I just couldn't manage the whole, the whole thing. I just kept thinking this TB... even to this day, even to this day... a lot of people were in there and it must have been as tough for them as it was for me, you know coming out of there.³³

Stigma

For many adults who experienced tuberculosis before 1960 the disease can be seen as a turning point in their lives. It may have marked the end of a romantic relationship or engagement, loss of job prospects or other life event. Children, however, rarely had a fully-formed idea of where their lives were going before tuberculosis, so a change of direction was less apparent. None of the interviewees mentioned that their tuberculosis experience had been a turning point in their lives. They were instead left with a feeling of loss for all that the disease had robbed them of. Losses mentioned included: a secure life with their family, an ability to be a doer rather than a dreamer, close relationships with their siblings, loss of childhood, and an ability to live spontaneously rather than clinging to the security of institutional regime.³⁴ For those children in the past the stigma of the disease and the trauma of separation from family featured more strongly in their stories than seeing the disease experience specifically as a turning point.

Erving Goffman in his classic 1963 text describes a person being stigmatised when evidence arises of:

his possessing an attribute that makes him different from others in the category of persons available for him to be and of a less desirable kind ... He is thus reduced in our minds from a whole and usual person to a tainted, discounted one. Such an attribute is stigma.³⁵

Stigma against the tuberculosis has diminished over the years and to many may not seem relevant to the present day. Goffman identifies divorcees and those of Irish ethnicity as groups where previous stigma has diminished.³⁶ The tuberculosis could be added to this list. As a stigma lessens, however, it is still harboured in certain sections of society. In the case of tuberculosis, for example, there may be a generational effect as people over a certain age, or those who were particularly affected by proximity to the disease may hold on to a fear.

Useful in measuring stigma is the work of the sociologist Emory Bogardus who devised a measure of social distance in 1925 much of which is relevant to the experience of tuberculosis sufferers.³⁷ It includes questions about various forms of social interaction, which can be related to any stigmatised condition. Such as, how would you feel about renting a room in your house to a former TB patient?, having a former TB patient as a neighbour?, having a former TB patient taking care of your children for an hour or two?, any of your children marrying a TB patient?, or sharing your workplace with a former TB patient? A further question could be added such as would you continue to

visit and call at the house of a friend who developed tuberculosis? The testimony of one survivor of tuberculosis suggests that the answer would have been negative if many of her friends and acquaintances had been asked the above questions. She explains:

I was snubbed and totally avoided by some of my closest friends when I was recovering from TB. I think most people were terribly afraid and I might have been the same if the situation had been reversed (who knows) but the greatest hurt came from employers who just didn't want people like me about them.³⁸

This snubbing had a major impact on life. One interviewee commented that her Auntie had moved house after her treatment for tuberculosis as she was so upset that, 'people that she had been friendly with, sitting in their garden in the summertime [now] ... never bothered with her'.³⁹ The explanation for this apparent 'knock on effect' for friends and relatives is explained by Goffman who argues, 'the problems faced by the stigmatised person can spread out in waves of diminishing intensity. This can be one reason why connections are terminated or cooled'.⁴⁰ Friends can feel that associating friendly with a stigmatised person reduces their own status.

Tuberculosis is a 'concealable stigma', which brings its own problems. In most cases the sufferer cannot be identified by their physical appearance.⁴¹ This means that they must decide whether to reveal or keep secret their past. The effort to hide parts of the past, such as a long stay in a sanatorium, can create great stress. Smart and Wegner write, 'in the effort to hide their true identities, those with concealable stigmas must face an internal struggle that leads to anguish and perhaps even to psychopathology'.⁴² When someone deliberately hides something such as a tuberculous past, they are then vigilant to the risk of exposure and also can have the unpleasant experience of hearing what others truly feel about their hidden shame. Every time tuberculosis is mentioned in a conversation, or seen on a television programme they must decide whether to declare their association or to continue hiding it. The person must choose every time whether to remain a 'discreditable' person or run the risk of becoming 'discredited'.⁴³ The stress this can cause is clear from the testimony of Alice. She explained that in her job,

you had to fill in an application form. And you had to put down your ailments, now I did not put down that I had TB, you know. And then I became a convenor for the union and I fought with management that you should not be going back that far in somebody's medical history. But I was thinking of

myself and maybe other people who were there had had it too, way back. And for instance the first-aider she had access to all those charts and on one occasion somebody asked somebody's age. And they were discussing this person's age and she said, 'I'll soon find out the age'. And she went out and looked up her chart, which was totally wrong. Well after that I got them removed from her office, from her medical room to Personnel's Office and they were locked up then. ... Well it was the stigma of me having TB, you know.⁴⁴

Alice was the only interviewee, out of fifty-three, who made changes to the consent form to further protect her anonymity and it is clear that keeping her tuberculous past concealed remains a stressful issue for her.

