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**A Narrative Analysis of The Stories of Parents whose Children are  
Born with CTEV**

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I would like to acknowledge the assistance of my teachers, and especially my parents.

## **Abstract**

Since the mid-1990s the increasing availability of the internet has allowed more and more people to express themselves through electronic self-publishing. The Internet has led to an explosion of self-expression. People tell their stories and conduct group discussions with others from around the world, on message boards, home-made websites devoted to personal interests and by writing public blogs.

This study examines the publicly told stories of parents whose children have the congenital condition of CTEV, known as Talipes or Clubfoot, a condition that affects around 1 in every 500 children born. A small number of people with the condition go on to experience significant impairment.

The aims of the dissertation are twofold. Firstly, to discuss some of the ways that theorists in a range of disciplines: sociology, medical sociology and disability studies, have sought to discuss the way illness, congenital impairment and disability are defined and addressed within society. The second is to examine the electronic texts –the stories - written by the parents of children with a CTEV diagnosis to draw out themes and concepts in them and examine how they relate to the theoretical ideas.

Analysis of the texts of stories follows approaches taken from narrative analysis – particular narrative medicine – and discourse analysis. Analysis of the

stories is conducted using the narrative typology developed by Arthur W Frank in his 1995 book *The Wounded Storyteller*.

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## **Introduction**

Congenital Talipes Equinovarus, also referred to as Clubfoot and hereafter referred to as CTEV, is a condition that is generally diagnosed during pregnancy or at birth.

Many parents whose children are diagnosed with the condition, and people with the condition, have used the wide availability of Internet self-publishing and internet communication since the late 1990s to voluntarily tell their stories publicly, as well as sharing them with others in a similar position. This has the effect of creating what could be called virtual communities. The members of these communities engage in sharing their experiences and assisting each other with support and information regarding the condition. The aim of this study is to examine the personal stories of the individuals who are affected by a diagnosis of CTEV, to find out what constitutes their stories: what issues could be said to inspire the storytelling, what kind of knowledge is shared and some of the effects telling stories might have in the context of the condition.

The study utilises a range of theory to situate and comment on what the stories may reveal. Theoretical ideas have been adopted from the fields of Sociology, Disability Studies, Medical Sociology, Narrative Medicine and Discourse Analysis. These disciplines have all developed theories and critiques in regard to the way difference is recognised and responded to within society. Examples of this would be critiques from the field of Disability Studies of the

orthodoxy of the medical or tragedy model of disability [Barnes et al 1999 p 77] and discussions in Medical Sociology regarding the way in which illness is constructed and perceived.

CTEV is a medically classified condition that fits into the category of 'congenital deformity', but only sometimes results in impactful impairment and disability. Therefore it exists at the intersection between illness, impairment and disability. Examination of stories which detail responses of people to a diagnosis which, in most cases, has a widely variable prognosis, could well illuminate some of the key theoretical issues surrounding illness, disability and difference.

Analysis of the stories aims to highlight where they show common or contradictory themes. This enables further evaluation of how these themes engage with, and illustrate, the concerns that surround the condition of CTEV specifically, and also some of the broader theoretical ideas discussed.

The study uses qualitative analysis adopting techniques of narrative analysis and discourse analysis to identify themes and draw conclusions. The narrative analysis applies the typology developed by Arthur W Frank in his book *The Wounded Storyteller* as a 'restorying' template [Cresswell 2007 p56]. Frank's typology could be said to occupy the field of Narrative Medicine.

The study will be presented in four sections. The first will provide context by considering the condition itself: its prevalence, how it is medically defined and a

brief history of the way it has been treated throughout history. The second section discusses a range of pertinent theoretical perspectives regarding medical discourse and the way illness, impairment and disability is constructed within culture and the roles different narratives assume in these areas. The third main section will utilise Frank's narrative typology to present an analysis of the stories chosen, situating them within the framework offered by the typology and discussing how emerging themes relate to theoretical perspectives. The fourth section will draw some brief conclusions.

## **Review of Previous Literature Pertaining to the Study**

There is a small existing range of literature which examines parental responses to diagnoses of infant conditions. Available studies in this area focus on the protocols of different treatments for specific conditions without necessarily addressing theoretical concepts. Whilst analysing parental responses, none is designed to explore a theoretical basis for them.

Heiman [2002] examined the general resilience and coping strategies of families faced with disability and impairment in a child. This study looked at a range of disabled children with physical, learning and intellectual impairments living within their families, and how the families were affected on an emotional and practical level. One of the conclusions in this paper with regard to diagnosis that is relevant to the current study is that a large majority of parents (84%) reacted in a negative way to receiving a diagnosis. The reactions were both emotional, such as feeling sad or worried and physiological, such as inability to sleep and crying. 12% of the parents studied reported no negative or positive responses to diagnosis. The study was conducted with parents of school-age children with a range of disabling impairments that had placed their children in Special Education, therefore the comments made were both in context of wider opinions sought by the researcher and also with often significant historical perspective from the subjects.

Goldbeck [2006] examined the impact on parents of chronic conditions in their children using the Ulm Quality of Life Inventory for Parents with respect to diagnosis of childhood diabetes and cancer. The majority of parents in this study also experienced negative emotional impact, as well as restrictions on their family activity due to caring for their child and following regimes of treatment. An interesting conclusion made from this study is that, despite the overall negative impact on Quality of Life, parents report that diagnosis of serious chronic conditions does, in many cases, bring families closer together in supporting each other.

Oprescu et al [2013] examine the use of the internet by parents of children with CTEV. The study offers a detailed content analysis of message board activity in relation to Uncertainty Management Theory and Brasher's schema of information-seeking behaviours, with the aim of examining how parents use internet resources to manage their uncertainty. The main pertinent conclusion of this study is that what could be called the community of CTEV parents acts as a major 'unofficial' conduit of information, guidance and support. The study proposes that this could well occur because the 'official' medical provision in these areas is deficient.

Thus far, only one other study has examined the general response of parents whose children have CTEV. Pietrucin-Materek et al [2011] interviewed 15 families of children aged between 5 months and 14 years. They identified three

key themes in their study of parents psycho-social responses to having children with CTEV. Firstly, the study found their subjects reported negative emotional responses to diagnosis. They conclude that more attention should be paid by healthcare professionals to the emotional impact on parents of their child's CTEV diagnosis and treatment. However, because CTEV can be a marker for Down Syndrome and other syndromic conditions, some parents expressed relief when it transpired their children did not have more complex issues. Secondly the study found that parents face everyday practical and emotional difficulties during treatment and beyond. These included the effects of regular hospital visits, difficulties with finding appropriate childcare, following the strict regime of treatment and difficulty in accessing information and support. Although a range of online support is available, parents who were not comfortable using internet felt disadvantaged. Thirdly, this study found that a majority of parents worried about their child's body image, their ability to participate socially and the impact 'difference' might have on their child's self-confidence.

## Methodology of the Study

For this study the stories chosen for analysis are written by parents and posted publicly online. The key theme is therefore how parents respond when their child receives a diagnosis. By their nature and genre some of the texts by parents are historical accounts.

The texts were found in three ways:

1. Use of internet search engines, in this case Google, using the following

search terms:

*Talipes, CTEV, Club Foot*

Allied with other terms:

*My, Our, Personal, Story, Journey*

To search blogs the names of specific blog sites were also added:

*Blog, Blogger, WordPress, Tumblr*

The phrases were chosen to return a broad range of results, taking into account the ways that search engines rank results algorithmically.

The process was repeated as control using a second search engine: Bing.

2. Following links from 'official' sites –run by charities etc - where users could post their own personal links.
3. The cross posting of links from users personal sites.

For each of the terms used the first 30 results were examined. These were further filtered using three main criteria of rejection.

1. Pages were 'ghost' entries and contained no relevant information.
2. The stories were not public, in that accessing them required subscription to a Social Network site, or the users had pass-warded content as private.
3. The pages requested further information or subscription.

The remaining pages were filtered according to content. No account was taken of nationality, gender, ethnicity nor socio-economic factors, which could be part of any future study.

Searches provided a very large range of material. 21 main texts were chosen for analysis. These ranged from long term blogs, to much shorter message board posts. Each was chosen after being adjudged to reveal enough pertinent information to constitute a 'story'. In addition, some shorter texts were used, such as comment replies to blogs, newspaper articles or contributions to discussion board threads. The study also examined several threads on topic-specific discussion forums with a large number of contributors – offering what could be called 'fragments' of stories pertinent to the topic discussions.

The stories chosen were coded according to the three parts of the narrative typology: Restitution, Chaos and Quest before quotes were extracted to illustrate themes.

## **Limitations of the Study**

Use of texts published via the internet necessarily means the stories are told by people who have access to the internet and the knowledge and resources to author and publish autonomously. This excludes the stories of people without capability to utilise the internet, or those unable to relate their stories in writing. The sites used were written in English only. These factors must be borne in mind when considering the sample texts used, in that they will restrict the cohort to those who have volunteered their stories publicly. No follow up was attempted.

## **Ethical Concerns**

The study was ethically approved by the University of Leeds before being undertaken. With the exception of one text, a personal email for which usage permission was granted, all the texts studied are in the public domain.

## **Features and History of Congenital Talipes Equinovarus (CTEV)**

CTEV (sometimes referred to as Talipes or Clubfoot) is an umbrella medical term which refers to a complex idiopathic congenital condition affecting the foot and lower leg. It can occur as a discrete issue, or in a small number of cases in conjunction with other congenital issues.

The incidence of the condition is variable throughout the world. The variation may be due to different collection and reporting methods, and also the inclusion, in some data of other similar appearing conditions, such as the Metatarsus Adductus and Positional Talipes (PTEV). The incidence of Talipes in the population of the U.S. – as representative of a WENA nation - has been measured as 2.5 per 1000 live births. This is comparable with a prevalence of palatoschisis (cleft palate) as about 1 per 1000, Down Syndrome as approximately 1 per thousand and Cerebral Palsy at approximately 2 per 1000 in WENA nations. [Derijcke et al 1996, Morris 2009, Scope.org online]

Males are, on average, twice as likely to be affected than females.

