

## **An uncertain future: infertility and chlamydial infection**

PIERCY, Hilary <<http://orcid.org/0000-0002-7663-8858>>

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## **An uncertain future: Considering the possibility of infertility as a result of chlamydial infection**

### **Introduction**

This chapter considers the extent to which women regard an episode of genital chlamydial infection as a threat to their reproductive capabilities and the ways in which they manage the resultant anxieties. This discussion is founded upon the findings from a qualitative research study undertaken in central England which explored the experiences of women who were diagnosed with genital chlamydial infection and the ways in which they made sense of that experience.

A particular source of anxiety for these women was the extent to which the episode of infection had damaged their reproductive capabilities. Chlamydia is a recognised cause of tubal infertility because the infection can damage the fallopian tubes. However at the time of infection it is not possible to identify whether or not damage has occurred and it is unlikely that this information will come to light unless efforts to conceive are unsuccessful.

The theory of uncertainty management provides a framework within which to understand how these women used biological and temporal information in order to interpret their infection experience and make an estimation of tubal damage on the basis of their interpretation. Fertility anxieties present a significant emotional burden for women and the professionals who care for them. These estimations constitute a coping technique through which they managed this emotional burden.

### **Chlamydia - a threat to fertility**

Chlamydia is a bacterial sexually transmitted infection (STI). It is the most commonly diagnosed STI in the Genitourinary Medicine (GUM) clinics of England. The infection is easily treated with antibiotics which have a high cure rate. However, as it is commonly asymptomatic in both males and female, infection may go undetected for potentially lengthy periods of time. Chlamydial infection can cause a number of serious complications in males and females including pelvic inflammatory disease which is a recognised cause of tubal infertility in women.

Over the past ten years, increasing effort has been directed towards tackling this infection in England. Health promotional activities have been directed towards improving public awareness of the infection, primarily these comprise posters and leaflets which provide key facts about the infection. Three facts dominate this literature; the indiscriminate and asymptomatic nature of infection and the possibility of female infertility as a consequence of infection. Even though Chlamydia affects men and women equally, the media portrayal of Chlamydia is almost exclusively in terms of the threat that it poses to that most central aspect of female identity. For example, the caption for a recent advertisement which portrays a cartoon female character reads "*Chlamydia is a sexually transmitted infection that often doesn't have noticeable symptoms and can make you infertile.*"

Although the link between infection and infertility has been established in pathological and epidemiological terms, a considerable number of unknowns remain. Tubal damage occurs as a result of pelvic inflammatory disease (PID). PID is estimated to occur subsequent to Chlamydial infection in 10 - 40% of cases (Stamm, Guinan et al. 1984), however, the diagnosis of PID depends on presentation of symptoms and a proportion of infection is known to be silent and undiagnosed because it is asymptomatic (Paarvonen and Eggert-Kruse 1999). Therefore, in any individual case it is not possible to determine whether PID has occurred. It is also difficult to

determine how long it takes for PID to occur after an initial episode of infection and whether the length of undetected infection increases the chances of developing PID because of the difficulty in determining the length of infection. A final consideration is the relationship between PID and tubal infertility. Women with a history of PID are more likely to have tubal infertility than those with no history or evidence of PID (Westrom 1994) and prompt treatment in those with symptoms appears to be important in reducing the risk of PID and infertility (Hillis, Joesof et al. 1993). Overall however it is not possible to estimate the probability of tubal damage as a result of PID or the probability of infertility as a result of a single episode of infection.

In the literature, infertility is identified as a risk of infection, but in a non quantifiable way. Risk, the likelihood of adverse effects as a consequence of a specific event, (Lupton 1999), is portrayed as a probability. As with all risk appraisals, any calculation can only be made on an aggregate basis and transformation of this information to the level of the individual is difficult (Lauritzen and Sachs 2001). There are fundamental difficulties in attempting to translate the findings of scientific data drawn from study populations to their consequences on an individualistic basis. Risk is the property of the epidemiological population from which it is derived rather than the property of any individual within that population. However this does not preclude the inevitable question that any individual will ask, and the issue of greatest personal relevance to them, namely the extent to which the data relates to them. In other words, what is the likelihood that they will be infertile as a consequence of an episode of infection? Therefore this is an area which is fraught with uncertainty.

### **Uncertainty management**

Uncertainty is a perceived inability to assign probabilities to outcomes (Penrod 2001). It is recognised as a central component of any illness experience (Babrow and Kline 2000) where a number of components including unpredictability, and lack of information are considered to underlie the process (McCormick 2002). Developments in medical technologies have made it increasingly possible to detect disease at progressively earlier stages and provided information about the probability of disease development. Consequently, the amount of uncertainty associated with disease development and progression has increased with a consequent focus on its impact (Brashers 2001; Hedestig, Sandman et al. 2003; Howell, Fitch et al. 2003). The rational response to this, to which we are expected to aspire is reduction uncertainty (Bradac 2001). Information and the degree of personal control that it affords is commonly cited as the means by which to reduce that uncertainty (Deane and Degner 1998; Eisinger, Geller et al. 1999; Lemaire 2004). The required information, an understanding of disease processes and an established cause-effect relationship, is however rarely available.