Positive emotional response

For some of the interviewees the tuberculosis experience seems to have been quite positive. A pair of siblings peppered their interview with phrases regarding the sanatorium like 'ooh I loved it', 'we had great times' and 'Cloud Nine'. They went back to visit Crawfordsburn Hospital, where they had stayed, and felt very nostalgic to see the little beach on which they had played.⁴⁵ Similarly another woman was hoping that the interview would lead to her getting back in touch with sanatorium friends from the 1950s. Another interviewee was taken to a hostel as a newborn baby, while her tuberculous mother was hospitalised.⁴⁶ They had valued and talked a lot about this shared experience. The mother died recently and her daughter was very grateful to have the memories captured on tape. In a later letter she wrote, 'Thankfully she lived a long life where we had plenty of long chats and I heard all the details of her time in hospital.'⁴⁷ For them the interview was part of their shared history. For others the interview appears to be part of a process of finding out more about their past. One woman was planning a trip to her old hospital. As she explains:

It's a thing I haven't thought about in years and since speaking to you I wish I did know more. But whenever I saw in the paper several years ago about the hospital being turned into flats or apartments? I remember reading that and thinking oh look at that (laughs) I'd love to go and see what that looks like. And I think I said to some of our children I used to be in hospital there.⁴⁸

Another interviewee was prompted by the process of recall stimulated by the interview to take a trip to the Newspaper Library in Belfast to look for reports of her trip to Switzerland with other tuberculous children. She later wrote

that 'my visit to the Newspaper Library was both a profitable and emotional experience.'⁴⁹

Deciding to speak

The people above did not suffer significantly from the trauma or stigma that plagued others. However, the stigma surrounding the disease might explain why some people took so long to talk about their experience. Tuberculosis survivors could be complicit in the silence within their own family.

I was thirteen or so when I got home and I never spoke about it for years. ...my sister can remember I never spoke ever. I didn't want people to know I was in sort of thing. ... and I suppose the environment I was in too, down the lower Falls Road, it wasn't sort of place to be if you weren't too well, or if you weren't strong or whatever, you know. I used to be very, very aware of that. That's what I used to think, I just won't talk about that.⁵⁰

As the years passed Tommy found it difficult to deal with the personal problems he developed after spending his childhood (age three to thirteen) in hospital. He felt:

We were children who were with ourselves and that was about it. And you were really cut off from kids who were healthy and well. So ... you took this sort of thing on board like, that you were different from everyone else. ... [Society] just wanted you out of the way because you had this disease.⁵¹

Some years after he left hospital Tommy tried to find his teachers, as education had been his only comfort during hospitalisation: 'Those teachers I had they were exemplary'. But he couldn't find them. On another occasion he had told a man with whom he attended an Alcoholics Anonymous meeting about his past. Unfortunately in this case the issue of confidentiality and support did not apply to his tuberculosis. Tommy heard him telling one of the other guys, 'he used to have TB'. As Tommy stated, 'Like that gets to you, "Killer", like you've a badge.' In this case revealing his concealable stigma confirmed Tommy's worst fears that people did not understand.

Later Tommy went to see the hospital that he was a patient in before it was knocked down.

Just to see what it was like ... I went down to see the hospital just before, I didn't know they were going to demolish it. And I just went in one day to see and it was exactly the same. ... I actually walked up the stairs. I remember the big wooden staircase, the huge, big wide staircase and I went up them

TB Infants' Ward at Crawfordsburn Hospital, 1953.
Source: Northern Ireland Tuberculosis Authority Eighth Annual Report, 1953.
This body disbanded in 1959.



...I can see it now. It scared me, frightened me a wee bit, you know what I mean, ... they weren't that much different, the colours weren't, the colours and the wooden paneling round the other wards. It was still there and the big doors.