The basic physical features of the condition are in the form, shape and direction of the foot. Children are born with either one or both feet pointing and curving inwards and with an inability to flex into alternative positions. This is caused by the positioning of the complex bone structures of the foot. Not only are the bones rotated but they are held in place by muscles, ligaments and

other connective tissues. Treatment is therefore complex and multi-faceted and involves both bones and soft tissues.

Even when treatment is considered successful, in many cases the foot is shorter and wider than average and the calf muscle is smaller than average [Gamble et al 2012]. In serious *atypical* cases the features are more pronounced.

The earliest documentation of CTEV has been traced to Ancient Egypt. Although there has been discussion regarding the cause of his deformity, with some suggesting poliomyelitis, retrospective diagnosis of the skeleton of Pharaoh Siptah (circa 1200 BCE) has concluded that he had left foot Talipes [Aufderheide et al 1998 p76]. There is a vast literature on the appearance of CTEV in ancient mythology, most notably in the Greek myths of Hephaestus and Oedipus [Stiker 1999 p47, Ebenstein 1986].

Talipes cases are generally idiopathic and medical opinion remains divided on their cause. Miedzybrodzka [2002] outlines theories and research regarding the aetiology of the condition. She describes several hypotheses which are subject to ongoing research and investigation. One hypothesis has been disproved. This is referred to as the positional hypothesis, which posited the condition is caused by mechanical compression according to the physiology or cyclic activity of the mother. As early as 1939 researchers suggested that the similarities and variation of cases could not accord with the positional

hypothesis [Idleberger 1939]. With the introduction of foetal scanning technology, medical professionals can detect Talipes long before the foetus has reached a size where positional factors could be considered a major influence. Positional factors *can* lead to Positional Talipes (PTEV), which appears superficially similar, but is a different condition than CTEV.

A vast majority of cases (about 75%) are idiopathic, with an unknown cause. The remaining cases are considered genetic, in that they occur where one or more close family members were also born with the condition. The exact way in which these cases occur is still unclear. The 'genetic' influence does not follow the classic Mendelian pattern [Jones 1993 p31-34], which can be used to statistically predict the instances of genetic conditions following on in families.

## **Treatment**

In considering treatment of CTEV Dobbs et al [2000] sum up the history succinctly when stating:

“It is striking when reviewing the history of clubfoot management to see how the same mistakes are made time and time again by the treating physicians.”

From Hippocrates (d. 377 BCE) onwards [Mason 2013], CTEV was either left untreated or, when treatment has been recorded, it was done by often forceful manipulation techniques in early childhood. In line with the development of medicine as a formal discipline in the WENA nations – and its increasing

separation into sub-specialisms throughout the Modern era, CTEV gradually became the preserve of orthopaedic and paediatric specialists. It could be said that the diagnosis and treatment began to be defined along the lines of the process of medicalization from the 18<sup>th</sup> century onwards.

Frick sums up the pattern of treatment from 1848 to the present as moving “from nonoperative to operative and back to nonoperative.” [Frick 2001]

A key change in treatment occurred as a result of the rise of surgery after the introduction of surgical technologies towards the end of the 19<sup>th</sup> Century including aseptic surgery, anaesthetics and pneumatic tourniquet techniques. Through the early part of the 20<sup>th</sup> Century surgery was used in more and more cases, alongside forceful manipulation. Frick describes six major strands of surgical technique which developed until the 1970s. The variations in some of these techniques were as a result of differing opinions about the definition and classification of the condition. Notably, the sixth of these is the “à la carte” approach: “Do only what is necessary to get a good correction of the foot.” [Frick 2001], although this statement is arguably closer to a definition of ‘carte blanche’.

It was not until the last few years of the 20<sup>th</sup> Century that medical professionals and patients began to question the effectiveness of surgery beyond the initial stages of treatment. A 1992 study found a high level of undercorrection and overcorrection in infant surgery that subsequently

required further surgical intervention. A 2006 study was the first to follow up surgical treatments into adulthood, concluding that the scar tissue from early surgical intervention becomes significant factor in later-life, often leading to levels of impairment amongst a majority of subjects that “significantly... [impacts]...quality of life” [Taraf and Carrol 1992, Dobbs et al 2006]

The currently used non and minimally operative manipulative treatments, mainly the Ponseti Technique, only began to become widespread in the 21<sup>st</sup> Century. Under Ponseti’s treatment regime, the deformity is treated with a series of casts, manipulations and the use of special footwear. Some patients also undergo a simple, minimally invasive operation called a tenotomy to release their tightened Achilles Tendon. In the USA and the UK the first medical textbook by Dr Ignacio Ponseti was published in 1996. Only after 2000 was the technique offered in more than one clinic and by practitioners other than Ponseti himself.

“Since approximately 2000, there has been a spectacular increase in number of countries using the Ponseti method.” [Shabtai et al 2014] Treatment outcomes for CTEV are generally considered to be positive. Advice published by Great Ormond Street Children’s’ Hospital in the UK states: “In the vast majority of idiopathic cases, the affected foot becomes essentially normal and the child can use it fully.” [GOSH – online]. Studies have shown that surgery now occurs in only about 10% of cases, mainly classed as very severe and ‘atypical’.

The question as to why the most commonly occurring congenital deformity has been subject to so little medical research and standardising of treatment is one which certainly deserves further study.

CTEV ranges from minor physical deformity that does not materially hinder function to severe disabling impairment. It is not considered in itself as a life-threatening condition, nor does it have the impactful developmental implications of syndromic conditions. As such effects are often subtle and – in visual terms – pass un-noticed. Although it is difficult to make any direct comparison, a broad analogy could be drawn with conditions such as cheiloschisis (cleft Lip) and palatoschisis (cleft palate) in that they too have a relatively high prevalence and occur with wide variation from minor cosmetic to severe. Both attract – in WENA nations – early medical intervention which can be conservative or more radical. However, these two conditions are facially situated, and can also have an effect on sensory and communication function. Cheiloschisis and palatoschisis are almost always treated with surgery to the face [Das et al 2014]. In the plainest terms, cosmetic and even functional differences arising from CTEV can easily be hidden under clothes and shoes.

## **Arthur W Frank's Typology of Illness Narratives**

In his 1995 book *The Wounded Storyteller*, Arthur Frank develops a typology of three 'illness narratives'. The first of these is the Restitution Narrative. This is the story of an illness or condition which is closely analogous with the Sick Role, as described by Talcott Parsons [Parsons 1964]. Frank's description of Restitution is that it describes a person becoming ill, then striving to get well, accepting the assistance of professionals and finally achieving a return to wellness and 'normality'.

The second part of the typology is the 'Chaos Narrative'. This describes the story from the point of view of the subject of illness. Having been diagnosed with an illness or condition, the subject is faced with a range of simultaneous and overlapping issues. The subject is often overwhelmed by an excess of questions and concerns: a whole series of known knowns, known unknowns and unknown unknowns. Their expectations of – inter alia - bodily control, societal role, self-conception and expectation of life-course options are all thrown into doubt. Often the chaos narrative is one which is extremely difficult for the subject to even express. They may be too physically ill or medicated to express their thoughts.

Frank's third narrative is that of the Quest. He allies this with membership of what he describes as the 'Remission Society'. Frank's argument is that serious illness which defies a simplistic cure cannot fit into the Restitution narrative, as

the boundaries between wellness and illness, especially 'normality' and 'difference' are ill-defined and constantly shifting. The Quest is a way of describing the process by which the subject realigns their frames of experience and embraces illness or impairment as part of long-term or lifelong reality.

Frank applies his ideas mainly to conditions such as cancer. However, his narrative typology is useful in a broader context when examining the role of the 'patient' with any condition or illness, or the disabled person, facing difference that, whilst existing in the social, is generally defined in medical terms.

For infant diagnoses, the typology cannot be directly applied to the subjects themselves. Instead, those around the subject, parents, family members and medical professionals experience the condition by proxy. However, examining their stories using Frank's typology provides a useful way of framing, describing and analysing their experiences of, and responses to, diagnosis and treatment.

## **Discussion of Modernist and Postmodernist theoretical approaches to Illness and Disability**

The Restitution narrative echoes Parson's sick-role in one key aspect. It is outside-in: an imposition from society onto the subject. Whilst engaged in the sick-role, a person undergoes a temporary but radical status change. A *person* becomes a *patient*. Patient status means that society grants permission for the normal person to become temporarily and radically *un-normal* whilst undergoing the processes of treatment. The demands and expectations placed on a person's function and deportment within society are temporarily relaxed. Illich refers to this as becoming a "legitimized deviant", in that subjects are allowed to exhibit difference. [Illich : 1976] Their role in society is place-marked whilst they enter a temporary zone of illness and recovery, before returning.

The sick role could be described as an exemplary Modernist formation, in that it is built on a foundational series of 'social facts', which treat the values and expectations of culture and the individual's position within culture as neatly defined and more-or-less fixed. Social facts create the conditions where scientific empiricism can function unchallenged [Brown 1995]. The Chaos and Quest narratives provide the subject with an alternative, a way of countering the idea of Restitution in a postmodernist context. In suggesting this, use of the term Postmodernist (and the term Modernist) as Frank does, is as a way of

signalling a “thick description of the feel of the difference...[in approach]” [Frank 1995 p4], not to indicate some defined cut-off point and therefore stumble into a wider debate over definitions, but to broadly indicate two general approaches to knowledge. The Modernist approach being one where knowledge is a ‘master text’ framed within the “Grand Narrative”: the pursuit and understanding of knowledge in the context of overarching theories, universally applicable rules and laws, arising from, and leading to, hermetically sealed ontological viewpoints and ideologies that aim to assert dominance in the ways of seeing and being within the world. [Lyotard 1979]

Modernist medicine, as a branch of Modernist science, is predicated on a technical, empirical approach to knowledge. As Foucault elucidates, this meant a shift in the perspective of medical assessment: from the involved and subjective historical question “What is wrong with *you*?” to the disinterested and objectively geographical “where does *it* hurt?” [Thomas Flynn in Gutting 1995 p33]. The Enlightenment empirical view of knowledge relies on systematic classification of the physical world, assuming a Platonic paradigm of the physical world existing in a factually stable ‘ideal’ form against which ‘abnormality’ and ‘unnaturalness’ can be calibrated. Where humans are concerned this also assumes Cartesian Dualism between unseen mind and visible body; a separation of what Arthur and Joan Kleinman call the “body-self” that experiences an “infolding” and “outfolding” interaction with the social

and cultural world, into its constituent parts of the *objective* carnal physical world of the body and the *subjective* person inhabiting the body [Kleinman and Kleinman, in Frank 1995 pp27, 28]. One of the features of this shift in the way medical knowledge was constructed and perceived was that it allowed the dissection of a whole human subject - the 'you' in 'what is wrong with you?' - into objective component parts – the 'it' in 'where does it hurt?' - which could then be repaired. The body as an entity of the self, became 'anatomy' (a word, notably, derived from the Ancient Greek for 'cutting up'); dissected into its object component parts to be measured against systematic classification. Modernist Medicine, by treating bodies as inanimate scientific objects of study and manipulation, collections of components, disavows infolding and unfolding. "The [medical] professional de-historicises the disease," viewing people as decontextualized from the social world. [Good & Good in Mattingly et al 2000 p51], Hence, assuming this *medical* paradigm, Parsons' sick role places the 'self' into a cryonic state of social action, overlooking the ways in which social action is defined, including the social and cultural fields within which empirical science itself resides.