Although uncertainty reduction is a desirable outcome for some people in some situations, it is not the only valid approach. Furthermore, the information required to reduce that uncertainty is often not forthcoming; disease processes are rarely understood with certainty and the cause-effect relationships which result in their development are highly complex. Information about this relationship is derived from populations and therefore the information that they provide is rarely applicable in an individualistic and unambiguous way. Uncertainty management provides an alternative approach. Whilst it encompasses uncertainty reduction as one possible outcome, it also embraces uncertainty increase and uncertainty maintenance as both legitimate and acceptable (Bradac 2001). It is increasingly recognised as a valid response, particularly in relation to chronic illness (Crigger 1996) and in conditions where treatment or cure is not an option. Uncertainty in these situations provides opportunity for hope and optimism (Brashers 2001), a form of resistance to the threat of our created narrative of the self (Rose 2000). Information in this context is a tool to

manipulate uncertainty in a desired direction, in the ways in which it is presented and interpreted. Such information can be drawn from a number of sources and includes both statistical data and individual cases which are variously used to either reinforce or contradict one another. Thus a poor prognosis in statistical terms may be balanced by a verbal example which presents the exception to the rule (Bradac 2001).

### **The study**

40 women aged 16-29 years took part in the study, 33 had no children, 7 had children and 2 were pregnant at the time of the study. The majority (34) were recruited in the genitourinary medicine (GUM) clinic whilst attending in conjunction with an episode of chlamydial infection. A minority (6) were recruited through the town centre family planning clinic serving the same population. Their inclusion provided a longer term perspective of the experience as their infection was a less recent experience. The women were interviewed in the place of recruitment using a largely unstructured approach. An opening question invited the participant to describe their infection experience. This initiated a wide ranging discussion within which their understanding of the infection and related anxieties, concerns and experiences were explored. Interviews were fully transcribed and analysed using a constant comparative method in accordance with the principles of grounded theory (Glaser and Strauss 1967; Strauss 1987; Strauss and Corbin 1990).

### **Concerns about infertility**

Female infertility was the one sequela mentioned repeatedly in the data. This is perhaps not surprising given that the dominant social and cultural expectation in Western culture is of women as mothers. Women have traditionally been viewed as reproducers, regardless of their intention or ability to fulfil that function (Shildrik 1997) and it is in these terms that their existence has been justified (Morrell 1994). Their bodies have been socially constructed in terms of reproductive capability and function, viewed as production units in the commodified production of children (Martin 1987). In a society where infertility represents a flawed social identity (Whiteford and Gonzalez 1995), an infection with the propensity to damage reproductive capability represents a threat to their identity as mother and therefore woman.

Several of the women assumed an inevitable relationship between infection and infertility; on discovering that they had chlamydial infection, they assumed they were infertile. As Julie described, the impact of infection produced a rapid transition from a feeling of invulnerability to one of assuming inevitable consequences, from *"it's not going to happen to me"* to *"it really worried me, not being able to have children."*

This is not an unreasonable assumption, given that the link between the two has been portrayed so forcibly in the public information surrounding this infection. The realisation that this infection can be and indeed is something that happens to you transports someone from the safety of being uninfected to the danger of being infected. Consequently, they move from being detached from the health information messages to identifying with them. In the process the term 'can cause infertility' is interpreted as 'does cause infertility.'

It was a relief therefore to discover that the linkage was not assured, however the fundamental question 'has it caused damage to me' remained unanswered. This raised two issues for the individual. Firstly there was an imperative to consider the cause and effect relationship between infection and infertility and determine the extent of personal risk. This was summarised in the question asked by Isobel and echoed by the majority of the other women.

*"Is my insides totally clear now or is it a little bit damaged, could it affect me having a child later?"*

The second and related requirement was to manage the uncertainty that resulted from this situation. Their uncertainty centred upon the question of whether tubal damage had occurred and the consequent long term effects, a question to which there is no definitive answer. In the absence of other information, the women created their own estimations of association and constructed their own causal relationships using self selected markers of longevity and severity.

### **Sources of information**

In constructing their own interpretation of the causal relationship, the women drew upon two key information sources. The first of these was the professional information. In written form this is exemplified by health promotional materials which establish a link between infection and infertility in a vague and non quantified way. The second was lay information; examples of individuals who had discovered that they were infertile as a result of chlamydial infection contracted some time previously. The women drew on cases studies that they had become aware of through personal communication or through the media and identified with them. In doing so they reflected specific anxieties about aspects of their own infection episode.