Tommy appears to have been very interested in his past and he was keen to talk to someone about it, in a situation where confidentiality was guaranteed. Tommy spotted the request for interviewees in a local newspaper and the resulting interview was articulate, poignant, and very sad. It appears that when the letter was printed Tommy had been feeling ready to talk for a while.⁵²

In some cases sufferers of tuberculosis may have wanted to talk about their experience but felt that their family didn't want to listen. This appeared to be the case in another family I spoke to. Karen, wrote with regard to her sister, Amy, who now lives abroad, but had been in hospital with tuberculosis at the age of four. She had little information and only remembered about the history as she had overheard her sister mention it recently. Amy gave an email interview which revealed a lot of unresolved issues. The fact that Karen made the initial contact showed her interest in the subject yet she did not ask her sister about it. Amy gave permission for her interview to be shared but it was thought that it would be better if the sisters spoke to each other about their past. Amy was only four at the time of her TB but she explains how she felt:

I don't remember any family member saying anything about me being away or being

back. I felt I had lost my place in the family. As for lasting effects, I never trust anyone and I have an ongoing abandonment issue which I have had to have tons of therapy for.

She wrote that, 'Karen or any other member of my family have never mentioned my stay at Crawfordsburn. I don't know why and I don't know why I never asked them either. ...Up until the present time, no members of my family have ever showed any interest in discussing my illness or my stay in Crawfordsburn, but if there's an interest now, that's great!' Once more this appears to be someone who was very keen to talk about her past experiences but didn't feel she had a receptive audience. She sought out therapy to help deal with issues raised by her hospitalisation at such a young age. When Amy returned home from hospital, she says, 'the neighbourhood children must have been told to stay away from me as I remember not having anyone to play with and my mother saying, "you don't need anyone, you have your sister".' This last remark seems ironic in light of the silence that developed. A recent letter from Amy revealed that her sister had since written, 'that she only realised now how upsetting it must have been at the time'. Amy comments 'perhaps we must all find our own way through the pain' but it would appear that for some even a late breaking of the silence is helpful.⁵³

Health

In recent years membership of societies for polio survivors have increased once more as post polio syndrome affects previous sufferers. It is possible that health issues relating to past

tuberculosis experiences have caused some interviewees to respond to the request for interview in a similar way. With one woman, Olive, her response was directly related to her health. Olive had not experienced much stigma and had had a relatively happy time at the sanatorium at the age of fourteen. She got on well with the staff and described the fun they had together. Unfortunately her tuberculosis and subsequent operations left her with various recurring lung problems. When Olive saw the request for interviewees in a local newspaper she thought it might lead to medical help. She was happy to have her story recorded, even when she realised it was for historical rather than medical research.⁵⁴ Olive was referred back to medical expertise. Another woman's health problems kept her remembering her tuberculosis she explains:

I would be registered now with ... Chronic Obstructive Pulmonary Disease and my lungs never developed properly [due to the TB]. So thank God for antibiotics, I mean I would need antibiotics every two to three months.

This after-effect is apparently common as she found out when she was admitted to hospital with lung problems, 'there was about ten in the ward, roughly about my age and they'd all had TB when they were young' and the doctor said, 'this is as a result of your TB as a child'.⁵⁵ For these people tuberculosis has left a lasting physical impact. Two other respondents had either just been for an X-ray or were just about to go for one.⁵⁶ So it seems likely this may have influenced their decision to be interviewed. Another woman commented that although she was left with no health problems from her tuberculosis she was never allowed to forget it by health professionals. She explained:

All through my life this has followed me. Everywhere I go. Em, no matter when I've been in hospital. When I had my first son. He was tested immediately when he was born, that was over in England ... no matter when I've been in hospital for what ever reason ... they've always informed me I have to go and have a chest X-ray... So it follows you all your life.... I did get fed up with it after a while, because I don't smoke ... [and] I don't have any lasting problems.⁵⁷

Although this lady had no problems many others did and, as their health deteriorated with age, it made them think again of their TB past. It seems possible that this spurred some to respond to the request for interviewees.