The term Postmodernist is used by Frank to describe a move towards a position which accepts a multifaceted diversity of coexisting ontological positions, the power dynamics inherent in any choice of discourse and the understanding that 'truth' is a mutable idea that in every case exists in relation

to context. Lyotard uses the phrase 'little narratives', which supersede Grand Narratives as a way of describing and negotiating a way through the world. This approach offers a constantly reflexive, self-interrogating relationship to knowledge which questions the way in which it is constructed from the interplay of power-relations in the discourse which both describes and propagates them; recognising that all social processes are dependent on the cultural moments within which they occur. With reference to illness, Frank describes the postmodern as beginning "when ill people recognise that more is involved in their experiences than the medical story can tell." [Frank 1995 p6]

In terms of medicine the 'Modernist' viewpoint has been forcefully challenged by writers such as Illich and Foucault. Illich describes 'Medicalisation': medical professions gaining more and more control over the peoples' lives as a function of the discourses of political power. Importantly, Foucault highlights the way medical discourse acts within Modern society as the key agent of discipline, enacting social control over individuals according to his conception of 'biopower' [Illich Medical Nemesis p31, Foucault The Birth of the Clinic].

Lennard Davies explores the influence that scientific classification has on concepts of 'normalcy'. He argues that measuring and classifying the natural world creates a scientific ideal of the physical human based on mathematical averages, as seen in 'l'homme moyen' (the *mean* average man) developed by Adolphe Quetelet. But what is average is contingent on what is measured.

Physical parameters such as height and weight can be empirically applied to inanimate bodies as if they were rocks and stars, but the functional attributes and abilities of zoetic people such as strength, intelligence, endurance, creativity, willpower, initiative or beauty are examples of 'qualities' which traverse the boundaries of Cartesian Dualism and are culturally defined (although some evolutionary biologists argue that beauty is a biological function [Leroi 2003 p348]). Measurements and the interpretation of them are only granted meaning by cultural discourse. In the context of the construction of normalcy and disability within Modernity, Davis follows Foucault by describing how the discourse of science acts as a conduit and tool of power in order to create and enforce the hegemonic idea of a useful and productive human. Davis neatly sums up his argument that science is a social and political practise by saying that the "able body is the body of a citizen." His argument is, that under the influence of the discourse and ideas of a Modernist society, the *l'homme moyen* becomes synonymous with 'normal'. Davis comments that the word 'normal' with its meaning of 'average' only emerged in English in 1840. [Davis : 1995]

Davis uses the metaphor of the 'bell-curve', where an ideal of 'normalcy' exists between the critical point of the curve and its root. The critical point of the curve is an unattainable Platonic ideal. *L'homme moyen* is a mathematical

chimera. Anyone whose 'averageness' stands outside the area described around this central line by the curve is not 'normal': not a citizen.

Parson's sick-role is an example of the application of 'normalcy'. Illness grants people legitimate deviation to move outside the curve and have their citizenship suspended until they recover. Rehabilitation is defined by, and predicated on, returning under the shelter of the curve. Medicine, therefore, is the gatekeeper of citizenship.

Irving Goffman, writing about what he calls the 'moral career' of personal adjustment to stigma, discusses a patient's uncertain response to the 'handicaps' that 'strike' due to polio. Goffman writes: "Here the medical profession is likely to have the special job of informing the infirm *who he is going to have to be.*" [Goffman pp48, 49 italics added] This implies that medicine does not only act to treat the anatomy, by managing the symptoms and physical effects of disease. but possesses the capacity to legislate and decree an identity to the self of the patient. This is done by 'informing' the patient, as if neutrally passing on some discovered news. However, this neutral 'news' is hardly neutral. Not only is there an assumption that "diagnosis is based on the certainties of scientific rigour and formal knowledge" [Gillman in Swain et al p 252], but it can in many cases, amount to nothing less than the radical and imperative transformation of the self.

Cure, correction and rehabilitation are thus defined and propagated, not necessarily by the incremental healing of wounds, the defeat of pathogens, nor the salving of pain, but by the effect these actions have in recreating people as citizens. This is achieved by controlling the body to conform to social and cultural norms. Stiker points to the paternalistic role of medicine in the treatment of disabled people and the process by which control is exerted. Impaired bodies undergo various stages of therapy in order to 'shape-up' to look and behave like the bodies of citizens. Returning under the bell curve of 'normalcy' is to seek shelter from difference under the 'cloak of competence'. [Edgerton 1967]. In terms of a congenital deformity, it is down to medicine to decide on what constitutes 'deformed' – cosmetically and functionally - in line with the social and cultural norms defining a citizen, and thus also the path of rehabilitation and therapy.

Medicine as a discipline sets the tone of the story, writing a master text which, to appropriate a term from postcolonial theory, defines the *uncivilised* sick as a 'subaltern' group who 'experience the *civilising* colonization of...[their]...experience'. [Spivak : Can the Subaltern Speak?] The defining feature of colonization is the vilipending of the culture of the colonized subject, privileging a colonial discourse by ignoring and over-writing the voice of the colonized. In the case of illness this means disregarding the narrative voice - the story - as told by the ill subject from their viewpoint. Palestinian poet

Mourid Barghouti sums up the colonial method: “It is easy to blur the truth with a simple linguistic trick: start your story from “Secondly.”” [Barghouti 2001] Medicine performs this trick with the ‘texts’ which makes up the individual lives and experience of patients. Their knowledge, voices and stories are secondary and subservient to the master text, visible not only in charts, notes, diagnostic guides, prescriptions and records, but in the ‘medical opinion’ of individual professionals. The written text of “the chart becomes the official story of the illness.” [Frank 1995 p12 ]

The discourse of medicine is one in which the medical professional is engaged with illness and disease and not with the patient and “tends to cast the sufferer in the role of a passive substrate, or medium, on which the more interesting player in the game, the disease, operates” [Fleischman in Shiffrin et al 2008 p478]. In other words : “The medical profession has first claim over the label of illness....irrespective of its capacity to deal with it effectively.” [Friedson in Swain et al 2003 p60]. This co-option of the primary claim is a necessary function of the colonialist game. The main engagement of the game is between the doctor and the “de-historicised object-in-themselves”, diseases [Young 1982]. The patient is cast as a passive player. This is analogous with the way that in ‘exploitation colonialism’ the game is between the colonial power and the resources exploited for profit [World Bank - online] and the pacification of

a substrate population by assimilation or elimination is a necessary process to expedite the game.

When illness appears 'most people remain willing to continue playing the Modernist game without question.' [Frank 1995 p12], as this is considered the best and sometimes only path to a speedy cure. It is seen and accepted as a necessary indignity. Patients enter into the medical field and submit to being authored as patients according to the master text. They follow the rules and conventions of the field – including their own unfamiliarity, disorientation and suffering - in order to negotiate, and ultimately exit the situation. Thereby, in adapting to and submitting to the rules of discourse, they accept the power relations inherent in the field.

When illnesses and conditions are non-complex in terms of aetiology, symptoms, diagnosis, treatment, recovery and timescales, it could be argued that the process works to the advantage of all parties. The medical professional retains its primary claim over illness but, provided everything *is* non-complex and the process runs smoothly, *does* have the capacity to play the hero and save the day. The patient, experiencing pain, discomfort and temporary impairment, follows the Parsonian script and finds the issue resolved. Partly - ironically - as a result of the 'advance' of medicine, which develops more and more elaborate technologies to deal with more and more elaborated issues: when physical issues grow more complex, the process becomes unbalanced

and dysfunctional. The further along the continuum of control that impairment or illness places a body the less predictable all the influential elements are. At certain points, in certain cases, the rules of the process cease to apply. In Frank's Remission Society, many illnesses, CTEV being one example, remain mysterious, complex and not easily diagnosed nor cured. They continue under treatment - unresolved and ongoing. They slip, slide and stall along the continuum of control and back again. The boxes labelled 'Patient' and 'Citizen', and the movement of the ill subject between them on which Restitution relies, reveal themselves to be not so sturdily constructed.

Frank alludes to Susan Sontag's metaphor of the two Kingdoms. Every person holds dual citizenship in the Kingdom of the Well and the Kingdom of the Ill. From time to time people are obliged to travel from the preferred Kingdom of the Well to dwell in the Kingdom of the Ill. If we take a Spinozist view of the self that, "the body is the passport, the warrant, the seal of ones identity" [Charon 2006 p87], members of the Remission Society are refugees, subjects of the Kingdom of the Ill temporarily granted visas of indefinite but non-permanent residence in the Kingdom of the Well. Their visas could be revoked at any time by the re-emergence of their illness. However, to extend Sontag's metaphor, there are other groups, whom cannot not easily find refuge in either kingdom. Congenitally impaired people, for example, whom may not be symptomatically ill in relation to their own, deeply individual, 'well' state, but

are medically defined as ill by being under treatment or ongoingly defective do not accord with the citizenship demands of either kingdom. Their treatments are “compensations and rectifications...[and]...replacements...through surgical means or long term treatments”. But without “suppression of the malformation as such.” They unintentionally resist what Frank refers to as “medicine’s single-minded telos of cure” and thus they defy the ‘sick’ category itself. These are people who can never be cured, but also whose ‘sickness’ is not an essential fact but what Carol Thomas refers to as “impairment effects”: bodily differences constructed and perceived as problematic or restrictive. By exhibiting impairment effects many disabled people are therefore obliged to play out the sick role “whether we are sick or not”, underlining the notion that they are expatriated to the Kingdom of the Ill but impelled to travel on false papers. [Stiker 1999 p167, Frank 1995 p183, Thomas 1999 p48, Davis in Swain et al 2003 p203] The metaphor works according to the binary oppositions of well/unwell, sick/healthy. But there is no accepted opposite of *lusus naturae*, no antonym of mutant.

In the Kingdom of the Ill the crucial requirement of citizenship is to *be ill*, to follow the script of Restitution, which, for many, such as the congenitally impaired, is an unachievable goal. Restitution in the form of rehabilitation and cure are all predicated on temporality and “the reconstitution of the body *and* self.” [Barnes et al 2003 p82 italics added] In the Kingdom of the Well

impairment that is incurable or merely treatable, is therefore forced to masquerade as wellness. As such it could be suggested that congenitally impaired people, are unable to achieve full citizenship in *either* Kingdom, and remain *denizens* of both with a precarious and contingent array of rights, complicated by dual citizenship and multiple statuses. [Standing 2014 p105] In doing this they present, to use Paul Hunt's words:

“[a]...challenge in their relations to” [the script of citizenship]: “ordinary life,” [and the cultural notions of] “what a person is...what he is for.. [and]...what is the criterion of his worth.” [Hunt 1966 – unpagged].

Foucault argues that in Modernity, these notions we could call ‘moral value’ – the criteria of worth constructed by “relations of power as embodied and developed in a particular society” - are imposed primarily through the discourses that constitute medicine. [Foucault 1988]

The creation of disabled and chronically impaired people as denizens is tartly described by Stiker as Society offering a form of infinite “detour” [Stiker 1999 p171], via regimes of often speculative and imposed rehabilitation and liminal conditions of social action, which enact symbolic extirpation from society. This is ‘Social Death’ [Finkelstein in Oliver 1993], as opposed to the real solution of actual death by exposure or other means. The detour: “control...[that]... take[s] the form of more or less permanent sequestration” is the alternative path that Hunt rails against in his refusal to be “put away out

of sight and mind...set apart from the ordinary” in a care home that is recognisable neither as a place of care nor a home. [Rose 1999 p270, Hunt 1966]

Bury [1981] discusses illness as ‘biographical disruption’. His thesis is conceptually similar to Frank’s ‘Remission Society’ in acknowledging illness as an ongoing process and not a fixed event. It also recognises that societal roles are liable to being plastic, hybridised and amorphous, and that self in relation to the social world is also an unfixed entity in a state of perpetual shift. The strategies that people employ to face illness therefore overlap. Progress can move forward but also stall or regress. But the self which is subject to a biography, as recognised by postmodernist thought, is continuously disrupted, existing in an ambiguous and ever-changing state of becoming rather than being. Biography is genre within discourse that imposes coherence on this process and thus can never be a full or objective account. The ideas seen in the work of Foucault, Judith Butler and others, view meaning and definition forged through an interplay between discourse and the subject. “Telling our story does not merely document who we are; it helps to make us who we are.” [Charon 2006 p 69]. The discourse of the self creates the self and vice versa. Hence, it could be argued that Bury’s thesis – in utilising the very idea of biography which *can* be disrupted - fails to completely acknowledge the fluidity

and uncertainty of the definitions on which it is based, assuming a classical idea of the fixed self separate from a story of the self.

The concept of (auto)biography itself is also mutable: “With the body in view, autobiography cannot claim immortality but must succumb to temporality.” [Charon 2006 p77]. Biography is also only one potential mode of narrating the subject and is subject to a set of genre rules and structural tropes. Even if we choose to view biography in a Classical/Modernist sense, as a dispassionate grand narrative of the self, or utilise the term as a symbolic shorthand for the life course, a key question arises. If illness disrupts a biography, at what point in the life of a person does their biography begin and end? For the subjects of this study – children with a diagnosis of CTEV - their patient narrative begins when they are still a twinkle in the eye of their parents, a transduced image on a sonographer’s screen or as a mewling new-born.

Biography is “predicated on...an adult-centred model of illness” [Williams 2000]. In an era where identification, diagnosis and treatment of physical conditions can occur whilst the subject is pre-natal, this is a thorny issue to address, as autobiography, in any interpretation, is predicated on the self possessing the ability to utilise discourse.

Like Frank’s typology, the three key stages of Bury’s thesis assume agency:

“firstly asking ‘what is going on here?’, secondly the “fundamental re-thinking of the person's biography and self-concept”. Finally, marshalling resources.” [Bury 1982]

For an infant or young child the assumption of personal agency over such actions and experiences in the formation of the biography cannot be sustained. In situations where agency is therefore unavailable, it is arguably not *illness* that acts as the disruption, but the subjection which results from the decisions of others – be they carers, relatives and, crucially, professionals – according to cultural discourse. The question then becomes: ‘Whose biography is being disrupted?’ and any definition of biography necessarily widens to include groups of people - each with their own specific agency and perspectives - with the subject as their, often passive, locus.

In the ‘Remission Society’ contingency exists constantly in the present tense. Each individual body at any given moment exists somewhere on, in Frank's phrase, a ‘continuum of control’ [Frank 1995 p30]. The subject is only regarded as ‘ill’ in relation to a set of cultural responses to their physical issues. One measure of this is the ability to be productive rather than consumptive on the resources of their cultural milieu. In the case of a WENA culture dominated by consumer capitalist ideologies the measure becomes economic and thus focussed on ability and capability to work to produce capital and consumption, and perform the rituals, such as self-care and bodily deportment

that Giddens calls the 'reflexive project' of personal responsibility - which constitute the habitus and underpin the structures and processes of consumer capitalism. [Giddens 1991 p32]

There are alternative, more transcendental, contexts in which disabled people can serve a purpose. These functions could be categorised using the contested and broad-brush terms 'spiritual' or 'idealistic', in that they are both hard to define or measure. Frank discusses an 'ethics of care' in which care, charity and empathy can serve a necessary function to the individual carer, the charitable and the empathetic: fulfilling a need to overcome their own 'lack' by utilising the 'abundance' of the cared-for or empathised-with subject. In this aspect the 'ill' do not function as economically productive but are key actors in the production of the care ethic. Another context is the emotional fulfilment and engagement that family members or loved ones can derive from the very existence of a person, summed up plainly by author Nick Hornby when discussing his son, who has autism: "...that's my kid and I love my kid." [Hornby 2000 - online]. Some also see usefulness in a category of 'Disability' as a necessary and radical countervailance to prevailing discourses. Hunt refers to the 'special insight' into the human condition that the voices of disabled people have and the contribution that this could make to reminding people that there is more-to-life, a point recognized also by Stiker when he suggests that the construction of a category of disability serves a *primordial* purpose in that it can

act as a prophylactic against the 'folly of certainty'. [Hunt 1966, Stiker 1999 p10]

Frank's use of the term Remission Society equates with the Social Model of Disability in that it locates illness in the social contexts of the body rather than the body itself: "Squarely within society." [Oliver 1996]. In the Remission Society people are ill, have conditions and bodily variations but the essential ongoing project is negotiating a path *through* the social that is fulfilling to the individual on their own terms. The key question becomes not "what is wrong with you?" or "where does it hurt?" but "how do I live a good life?" [Frank 1995 p156]. Although it could be argued that Frank avoids specific political engagement, opting instead to explore routes towards an ethics of the body, even the most politically focussed Social Model theorists are ultimately broadly concerned with similar issues. When a condition, illness or physical difference places someone in a position antithetical to the prevailing social context i.e. they *are disabled*, what can be done to negotiate life? What can be done to change or challenge the situation in favour of the individual?

Chaos is the person smothered by the coercive force of Restitution. Quest is someone trying to seek their own release. Quest explores answers to the question "How do I live a good life?" using the related ideas of the post-colonial voice and resistance. For Foucault, resistance is defined on the same terms as power, distributed throughout the sphere of force relations "in

irregular fashion: the points, knots, or focuses ... are spread over time and space at varying densities, at times mobilizing groups or individuals in a definitive way....” [Foucault 2012 p97]. The stories told by ill and disabled people offer resistance to the official version. This broadly equates with Bury’s stage of marshalling resources, invoking strategies than following medicinal or physical regimes.

Frank describes the Quest Narrative as being about “the voice finding itself.” [Frank 1995 p133], and it is in this way that Quest reflects post-colonialist thought. The boundaries between narratives, definitions and experience can never be neatly drawn but in seeking to find their own voice the subject begins the process of framing and creating an alternative version of the story, one that has the potential to reconfigure the relationships and definitions inscribed by the ‘official’ medical version.

## **Analysis of The Parents' Stories : The Restitution Narrative.**

In 13 out of the 21 stories studied, which detail the interaction with medical professionals, direct criticism is made of the medical professionals by the parents.