Tuberculosis as a non-concealable stigma

For some people their tuberculosis was a non-concealable stigma. For a number of interviewees their curved spine or chest surgery scars were only apparent when they were on the beach or swimming pool. One interviewee however was left with a short leg, which was always visible. He was a patient in a small local hospital for a number of years from the age of four. Their beds were outside during the day where they had interaction with the townspeople. Harry still lives in the same area and so it is a fairly regular occurrence to meet people who he knew from those days. 'People even still say to me, ...[I] remember coming up to see you when you were sort of a wee fellow in the hospital'.⁵⁸ He remembers meeting one of his doctors out in the town who said to him that when he was five, 'I can remember you looking over the edge of the cot.' He also met nurses who'd looked after him and other patients. Harry's condition causes children to stare at him, as he comments, 'Worst part was, even still, youngsters look at you. You have to get used to things like that.' The visibility of his condition also means that people remember his past experience and talk to him about it. Harry was asked to give his interview by a local doctor. He seemed happy to talk about his memories and gave a full, detailed interview. Harry is an example of someone who has often talked about his experience over the years. Ironically since his was a non-concealable form of tuberculosis, Harry did not feel that he experienced any of the stigma associated with the disease, because his was not infectious and the community could not be 'smitten'.⁵⁹

The impact of breaking the silence

Pennemaker's work discusses the healing power of confiding in others, and Smart and Wegner write that 'under certain conditions, as in the presence of a safe supportive audience or when one is able to preserve anonymity, making a concealed stigma visible may be beneficial'.⁶⁰ As discussed many of the interviewees were speaking about their tuberculous past for the first time. To gauge the impact of the interviews a questionnaire was sent to the thirty-three interviewees to ask if the interview process had affected their lives. In the intervening three years, three interviewees had died, and one moved away. There were therefore nineteen replies to the questionnaire leaving ten people for whom the impact of the interview remained unknown.⁶¹ Of the nineteen respondents seven had talked openly about their disease before they were interviewed, one to anyone interested and six to family and friends. The other twelve had not (one had mentioned it to medical staff, one to a therapist and one only to his wife).

Seven explained that they did not talk about their tuberculous past due to the stigma they felt was still in the community, and three simply did not want to bring up unpleasant memories.

Eleven of the nineteen interviewees who responded said that the interview process did not prompt them to talk about the subject afterwards or prompt further interest from others who were aware of it. None of them minded this and one was even relieved. Eight interviewees did, however, talk more about their experiences after the interview to family and friends. One interviewee wrote:

Thank you, it really helped me to talk about my experience, up until I had talked to you a lot of my family and friends did not know I had spent over a year in hospital. I was very happy to help.⁶²

Another woman wrote:

I did talk about my TB experience with both family and friends [previously]. [However] taking part in the project did prompt me to talk /reminisce about my experience. ... As it is such a long time since my illness there is a younger generation within the family who, as a result of your interview, instigated a renewed curiosity in that episode of their Mum's/Aunt's childhood. ...I appreciate your continued interest and I hope your research was as informative for you as the pleasure of my recollections for me.⁶³

Other responses concluded however that 'we must find our own way through the pain'.⁶⁴ One man wrote that 'The past is history, we cannot change it and if we have suffered unpleasant experiences, we must try not to allow these to dominate our lives',⁶⁵ and a woman concluded: 'I try not to look back and I have just got on with my life'.⁶⁶ The nineteen respondents wrote that the interview process did not have a negative impact. We do not know about the ten who did not reply. Although 'healing' was not the purpose of the oral history project discussed in this paper it would appear to have had a positive impact for eight people. For the majority, however, it did not cause any change in their communication about the events.

Those who did not wish to talk

We have looked at the responses of interviewees and the reasons many remained silent for years. There are clues as to why some people chose not to get in contact. In response to the newspaper appeal for interviewees a letter was received from a lady saying 'My husband was a TB patient while still at school ...He would be reluctant to contact you but I think would be helpful if you contacted him.'⁶⁷ His wife was

told it was best if the interviewee made first contact. His wife wrote back, 'my husband has asked me to tell you he will participate in your survey re tuberculosis.' Subsequently we did have a good interview where he explained how he now felt about his TB:

Obviously I still see that big ugly scar on my back but even that doesn't trouble me. I mean I go on holidays now and it doesn't concern me taking my shirt off. And if someone asks me what it is I just say well I had an operation away back in the mid-fifties and that's the scar from it. And if they ask me what it is well I try to be, I don't feel in any way defensive about it.⁶⁸

This man's initial reluctance appears to have been because he didn't think he had anything useful to impart. It would suggest that many people don't make contact simply because they don't think their story interesting enough. A sadder case started with a very promising response letter to the newspaper request. It stated 'I would be happy to talk to you with details of my illness.' The interview began with the interviewee chatting easily about a fairly unpleasant hospital experience during which they 'didn't remember any happy times'. In interview it transpired that something upsetting had happened in the hospital, which they didn't wish to talk about and the interviewee started to weep. The interview was discontinued and counseling offered. Unhappy memories of the time in hospital had led to blocking out most of the memories of childhood under the age of eleven.⁶⁹ This interviewee might represent another, hopefully small, group who found their hospital stay so traumatic that they couldn't bear to talk about it. In studies in America, polio survivors report 'having been sexually abused at three times the rate of the general population of people who were children in the '50s'. Dr Frick a psychologist specialising in polio sufferers, in the New York Times writes, 'If there was a paedophile in the family or on a hospital staff and a child was unable to run away, you can guess what might happen'.⁷⁰ There were many children with tuberculosis who were also unable to run away.

Another anonymous letter represents a group who chose not to be interviewed. It came from a person aged seventy with details of their tuberculosis experience. The events don't seem unusual. They were diagnosed at the age of eleven, then rested at home for six months, spent a further six months in a sanatorium, and finally continued the regime at home. 'After five months of excellent nursing and a good appetite and a watchful mother, my home care did the trick'. The writer married and had a large family without any further trouble: 'Forgive me for my



TB patient at Whiteabbey Hospital, 1952.
Source: Northern Ireland Tuberculosis Authority Seventh Annual Report, 1952.

anonymity [sic] but I'm shy when it comes to signing my name'. This brings us back to the stigma that some people seem to have felt more keenly than others. There is no clue as to why this writer did not want to be identified but may well represent a large group.⁷¹

As Paul Thompson has written, 'We cannot, alas, interview tombstones'.⁷² A further group who did not speak are those who died, both as a result of their disease, or from other causes. Therefore the interviewees were all tuberculosis survivors. Some relatives of the dead did speak but it is a group that could not be directly represented. Four of the interviewees who spoke died in the three following years, all aged seventy plus. Many other past patients may have chosen to come forward if the letter in the paper had appeared during their lifetime. One of those interviewees who died recently had been, his daughter felt, left with a 'lasting trepidation about consulting anyone medical so that, although he must have been feeling unwell, he didn't mention it. ...by the time he was taken to hospital it was just too late.' This late effect of his tuberculous past did not affect his desire to speak at interview but may, his daughter felt, have shortened his life.⁷³

Conclusion

The reasons for the dearth of pathographies from survivors of childhood tuberculosis are various. Primarily the shame and stigma that accompanied the disease and emotional trauma led survivors to hide their past rather than celebrate victory over the disease as is the case in

the 'restitution narrative' structure of many pathographies. In addition the nature of the disease influenced the pattern. Tuberculosis did not spike in seasonal epidemics in the same way as polio. This meant it did not hit a population with the same drama and human interest, factors that could increase the 'status' of a disease and its visibility in the media and literature. Personal testimonies are therefore very important to fill in the gaps with regard to childhood tuberculosis. The promise of anonymity meant interviewees were able to speak out without risking once more the spectre of shame. In general this appeared to be valued by the Northern Irish interviewees. One can ask however, how different would the interviews have been without anonymity, and would different patients have come forward in Northern Ireland if the forum to speak had been offered by an ex-patient rather than a historian?⁷⁴

This research has added to the growing body of oral history work, which has a role in recovering the memories of previously silent patients. It has shown how the operation of stigma and social distance influenced the lives and the accounts of many survivors of tuberculosis. Though not a quantitative sample this research has elicited individual experiences from the previously tuberculous, which confirm the results of work by Goffman, Bogardus, Smart and Wegner. The tuberculous clearly fit into Goffman's definition of the stigmatised and though this stigma has diminished over the years the memory of it is still felt by

those who have suffered. Interviewees confirmed this stigma by often revealing answers to the Bogardus measurements of stigma within their stories. Smart and Wegner's description of the 'concealable stigma' and the anguish this causes can also clearly be seen in the experience of some of the interviewees. This paper has attempted to untangle the complex reasons why some people in the

Northern Irish situation chose to speak or remain silent about their experience. Perhaps the echoes of the last roar of that great dragon tuberculosis are still being felt in Ireland as the stigma and shame linger on in memories. It is to be hoped that increasing awareness of the experience of these long ago children may encourage more to agree to be interviewed or to write about their tuberculous past.