- *“...the sonographer hadn't come across the condition very much and explained it as 'pigeon foot'.”*
- *“I remember being upset at the nurse because she kept trying to stretch out his feet to measure him.”*
- *“I was very pissed at the nurse practitioner's dismissal of my concerns”*
- *“My doctor and our nurses would not say much because they didn't know much about clubfoot. My husband asked if Cason would be able to have a normal life and their response was something along the lines of “most likely”. We had to wait for the Nursery's paediatrician to come talk to us for any more information. Once she came in, it was obvious that even she did not have enough information to comfort us.”*
- *“we simply believed that the treatment was just some massages at home in our leisure time (our male midwife said so).”*
- *“We consulted [sic] opted out of the consult with the resident Ortho. Surgeon...I am SO glad that we got the treatment done PROPERLY.” [sic]*

The variable information given to these parents accords with the variable nature of CTEV, the lack of consensus regarding aetiology, inconsistent

approaches to treatment and the proportionate paucity of research into the condition. This also supports the conclusion of Pietrucin-Materek et al that: “Such negative emotions and perceptions may be increased by a lack of parental knowledge about CTEV and misinformation, e.g. about the cause of the disorder.” [Pietrucin-Materek et al 2011] Arguably, congenital conditions are also potentially problematic in that they cross over between medical professionals. In the case of CTEV the stories reveal that the parents and infants patients will encounter a mixture of primary generalists, secondary and tertiary specialists, midwives, sonographers, OB-GYN doctors, genetic counsellors, paediatric doctors, orthopaedic surgeons, physiotherapists and plaster technicians, as well as a range of nurses and PAMs. If the condition is syndromic, or suspected to be so, the number of professionals will increase. However, each professional applies their own version of Restitution. As Frick states, in the 20th Century treatment for CTEV was administered was ‘a la carte’, with scant research available on comparative outcomes. Notwithstanding wilful ineptitude, each of the professionals encountered in this chain could be said to be acting according to their individual medical education, knowledge and experience. Any deficit is reported in the light of the parents’ subsequent knowledge and research. Lack of clarity or empathy from the professionals could therefore be attributed to deficiencies in the ‘system’ and

each professional's imperative to pursue the 'telos of cure', even from a standpoint of uncertainty.

Several of the stories exemplify Goffman's statement that the medical professional has the 'special job of informing the infirm *who he is going to have to be.*' [Goffman 1990] These stories demonstrate the imperial underpinnings of the Restitution Narrative, in that professionals autonomously make 'moral-value' judgements. Even if the intention is comfort it has the effect of defining or reinforcing the constructions of 'normalcy', applying the 'invidious distinction' [Leroi 2003 p15] between normal and not normal:

- *"I said out loud "I just want to scream and cry". My doctor and nurse both said "it's okay to cry". "You want a **normal** child and **this is not normal**"."*  
[emphasis added]

Later in the same story the parent reports:

- *"our paediatrician....explained to us that we could see Dr. Capehart ... and he has been doing this for years and was one of the best there is to take care of this disability. WOW ... "disability" that is hard to swallow. I hate that word and it makes me cry just to type it. But yes, she is considered disabled as of right now."*

The labelling of CTEV, a variable condition that *in some cases can lead to long-term impairment*, as a 'disability' means the paediatrician perpetuates the

hegemony of a medical/tragedy model of 'disability' on the child and the family, which leads to distress. It is exemplary of the colonial method, the use of a 'linguistic trick' to blur the truth, in this case by peremptorily imposing an identity with no surety that it is based on fact.

One parent comments on the 'disabled' label, in a message-board discussion about claiming Disability Living Allowance for an infant in the UK.

- *"We thought about it when Ben was born but didn't think he was disabled...and also didn't want him to be classed as disabled."*

Another parent expresses that their child:

- *"is no more disabled than the next person and I would hate to label him with something he would hate me for in the future."*

another states in a blog comment:

- *"I burst into tears saying, "my child is NOT defective." No matter how mild or severe his feet were, I could not and would not accept that label."*

Their insistent aversion to the 'disabled' label indicates the parents' understanding that a physically different body becomes a "repository for social anxieties...[such as]...vulnerability, control, and identity." [Garland-Thompson 1997 p6]

In the message board discussion other parents are conversely keen to identify and classify their children as 'disabled' Not all are as blunt as the person who announces:

- *“We got the full amount for our daughter...on DLA...you also get more child tax credit...which got us a nice little sum!!”*

However, there are three themes evident in the comments of parents advocating for their children to be considered disabled. Firstly, the children are impaired and facing laborious treatment regimes without any certainty of outcome. Secondly, there is a demand for the acknowledgement of the difficulties they encounter (e.g. accessing Blue Badge parking) and thirdly gaining access to financial assistance such as DLA and Carer's Allowance. Those parents who worry about labels are experiencing, for themselves and on behalf of their children, 'felt stigma' [Scambler 1986], and the discussion reflects the wider paradoxical dilemma faced by impaired people and their carers; accepting that: “unless you've got a label you can't access the Welfare State...or whatever will meet your needs.” [Gillman in Swain et al p253], whilst recognising the label itself is likely stigmatising.

Felt stigma pertaining to disability is also evident in the these comments taken from blog stories:

- *“We both cried a little, imagining a life of wearing braces, sitting in a wheelchair, being picked on. We imagined his brother getting in trouble for fighting bullies who picked on him. Our minds raced.”*
- *“I thought it would be awesome to have brothers together....boy stuff like baseball, football, and wrestling...but it will be different.”*

The first parents do not use the word ‘disabled’, but their description extrapolates a ‘disabled’ life for their child and the stigmatising impact this would have on the wider family. Their son’s biography has, in one sense, already been written in their imaginations and is based on cultural ideals. They envisage their child as stereotypically weak, helpless and reliant on his brother to defend him. Even though it is unlikely that these parents would have read the conclusions of Nabuzoka and Smith [1993] that young disabled people are twice as likely to be victims of bullying, their fears are not misplaced. They, and the second mother, discussing ‘boy’ stuff, are addressing gender roles. The fact that ‘it will be different’ means difference from hegemonic notions of masculinity (including ‘boyhood’ and ‘brotherhood’) as embodied in sport and play, in a culture where “masculinity is almost always thought to proceed from men’s bodies.” [Connell 1995 p45].

This discussion around ‘disabled’ stereotyping and terminology and its impact on identity highlights the power the medical narrative can enact. Symbolic interactionist theory names this choice as between the child being labelled a

'primary deviant', where some of their activities are different but attract nugatory social repercussions, or a 'secondary deviant' which has the effect of defining the person and constituting them as different. [Lemert 1967] When a medical professional uses words such as 'disability' or assume 'normalcy' they assign a label to the child which officially defines the deviance as secondary. Diagnosis framed in these terms could be seen as a moment of 'othering': situating the child outside the normalcy curve – declaring them a denizen - sometimes before they even are legally considered a child.

- *"I remember looking at their notes and seeing the words deformed right foot. I felt so angry, **my baby wasn't deformed, she just had a bent foot!** Does anyone else hate the word **deformed?**" [emphasis added]*

Arguably, even the choice of one word or phrase – for example, 'sorry' - in a verbal exchange can reproduce a negative effect by imposing a moral-value judgement. UK journalist Anne Atkins reports a doctor saying to her:

- *"“I'm **sorry** to tell you that your baby has a club foot.” He looked so gloomy that he might as well have been telling me my baby had two heads.” [emphasis added]*

My own father, recalling the day of my birth writes:

- *"The midwife took [the baby] downstairs down to the kitchen. I followed a moment later to offer her help. In the kitchen she got really upset and told me*

*that she was **extremely sorry but** the baby has club feet. She was really distraught. I found myself in the very strange position of having to comfort the midwife who was in floods [of tears] because my baby had club feet.”*  
*[emphasis added]*

Atkins is writing about the pressure she feels was put on her to terminate her pregnancy using CTEV as a potential marker for Down Syndrome. Her comments strongly suggest that her doctor is prepared to make the ultimate judgement of moral-value. My own Father’s testimony speaks for itself when allied with the knowledge that he and his brother were both born with CTEV and consequently my parents were sanguine about the diagnosis. Use of the word ‘sorry’ indicates the medical professionals allow their own emotional response to permeate the ‘empirical’ medical narrative.

- *“I am currently 24 weeks pregnant and found out that my fetus has bilateral clubfeet at 23 weeks and 6 days....The consultants who say it is a low risk – woudl [sic]they get on a plane what has say 10% risk of crashing?...I have been tricked into bearing a child I wish I would not bear, for their sake and mine , all because of the wait to get the diagnosis and no information about that it would be impossible to get a termination if they did find Talipes. The arrogance!”*

Many disabled people and writers on disability are extremely concerned about the role that genetic/eugenic selection plays in societies. Pre-natal screening

can enact a “subtly tyranny” contingent on the “dictatorship of the normal” [Jones 1993 p215]. Many might be horrified by the idea of terminating a pregnancy purely on the grounds of CTEV, although government statistics report that there were 8 abortions in the UK in 2010 due to “musculo-skeletal issues”, and Atkins’ newspaper report explores this from an anti-abortion perspective [BBC News 2011, Daily Mail online 2013]. In this account an expectant mother feels excluded from the decision making process as regards potential termination. She highlights the “*arrogance*” of the consultants in failing to address her opinion and using a delayed timescale which precludes *her* choice to judge moral-value, or to decide on the future for herself and her child. Restitution – ‘the telos of cure’ – over-rides all other factors.

## **Analysis of The Parents' Stories : The Chaos Narrative**

The Chaos narrative is an anti-narrative. It is about pain, confusion, frustration, speculation, anger, distress, ignorance and fear. It is about extant sensations and apparently involuntary emotional responses. It is situated in immediacy – more a fractured stream of consciousness unfolding in the ‘now’ than any structured history of reflection - and because of this often remains unvoiced. It occurs in a moment when the body finds “itself swept along by life’s fundamental contingency.” [Frank 1995 p120] As such Chaos defies the neatness of the ‘official’ Restitution narrative.

Broadly in line with the findings of Heiman that 84% of parents reported experiencing a negative reaction to a diagnosis of congenital condition, 16 of the 21 stories looked at used language that is indicative of Chaos. The phrases used in response to diagnosis in many cases portray extremes of negative emotional and physical reaction.

- *“We came home very distraught, unsure of what the future held for us.”*
- *“It came as an enormous shock...we went through the whole blaming ourselves thing.”*
- *“I was completely and utterly heartbroken.”*
- *“My heart broke that something was wrong with my child.”*
- *“In the car ride home, I howled so hard I thought the sky would crack.”*

- *“There was something wrong with my baby. I fought back tears. This isn’t what was supposed to happen today, this wasn’t what we were supposed to come here to be told. There was something wrong with my baby, what had I done wrong?”*
- *“My first reaction was NO! Not MY baby....He HAD to be wrong. I was having trouble wrapping my mind around it. My mind was in a whirl. I experienced some disappointment that the diagnosis was confirmed.”*
- *“I still felt it was unfair that I wasn’t going to have a **normal** new born”*  
[emphasis added]
- *“You expect that your own will be perfect ...For me, having to grieve the loss of the ‘**perfect and normal**’ baby was difficult and also difficult for other people to understand...”* [emphasis added]
- *My husband and I looked at him blankly and I immediately burst into tears as my ‘perfect’ baby was no longer **perfect**”* [emphasis added]

It could be argued that in these last five responses, the lexical choices indicate how powerful the hegemonic constructed ideas of ‘normality’ and ‘perfection’ are.