NOTES

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4. S T David, 'Public opinion concerning tuberculosis', *Tubercle*, vol 33 no 3, (1952), p 84.
5. James Deeney, *The End of An Epidemic. Essays in Irish Public Health 1935-65*, Dublin: A&A Farnar, 1995.
6. Northern Ireland Tuberculosis Authority Annual Report 1947, p 21.
7. Morbidity is the prevalence of disease, therefore the numbers sick with the disease. Mortality is the number dying from the disease.
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11. Michael Bury, 'Chronic illness as biographical disruption', *Sociology of Health and Illness*, vol 4, no 2, 1982, pp 167-182.
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13. Simon J Williams, 'Chronic illness as biographical disruption or biographical disruption as chronic illness? Reflections on core concept', *Sociology of Health and Illness*, vol 22, no 1 (2000), pp 40-67.
14. Catherine Kohler Riessman, *Narrative Methods for the Human Sciences*, California: Sage, 2008, p 11, p 55.
15. Arthur B Frank, *The Wounded Story Teller*, Chicago: University of Chicago Press, 1995, p 77.
16. Magdalena Harris, 'Living with Hepatitis C: narrative of chaos and quest', at <http://www.gendercentre.org.au> (accessed 31 March 2009).
17. Rosemary Conry, *Flowers of the Fairest*, Dingle: Brandon, 2002, p 214.
18. NITA Annual Report, 1957, p 9. Sixty-two percent of the orthopaedic patients in 1957 were polio admissions.
19. Patrick Cockburn, *The Broken Boy*, London: Vintage, 2005; Alison O'Brien, *Abandoned A Survivors Story*, Belfast: Brehon Press, 2008, are Irish examples. The Post Polio Support Group (Ireland) has also published *Polio and Us Personal Stories of Polio Survivors in Ireland*, Futureprint 2007, which contains twenty-nine personal testimonies. Cockburn, 2005, p 21. Wilson, 2005, p 17.
20. Harlan Hahn, "'The Good Parts": Interpersonal Relationships in the Autobiographies of Physically Disabled Persons,' Wenner-Gren Foundation Working Papers in Anthropology, New York: Wenner-Gren Foundation, 1983, pp 10-11.
21. Wilson, 2005, p 7.
22. Frank McCourt, *Angela's Ashes*, London: Flamingo, 1997, p 192.
23. McCourt, 1997, p 129. Browne, 1986, p 31.
24. As revealed in interview with OH53, born in Londonderry, April 1937, clergyman; recorded by Susan Kelly, 22 February 2004.
25. The diary of a distant cousin of Dr Raymond Hurt, private collection. B Macdonald, *The Plague and I*, London: Hammond, 1948.
26. RTE 'Documentary on One', 'On the White Death Trail', 21 July 2004.

27. Simon Guest, 'Cure, superstition, infection and reaction: tuberculosis in Ireland, 1932-1957', *Oral History*, vol 32, no 2 (Autumn 2004).

28. Ann Shaw, Carole Reeves, *The Children of Craig-y-nos: Life in a Welsh Tuberculosis Sanatorium 1922-1959*, Wellcome Trust, Milton Keynes, 2009. This book includes interviews with ex-staff and ex-patients.
29. Some were recorded in a day care centre for the elderly and one was recorded in the interviewers home.
30. Other interviewees were health or education professionals or relatives of children who had tuberculosis. The names of interviewees were changed to maintain confidentiality, some personal details have not been included in footnotes for the same reason.
31. Guest, 2004, p 63.
32. Interview with OH2, born in Belfast, July 1929, doctor; recorded by Susan Kelly, 22 February 2004.
33. Interview with OH32, born in Belfast, television repairman; recorded by Susan Kelly, 20 May 2004.
34. Interview with OH43, born in Annalong, pharmacy assistant; recorded by Susan Kelly, 15 June 2004. Interview with OH38, born in Belfast, engineer; recorded by Susan Kelly, 2 February 2004. Interview with OH40, born in Belfast, housewife; recorded by Susan Kelly, 8 June 2004. Interview with OH31, born in Belfast, nursing assistant; recorded by Susan Kelly, 19 May 2004. Interview with OH32, born in Belfast, television repairman; recorded by Susan Kelly, 20 May 2004.
35. Erving Goffman, *Stigma: Notes on the Management of Spoiled Identity*, New Jersey: Prentice-Hall, 1963, p 12.
36. Goffman, 1963, p 163.
37. Emory S Bogardus, 'Measuring Social Distance', *Journal of Applied Sociology*, no 9 (1925) pp 1461-1500.
38. Letter from OH21 to author, received February 2008.
39. Interview with OH11, born Belfast, November, 1932, weaver; recorded by Susan Kelly, 7 April 2004.
40. Goffman, 1963, pp 43, 44.
41. People who have had bone and joint tuberculosis may have visible deformities

such as a curved spine or short leg and those who've had chest surgery may have scars visible in certain circumstances.

42. Laura Smart, Daniel M Wegner, 'The Hidden Costs of Hidden Stigma', in Todd F Heatherton, Robert E Fleck, Michelle R Hebl and Jay G Hull (eds), *The Social Psychology of Stigma*, New York: The Guilford Press, 2000, p 221.

43. Goffman, 1963, p 123.

44. Interview with OH45, born in Belfast, February 1939, weaver; recorded by Susan Kelly 16 June 2004.

45. Interview with OH44, born in Belfast, January 1953, housewife; recorded by Susan Kelly 15 June 2004.

46. Interview with OH34, born in Co. Derry, January 1919, housewife; recorded by Susan Kelly 25 May 2004

47. Letter from interviewee OH34 to author, 22/5/06.

48. Interview with OH48, born in Lough Gall, August 1949, bank worker; recorded by Susan Kelly, 22 June 2004.

49. Interview with OH25, born in Belfast, April 1945, radiographer; recorded by Susan Kelly, 6 May 2004.

50. Interview with OH32, born in Belfast, May 1941, television engineer; recorded by Susan Kelly, 20 May 2004.

51. OH32.

52. OH32.

53. Interview with OH36, born in Belfast, June 1935, typist, recorded by Susan Kelly, 26 May 2004 and with OH36B, born in

Belfast, September 1943, housewife, recorded by Susan Kelly by email, 22 August 2004.

54. Interview with OH47, born in Antrim, October 1950, telephonist; recorded by Susan Kelly, 21 June 2004.

55. Interview with OH35, born in Island Magee, January 1931, secretary; recorded by Susan Kelly, 22 June 2004.

56. Interview with OH37, born in Belfast, December 1930, spinner; recorded by Susan Kelly, 1 January 2004. Interview with OH22, born Belfast, December 1941, office worker; recorded by Susan Kelly, 28 April 2004.

57. Interview with OH27, born in Kilkeel, March 1942, secretary; recorded by Susan Kelly, 10 May 2004.

58. Interview with OH26, born in Downpatrick, June 1940; recorded by Susan Kelly, 7 May 2004. OH26.

59. OH26.

60. J W Penebaker, *Opening Up: The Healing Power of Confiding in Others*, New York: Morrow, 1990, Smart and Wegner, 2000, p 237.

61. They may have died, moved away or chosen not to respond.

62. OH45B, subsequent letter Jan/Feb 2007.

63. Letter from interviewee OH25 to author dated 13 February 2008.

64. Interview with OH36B, born in Belfast, September 1943, recorded by Susan Kelly, 22 August 2004 via email.

65. Interview with OH49, born in Ballymena, August 1940, businessman; recorded by Susan Kelly, 25 May 2004.

66. Interview with OH21, born in Belfast, January, 1930, stitcher; recorded by Susan Kelly, 26 April 2004.

67. Letters from wife of interviewee OH49 dated 20/4/04 and 20/5/04.

68. OH49.

69. Interview with OH40, details of interviewee kept private; recorded by Susan Kelly.

70. Holcomb B Noble, 'Scientist at Work/ Nancy Frick: A First- Person Study of Polio's Painful Legacy', *The New York Times*, 10 November, 1998.

71. Anonymous letter in the possession of the author dated 22 April 2004.

72. Paul Thompson, *The Voice of the Past: Oral History*, third edition, Oxford: University of Oxford Press, 2000, p 5.

73. Letter from daughter of interviewee OH38 received February 2008.

74. Shaw, Reeves, 2009. The methodology of the Craig-y-nos project in Wales meant that the interviewees did not have anonymity, as the project started when ex-patients responded to a blog set up by one of the authors, herself an ex-patient. Meeting up with ex-staff meant the anger of some of the interviewees defused but their stories also changed and became moderated.

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