Diagnosis puts many parents in the position where they have to challenge their own ideas about the body and the social effects on the body of their offspring. As such it is not necessarily the ‘biography’ that is disrupted by the diagnosis but the hegemonic ideals which operate in culture. “The pressures on

parents...to produce normal children appear to have less in common with celebrations of diversity than with pursuing conformity and normalisation of the body” [Priestley in Swain et al 2004 p95].

The Chaos here is not that of the degraded body, but still reveals “vulnerability, futility and impotence” of the constructions that surround the body [Frank 1995 p97]. The ideals of normalcy cherished by expectant parents are immensely powerful but also narrowly defined, and demonstrably show lack of resilience under the pressure of anxiety. The constructions are revealed to be brittle, and the pressure causes them to shatter.

The shattering effect is summed up by one set of parents who say:

- *“But that moment in time changed the course of our lives. It made us struggle with what we believed. How we would live.”*

Another Mother reflects similar sentiments in terms of her religious beliefs:

- *“Why did I seem to lose my faith in God when this happened? Why did I not trust...God? ...Faith seems to be the first thing to go.”*

It is notable that in some stories the medical professionals are criticised for remoteness and failure to acknowledge the emotions involved. This is where the treatment of the people as substrates can actuate the ‘chaotic’ response triggered by the diagnosis:

- *“It’s funny how to someone who deals with stuff like this every day. It wasn’t a big deal to them. It’s not like that day changed the life of that ultrasound tech or the doctor. It was all so...formal. Distant. Very medical.”*
- *“getting information out of the professionals has been difficult. Very stressful.”*
- *“Dr. Capehart came in and said he was “very pleased with the left foot and ankle and he hates to try to guess because he always gets it wrong but he is thinking we may not have to do surgery on Megyn's left foot” [italics added]*

In the last case Dr Capehart could even be said to fan the flames of Chaos. Even if we apply an assumption that he might have been attempting humour, there is a difference between rationally discussing statistical uncertainty of outcomes and proclaiming to a parent that, not only is he engaged in guesswork, but that he *“always gets it wrong”*. The lack of acknowledgement of the effect such a comment might have on the patient/parent could be interpreted as failure to engage in an empathetic relationship with the parent and ‘honour the chaos story’ [Frank 1995 p108]

## **Analysis of The Parents' Stories . The Quest Narrative**

The moment of chaos can act as a radical transition point. Chaos reveals Restitution to be a Modernist myth, and opens up possibilities for the subject to search for other ways forward. Ways forward are what Frank describes as Quest.

Applying the Quest narrative to the parents of diagnosed babies and infants is complex and problematic. Frank characterises Quest as the “belief that something is to be gained through the experience”, even if the ‘something’ is not immediately apparent or clear. It contrasts with the Modernism of Restitution, in which the objective is completion [Frank 1995 p164]. Quest, therefore could be interpreted as the acceptance of a state of becoming rather than being.

Frank sub-divides self stories of Quest into three facets: Memoir, Manifesto and Automythology. The typologies were defined pre-Internet, and were initially applied to “formal autobiography”. As such, Automythology - the narrative of rebirth - is not an aspect that is commonly found amongst the parents' stories, as it demands a historical perspective. Narratives of Automythology remain the preserve of traditional publishing which places it in the autobiographical sub-genre of ‘Mis Lit’. But the self-told nature of the stories examined could class them all as Memoir, in that they relate the story of a child's CTEV as part of an ongoing personal or family blog, or as part of

another self-told genre, the ‘birth story’. Aspects of quest : the assimilation of the ongoing medical treatments into the everyday life of the family, the “vocational and personal changes in...life...” [Frank 1995 p116] and the becoming ‘journey’ are all visible in the texts studied. An example being the parent who writes about:

- “...*just trying to figure out how to be parents to a kid with a disability*”

For many of the texts, the emergence from Chaos is not clearly defined or explicitly stated, but visible in the way that the writing shifts over time, from immediate, emotionally explicit writing where the CTEV is the main topic, into a more reflective mode, where CTEV, although still important, become concatenated into the wider story. Examples of this can be seen in posts that are about the child’s illness, but with CTEV as a stated or implicit secondary theme.

- “*We used to think that nothing could be worse than going through the first 24 hours after casting for clubfoot. But now, we’re not so sure because Eli has his first cold... over the last two days or so he’s made Linda Blair look like an amateur.*”
- “*Poor little G is sick. Nice, old-fashioned cold, and he's miserable.*”

In many cases, especially those stories written on blogs, after the first year the posts become irregular or end completely. It could be said that the abatement

of the written story indicates ongoing Quest. The storytellers move on to the next stage of the journey. This could be for many reasons. Birth and early-years blogs are difficult to sustain once the child is older and more active outside the family home and the parents have returned to work and have less time to write. Stories are written for an implied audience of intimates at a time when the parents are sequestered at home by the infants needs, but this need diminishes. Parents may also write their stories as a way of reaching out in the chaotic moment when they feel isolated, but subsequently, via the internet or personal connections, develop support networks, lessening this need. However, some of the parents explain how, over time, they adapt and cease to experience chaos. In some cases this is because the treatment has been successful:

- *“It has been difficult to keep this process of blogging about Braeden's feet going when I feel like there is nothing new to write about. The length between visits to the doctor have become longer and Braeden's feet are where they should be. I look back at the past 14 months and the issue of club feet seems almost non-existent.”*
- *“If I could have known then what I know now, I would not have cried myself to sleep that night.”*

- *“When he had SO much going on, it seemed like that was the way it was going to be. Now, life with G is pretty low-key... I feel like just maybe, yeah, we'll make it.”*

But even when the medical issues are ongoing, the approach, in many cases is demonstrative of coping and resilience.

- *“He may have things in his future, but I'm not dwelling on those.”*

Frank states the Quest as Manifesto carries “demands for social action,” expressing that “Society is suppressing a truth about suffering, and that truth must be told.” [Frank 1995, p121]

The exact role the Internet has played in the changing of medical approaches to CTEV is an area that invites specific further study. But the timescales of the wide availability of internet access and the rapid changes in treatment correlate, suggesting a causal relationship between the two [NPR.org online]. Ponseti was working in Iowa City, a small University town in a rural area of the USA. It is likely that the advent of the internet gave parents access to his work. In the USA the nosurgery4clubfoot user group was founded in 1999. In the UK, the STEPS charity became, in the early 2000s the focus of advocacy and advice for the Ponseti method.

Exchanges of information on the message boards of self-help groups and charities is one place where Manifesto narratives can be observed. This

involves a range of practical help which derives from learned experience and offers knowledge that is largely absent from medical advice [Fox 2013] But further to practical tips and tricks, the ‘truth’ – in this case that cure is an imprecise project, simple treatments are actually not so simple and that more often than not surgery is unnecessary - is told.

In the case of the STEPS message board this can be seen – especially in discussions from 2002-2004 - in the way parents share their experiences and act as providers of informed detail regarding treatment which, at that time was not widely available in the UK.

- *“Please be sure to ask lots of questions about the doctors who claim to be using the Ponseti method.”*
- *[ask your doctors]...“Where were they trained? How many cases have they treated? How many casts does it take to complete correction (should be 5-7 and no more than 9)? What type of casts are used (should be toe-to-groin, changed every 5-7 days)? What percentage of their patients are successfully corrected without additional release-type surgeries (not counting tenotomy) or other deviations in treatment (should be 95-97%)? What is their protocol for bracing after correction is obtained...?”*

This extends to the discussion, including praise and criticism, of individual hospitals and consultants, with users exchanging a range of opinions regarding the effectiveness of techniques used.

- *“We were given no help, information or advice. After I found out about the Ponseti method, we decided that's what we wanted for Struan. I asked our consultant about it, he told us that's what he was using. After 5 months of casts he told us that Struan's feet would not correct without the conventional surgery, he wasted so much of our time. I...[demanded]...a referral to Rachel Short, armed with print outs of case histories from the Ponseti site..”*
- *“If you would like to use the Ponseti method for your children, I would highly recommend trying to get a referral to Naomi (or the doctor of your choice) as soon as possible.” [refers to Dr Naomi Davis, an early UK advocate of The Ponseti Method]*

These comments exemplify discussions and comments that appear many times, as well as on some of the parental blogs. Quest as Manifesto, for many parents, can be seen in them becoming lay experts in the condition and the treatments they feel best suits their children, compelling them to lobby and advocate for these treatments. “The increased availability of medical information can enable them to become informed medical consumers” [Opreescu 2013]

As in the examples cited above There are a significant number of comments that express suspicion about orthopaedic specialists and an unresponsive, uninformed and disjointed medical system, especially given that one of the tenets of conservative, non-surgical treatment is that it be done as early as possible:

- *“The powers that be do not understand the urgency of sorting out this problem for our babies.”*
- *“We have had the experience of going to a consultant who said he followed the method, but in fact he did not.”*
- *“Anthony’s feet were still pointing down and our consultant was saying they were corrected. After sending photos to Dr Ponseti, we found out they were not corrected at all.”*
- *“We are now seeing a new doctor. I’d like to say that Dr. Capehart was not providing the care that Megyn needed... She is in pain and it is noticeable.”*

It could be argued that what these parents are engaged in is resistance to the imperialist medical narrative which attempts to impose Restitution ‘a la carte’. This is achieved by presenting credible information that counters the ‘professional’ knowledge they are presented with. In the USA parents also are able, in many cases, to exercise market choice to select doctors and utilising infrastructure which has developed to facilitate this. As an example, some of them report using a charity called Angel Flight, which offers free domestic air travel for medical purposes, in order to attend clinical appointments with their chosen doctor. Increasing use of market models and patient choice since 2003 [Dixon et al 2011] means that parents in the UK can, in many cases, utilise similar strategies.

## Conclusions

The stories told by parents reveal, broadly in line with previous research, [Pietrucin-Materek et al 2011, Heiman 2002, Goldbeck 2006] that a majority experience a negative reaction to a diagnosis of CTEV. As well as the practical stresses of following medical regimes, the diagnosis challenges the powerful discourses that construct parents' expectations of normalcy.

The negative response is often exacerbated by deficits in up-to-date knowledge of medical professionals and the lack of clarity and detail of information provided by official medical sources at the time of diagnosis and beyond. This reflects the tension between medicine's pursuit of the 'telos of cure', and the reality of a condition which remains little understood and where treatment has uncertain and variable outcomes. In some cases there is also a perceived lack of empathy from professionals, which could be interpreted as medicine continuing to follow an imperial Modernist path by treating the condition whilst the individuals involved remain de-contextualised 'substrates' often denied substantive and satisfactory participation in the story.

The study finds that parents have responded to these issues by sharing their stories and creating unofficial communities to address the deficits they encounter. This has led to them often affiliating together to develop strategies of resistance, using the Internet to pursue advocacy, lobbying and the exercising of choice to influence the way their children's condition is treated.

The evidence suggests that these strategies could well have acted to accelerate the rapid fundamental changes in the way CTEV is medically treated.

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## **Bibliography of Sources**

AUFDERHEIDE, Arthur C, Rodriguez-Martin, C 1998. **The Cambridge Encyclopaedia of Paleopathology** Cambridge Cambridge University Press,

BARGHOUTI, M. 2002. **I Saw Ramallah**, Cairo American University in Cairo Press.

BARNES, C., MERCER, G. & SHAKESPEARE, T. 1999. **Exploring Disability**, London Wiley.

BÖÖK, J. A. 1948. **A Contribution To The Genetics Of Congenital Clubfoot**. Hereditas, 34, 289-300.

BROWN, P. 1995. **Naming and framing: the social construction of diagnosis and illness**. Journal of Health and Social Behaviour, 34-52.

BRUHN, M. 2010. **Did Yesterday's Patterns of Colonial Exploitation Determine Today's Patterns of Poverty?** Available from:

<http://blogs.worldbank.org/allaboutfinance/did-yesterday-s-patterns-of-colonial-exploitation-determine-today-s-patterns-of-poverty> - accessed Oct 2014

BRYMAN, A. 2008. **Social Research Methods**, Oxford Oxford University Press.

BURY, M. 1982. **Chronic Illness as Biographical Disruption**. Sociology of Health & Illness, 4, 167-182.

BURY, M. 2001. **Illness Narratives: fact or fiction? Sociology of Health & Illness**, 23, 263-285.

CHARON, R. 2006. **Narrative Medicine: Honouring the Stories of Illness**, New York Oxford University Press.

CONNELL, R. W. 1995. **Masculinities**, London Polity Press.

- CRESWELL, J. W. 2012. **Qualitative Inquiry and Research Design: Choosing Among Five Approaches**, London SAGE Publications.
- DAS, V., DAS, R. & SELUKER, P. 2014 **Cleft Lip and Cleft Palate**. International Journal of Preventive and Clinical Dental Research Issue 3 Online available at <http://ijpcdr.in/IJPCDR/index> accessed January 2015
- DAVIS, KEN, 2003 The Crafting of Good Clients Chapter 30 in SWAIN, J. 2004. **Disabling Barriers, Enabling Environments**, London SAGE Publications.
- DAVIS, L. J. 1995. **Enforcing Normalcy: Disability, Deafness, and the Body**, London Verso.
- DAVIS, L. J. 2002. **Bending Over Backwards: Disability, Dismodernism, and Other Difficult Positions**, New York University Press.
- DERIJCKE, A., EERENS, A. & CARELS, C. 1996. **The incidence of oral clefts: a review**. Br J Oral Maxillofacial Surgery, 34, 488-94.
- DIXON, A., MAYS, N. & JONES, L. 2011. **Understanding New Labour's Market Reforms of the English NHS**. London: Kings Fund.
- DOBBS, M. B., NUNLEY, R. & SCHOENECKER, P. L. 2006. **Long-term follow-up of patients with clubfeet treated with extensive soft-tissue release**. J Bone Joint Surgery America, 88, 986-96.
- EBENSTEIN WILLIAM 1986. **Toward an Archetypal Psychology of Disability Based on the Hephaestus Myth**. Disability Studies Quarterly 2006, Volume 26, No. 4
- EDGERTON, R. B. 1967. **The Cloak of Competence: Stigma in the Lives of the Mentally Retarded**, London University of California Press.

- FINKLESTEIN, VIC 1991 **Disability : An Administrative Challenge?** in
- OLIVER, M. 1993. **Social Work: Disabled People and Disabling Environments**, London Kingsley
- FLEISCHMAN, SUZANNE **Language and Medicine**: Chapter 24 in
- SCHIFFRIN, D., TANNEN, D. & HAMILTON, H. E. 2008. **The Handbook of Discourse Analysis**, London Wiley.
- FLYNN, THOMAS 2005 **Foucault's Mapping of History** : Chapter I in
- GUTTING, G. 2005. **The Cambridge Companion to Foucault**, Cambridge Cambridge University Press.
- FOUCAULT, M. 1988. **An interview with Michel Foucault conducted by Michael Bess, San Francisco (3 November 1980)**. *History of the Present* 4 (Spring 1988): 1-2, 11, 13.
- FOUCAULT, M. 2002. **The Birth of the Clinic**, London Taylor & Francis.
- FOUCAULT, M. 2012. **The History of Sexuality: An Introduction**, London Knopf Doubleday Publishing Group.
- FOX, S. 2013. **After Dr Google: Peer-to-Peer Health Care**. *Paediatrics*, 131, p224-p225.
- FRANK, A. W. 1997. **The Wounded Storyteller : Body, Illness, and Ethics**, Chicago University of Chicago Press,
- FRIEDSON, E. 1970. **Profession of Medicine: A Study of the Sociology of Applied Knowledge**. London University of Chicago Press
- FRICK, S. L. 2001. **Historical Overview of Clubfoot Treatment - Journey to the Ponseti Method** [Online]. orthocarolinaresearch.org  
Available:  
[http://www.researchgate.net/publication/237223344\\_Historical\\_Overview\\_of](http://www.researchgate.net/publication/237223344_Historical_Overview_of)

[Clubfoot Treatment - Journey to the Ponseti Method](#) ] – Accessed May 2014

GIDDENS, A. 1991. **Modernity and Self-identity: Self and Society in the Late Modern Age**, Stanford Stanford University Press.

GILLMAN, MAUREEN 2004 **Diagnosis and Assessment in the Lives of Disabled People: Creating Potentials/Limiting Possibilities**: Chapter 38 in SWAIN, J. 2004. **Disabling Barriers, Enabling Environments**, London SAGE Publications

GOFFMAN, E. 1990. **Stigma: Notes on the Management of Spoiled Identity**, London Penguin Books, Limited.

GOLDBECK, L. 2006. **The impact of newly diagnosed chronic paediatric conditions on parental quality of life**. *Quality of Life Research*, 15, 1121-31.

GOOD, B. & GOOD, M.-J. D. 2000. **“Fiction” and “Historicity” in Doctors’ Stories. Narrative and the cultural construction of illness and healing**, also in: MATTINGLY, C. & GARRO, L. C. 2000. **Narrative and the Cultural Construction of Illness and Healing**, London University of California Press.

GUTTING, G. 2005. **The Cambridge Companion to Foucault**, Cambridge Cambridge University Press.

HEIMAN, T. 2002. **Parents of Children with Disabilities: Resilience, Coping, and Future Expectations**. *Journal of Developmental and Physical Disabilities*, 14, 159-171.

HERMAN, N. J. 1995. **Deviance: A Symbolic Interactionist Approach**, London General Hall

HUNT, P. 1990. **Stigma: The Experience of Disability**, London Chapman.

IDLEBERGER, KARLHEINZ. **Die Zwillingspathologie Des Angeborenen Klumpfusses: Untersuchungen an Einer Unausgelesenen Zwillingsserie Von 25 I Paaren.** Stuttgart: Ferdinand Enke Verlag, 1939.

ILLICH, I. 1976. **Limits to Medicine: Medical Nemesis : the Expropriation of Health,** London Penguin.

JONES, S. 1993. **The language of the genes : biology, history and the evolutionary future,** London, HarperCollins.

KLEINMAN, ARTHUR, and KLEINMAN, JOAN. "**How bodies remember: Social memory and bodily experience of criticism, resistance, and delegitimation following China's cultural revolution.**" *New Literary History* (1994): 707-723. In FRANK, A. W. 1997. **The Wounded Storyteller : Body, Illness, and Ethics,** Chicago University of Chicago Press

LEROI, A. M. 2005. **Mutants: On the Form, Varieties and Errors of the Human Body,** London Harper Perennial.

LYOTARD, J. F. 1984. **The Postmodern Condition: A Report on Knowledge,** London University of Minnesota Press.

MATTINGLY, C. & GARRO, L. C. 2000. **Narrative and the Cultural Construction of Illness and Healing,** London University of California Press.

MIEDZYPBRODZKA, Z. 2003. **Congenital Talipes Equinovarus (clubfoot): a disorder of the foot but not the hand.** *Journal of Anatomy,* 202, 37-42.

MILLER, B. 2012. **The Parents' Guide to Clubfoot,** Alameda CA Hunter House.

MORRIS, J. K. & ALBERMAN, E. 2009. **Trends in Down's syndrome live births and antenatal diagnoses in England and Wales from 1989 to**

**2008: analysis of data from the National Down Syndrome Cytogenetic Register.** BMJ 2009

NABUZOKA, D. & SMITH, P. K. 1993. **Sociometric status and social behaviour of children with and without learning difficulties.** J Child Psychology Psychiatry, 34, 1435-48.

NELSON, C. & GROSSBERG, L. 1988. **Marxism and the Interpretation of Culture,** Chicago University of Illinois Press

OLIVER, M. 1993. **Social Work: Disabled People and Disabling Environments,** London Kingsley

OLIVER, M. 1996. **Understanding Disability: From Theory to Practice,** London Palgrave Macmillan.

OLIVER, M. & BARNES, C. 2012. **The New Politics of Disablement,** London Palgrave Macmillan.

OPRESCU, F., CAMPO, S., LOWE, J., ANDSAGER, J. & MORCUENDE, J. A. 2013. **Online Information Exchanges for Parents of Children With a Rare Health Condition: Key Findings From an Online Support Community.** Journal of Medical Internet Research, 15, e16.

PARSONS, T. 1964. **The Social System** New York The Free Press of Glencoe, Collier-Macmillan.

PATON, C. 2011. Mays N, Dixon A and Jones L (eds), **Understanding New Labour's Market Reforms of the English NHS,** King's Fund, London, 2011, The International Journal of Health Planning and Management, 26, 484-487.

PELTIER, L. F. 1990. **Fractures: A History and Iconography of Their Treatment,** San Francisco Norman Pub.

- PIETRUCIN-MATEREK, M., VAN TEIJLINGEN, E. R., BARKER, S., FORREST KEENAN, K. & MIEDZYPBRODZKA, Z. 2011. **Parenting a child with clubfoot: A qualitative study**. International Journal of Orthopaedic and Trauma Nursing, 15, 176-184.
- PRIESTLEY, MARK 2004. Generating Debates : Why We Need a Life Course Approach to Disability Issues. Chapter 14 in SWAIN, J. 2004. **Disabling Barriers, Enabling Environments**, London SAGE Publications.
- ROSE, N. 1999. **Powers of Freedom: Reframing Political Thought**, Cambridge Cambridge University Press.
- SCAMBLER, G. 2009. **Health-related stigma**. Sociology of Health & Illness, 31, 441-455.
- SCAMBLER, G. & HOPKINS, A. 1986. **Being epileptic: coming to terms with stigma**. Sociology of Health & Illness, 8, 26-43.
- SCHIFFRIN, D., TANNEN, D. & HAMILTON, H. E. 2008. **The Handbook of Discourse Analysis**, London Wiley.
- SEIN, E. P. 2001. **Chronic illness: the child and the family**. Current Paediatrics, 11, 46-50.
- SEGRE, S. 2012. **Talcott Parsons: An Introduction**, Lanham MD University Press of America.
- SHABTAI, L., SPECHT, S. C. & HERZENBERG, J. E. 2014. **Worldwide spread of the Ponseti method for clubfoot**. World Journal of Orthopaedics, 5, 585-590.
- SHUTTLEWORTH, R., WEDGWOOD, N. & WILSON, N. J. 2012. **The Dilemma of Disabled Masculinity**. Men and Masculinities, 15, 174-194.

SONTAG, S. 1978. **Illness as Metaphor**, New York Farrar, Straus and Giroux.

SPIVAK, G. C. **Can the Subaltern Speak?** 1988 : available in: NELSON, C. & GROSSBERG, L. 1988. **Marxism and the Interpretation of Culture**, Chicago University of Illinois Press

STANDING, G. 2011. **The precariat: The new dangerous class**. London Policy Network.

STIKER, H. J. 1999. **A History of Disability**, Chicago University of Michigan Press.

SWAIN, J. 2004. **Disabling Barriers, Enabling Environments**, London SAGE Publications.

TARRAF, Y. N. & CARROLL, N. C. 1992. **Analysis of the components of residual deformity in clubfeet presenting for reoperation**. J Paediatric Orthopaedics, 12, 207-16.

THOMAS, C. 1999. **Female Forms: Experiencing and Understanding Disability**, Buckingham Open University Press.

THOMSON, R. G. 1997. **Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature**, New York Columbia University Press.

WILLIAMS, S. 2000. **Chronic Illness as Biographical Disruption or Biographical Disruption as Chronic Illness? Reflections on a core concept**. Sociology of Health & Illness, 22, 40-67.

YOUNG, A. 1982. **The Anthropologies of Illness and Sickness**. Annual Review of Anthropology, 257-285.

## Internet Sources – Selected Information and General

<http://www.steps-charity.org.uk/> Accessed March 2014

[http://members.tripod.com/ponseti\\_links-ivil/id5.html](http://members.tripod.com/ponseti_links-ivil/id5.html) List of links to archived discussions from Symposia and message board. *Personal Website of Dr Matthew Dobbs* Accessed December 2014

<https://groups.yahoo.com/neo/groups/nosurgery4clubfoot/info> *Support Group* Accessed March 2014

<https://twitter.com/hashtag/nosurgery4clubfoot> *Twitter page for Nosurgery4clubfoot* Accessed March 2014

<http://www.gpnotebook.co.uk/> *General Information about CTEV* Accessed May 2014

<http://www.gosh.nhs.uk/medical-information/search-for-medical-conditions/talipes/talipes-information/> *Medical and Treatment Information* Accessed May 2014

<http://www.aofas.org/footcaremd/conditions/ailments-of-the-smaller-toes/Pages/Clubfoot.aspx> *AAOFAS advice page* Accessed May 2014

[http://members.tripod.com/ponseti\\_links-ivil/id7.html](http://members.tripod.com/ponseti_links-ivil/id7.html) *list of international resources and user groups* Accessed May 2014

<http://embarrassingbodieskids.channel4.com/conditions/club-foot/?page=2> *General Advice* Accessed December 2014

<http://www.babycenter.ca/thread/83283/club-feet> *Discussion Board* Accessed December 2014

<http://babyandbump.momtastic.com/pregnancy-second-trimester/1360915-18-week-scan-mild-clubfoot.html> *Discussion Board Thread* Accessed December 2014

<http://www.nhs.uk/conditions/talipes/pages/introduction.aspx> Official Information and comments board for UK NHS users. Accessed May 2014

<http://talipestogether.com/> Support website and forum. Accessed October 2014

<http://www.netmums.com/> Netmums discussion forum with threads about CTEV Accessed January 2015

<http://blog.cbmun.org.uk/author/steve/> Post by Steve Mannion – orthopaedic surgeon who has been referred to as ‘The Indiana Jones of Surgery’ Accessed January 2015

<http://www.feetfirstworldwide.com/> Steve Mannion’s Charity site Accessed January 2015

<http://www.abdn.ac.uk/news/4043/> University of Aberdeen News. Report on the work of Dr Zosia Miedzybrodzka Accessed January 2015

<http://www.gentlebirth.org/archives/screen.html> A mother’s experience of Ultrasound Accessed October 2014

## Internet Sources - Stories

<http://www.npr.org/blogs/health/2014/01/27/265254533/how-parents-and-the-internet-transformed-clubfoot-treatment> *News Story about parents utilising the internet.* Accessed December 2014

<http://www.bbc.co.uk/news/health-14015096> *BBC News Story about late-term abortions* Accessed December 2014

<http://www.dailymail.co.uk/femail/article-2274668/My-baby-perfect-Why-did-doctors-push-abort-her.html> *Anne Atkins article* Accessed December 2014

<http://www.theguardian.com/books/2000/nov/08/fiction.nickhornby> *Interview with author Nick Hornby.* Accessed December 2014

<http://clubfootclub.org/category/stories/> *Story archive* Accessed March 2014

<http://www.ponseti.info/index.html> *Official Site of Ponseti at the University of Iowa* Accessed March 2014

<http://www.ponseti.info/patients-and-parents/parents/stories.html> *Story archive of the Official Site of Ponseti at the University of Iowa* Accessed March 2014

[http://www.steps-charity.org.uk/index.php?option=com\\_kunena&func=showcat&catid=1&Itemid=84](http://www.steps-charity.org.uk/index.php?option=com_kunena&func=showcat&catid=1&Itemid=84) *Steps Charity Forum on CTEV* Accessed November 2014

[http://www.steps-charity.org.uk/index.php?option=com\\_kunena&func=showcat&catid=4&Itemid=84](http://www.steps-charity.org.uk/index.php?option=com_kunena&func=showcat&catid=4&Itemid=84) *Steps Charity Forum for stories and blog links* Accessed November 2014

<http://www.mohea.com/mike/words/> *Adam's Story* Accessed November 2014

<http://www.poplarchick.com/cole/clubfoot/index.html> *Cole's Story* Accessed November 2014

<http://www.clubfootaustralia.com/connors-story/> Connor's Story Accessed November 2014

<http://ponderthepath.com/> Cooper's Story Accessed November 2014

<http://clubfootchronicles.blogspot.co.uk/2013/08/the-saga-begins.html> Eliot's Story Accessed November 2014

<http://georgi-clubfeet.blogspot.co.uk/> Georgi's Story Accessed November 2014

<http://dreamsandjourneys.blogspot.co.uk/> Grace's Story Accessed November 2014

<http://grantsluckyfoot.blogspot.co.uk/2008/10/first-post.html> Grant's Story Accessed November 2014

<http://apeachtreecitylife.blogspot.co.uk/p/our-harper-was-born-with-unilateral.html> Harper's Story Accessed November 2014

<http://adifferentfoot.freesevers.com/index.html> Kai's Story Accessed November 2014

<http://tinytootsies.blogspot.co.uk/> Lemmie's Story Accessed November 2014

<http://megynsstory.blogspot.co.uk/> Megyn's Story Accessed November 2014

<http://merrittsfunnyfoot.blogspot.co.uk/> Merrit's Story Accessed November 2014

<http://themommydialogues.com/meet-the-feet-theyre-incomplete-our-clubfoot-story/> Mia's Story Accessed November 2014

<http://www.refriedbeansandsalsa.blogspot.co.uk/> Om's Story Accessed November 2014

<https://daysofkay.wordpress.com/> Paisley's Story Accessed November 2014

<http://andbabymakes6.com/> Quinn's Story Accessed November 2014

[http://www.reddit.com/r/BabyBumps/comments/2qpawa/clubfoot\\_rosies\\_story](http://www.reddit.com/r/BabyBumps/comments/2qpawa/clubfoot_rosies_story)  
/ Rosie's Story Accessed November 2014

<http://awalkinmine.blogspot.co.uk/> Sarah's Story Accessed November 2014

<http://www.sarah.parker.clara.co.uk/talipes.htm> Scott's Story Accessed  
November 2014