*"On the tele, this woman said that she'd been trying for kids and wasn't able to have any and the doctor had asked her if she'd had chlamydia before and she said no and then when they did tests on her they found out that previously she had had chlamydia and it had gone away on its own and that's what had stopped her from having kids. So I was worrying if anything, if you know how long I've had it for because I didn't really know if it had done anything to me insides, anything like that."*  
(Liz)

and

*"I've read these awful ads, in one of my magazines that I read, and this lady, she got pains in her stomach, she thought she was pregnant and she was only 15 and she'd actually got chlamydia and now she's had a hysterectomy, she can't have kids and she's 15 years old"* (Jodie)

The diagnosis of an STI is rarely shared with others because of the social stigma associated with these infections. Consequently these accounts exist in a relative vacuum of social discourse and are therefore accorded disproportionate significance; few people will know of others who have had the infection and subsequently conceived without difficulty. Their personal and emotive nature makes them particularly powerful and memorable, all the more so because they are largely unchallenged. Additional perceived similarities between self and the subject of the account served to further strengthen the conviction that the infection had caused long term damage as Kelly explained.

*"I am worried because my neighbour next door, she can't have any children anymore and the reason for that is that she's had chlamydia as well, and when she had her first baby, her little lad, she went down to 6 stone and she went to the hospital and they tested her and she had chlamydia and I've lost quite a lot of weight rapidly, it's just dropped. Chlamydia doesn't really have anything to do with your weight but it's funny how she lost quite a bit of weight and so have I and we've both had the same disease."* (Kelly)

The women linked their assumptions about the probability of tubal damage to two factors, namely the duration of infection and the severity of symptoms. These concepts were employed either independently of one another or in conjunction with

one another. The underlying assumption in both respects was of a direct proportional relationship between cause and effect. Effectively, it was assumed that the more severe the symptoms, the greater the probability that damage had occurred. Similarly, the longer the estimated period of infection, the greater the probability of tubal damage.

The question however remains; what duration of infectivity and what degree of severity were assumed to cause damage and what constituted the knowledge base upon which these estimations were made? Although there was an implied objectivity in this causal relationship, the absence of any empirical data necessitated the objectification of subjective information, assessments and interpretations. For a few women it was simply commonsense; an infection that had been present for only a few weeks was unlikely to cause damage. In most cases however, it was evident that the women made personal assessments against the benchmark of information available to them, particularly lay sources of information.

### **Duration as an indication of damage**

It was assumed that the longer the infection had been present, the greater the probability that it may have caused damage. This would appear to be a reasonable assumption although there is no data to support it. However, it does not address the central question - how long does an infection have to be present for it to cause damage such that it affects fertility? The working principle adopted by those women who assumed they had escaped damage was that the length of time that it takes for damage to occur is greater than the estimated length of their infection, whether this was weeks, months or years. This was the basis upon which Shirley made her estimation of risk.

*"I just assume that because I could only have had it for a few weeks sort of thing that it can't really have done much damage but I don't know, whether these things can do much damage in a couple of weeks, I just assume that it didn't." (Shirley)*

Several respondents referred to the possibility that someone could have the infection for a long time and be unaware of the fact, often until they attempted to conceive. A range of information sources were quoted to support such explanations including media reports and the experiences of friends and acquaintances. However although they acknowledged that the infection was characterised by an asymptomatic stage, the underpinning assumption was that symptoms would occur at some point; that the infection would eventually become manifest albeit after a largely unspecified but possibly lengthy period of time. In this respect symptoms were viewed positively, particularly if they occurred sooner than expected as Jane explained;

*"I know when I've read leaflets that it says women can carry it for years without having any symptoms at all, well for a long time anyway, but I know that I hadn't had it that long and so I really didn't expect to get the symptoms as soon as I'd got them, I mean I'm glad that I had because I, now I've found out that I've got it but ...." (Jane)*

The appearance of symptoms enabled detection and treatment thereby shortening the duration of infection and the consequent implications. However complacency about the probability of having escaped tubal damage was tempered by concerns that symptomatic presentation may not have occurred in time to enable treatment prior to the occurrence of damage.

*"It might not flare up for 5 years and it's too late then, before you know." (Paula)*

### **Severity as an indication of damage**

An alternative interpretation of symptoms was as an indication of damage having occurred. The women had experienced a range of symptoms which they attributed to the infection. However the linkage with severity was confined to one specific symptom, namely the level of pain experienced. This was interpreted either as a direct indication of damage or as an indication of duration of infection which was in turn associated with damage. For Liz the level of pain equated directly to concerns of infertility.

*“That [infertility] did worry me especially like with the pain that I was having.”*

Jane made the same linkage although as this was the second episode of infection, she had opportunity to compare experiences. Subsequent to her first episode which was asymptomatic she became pregnant thereby confirming tubal patency. On this basis the severe pain associated with her second episode of infection was a matter of particular concern.

*“I know from the time before when I had it that it didn’t leave me infertile because I did get pregnant, but this time because of the severe pains that I’ve had in my tubes, it worries me more this time than it did last time.”*

Julie who did not know how long she had been infected but had experienced severe symptoms, sufficient to merit hospitalisation, assumed a threefold linkage. Firstly she linked severity and longevity on the basis of her own experience

*“Obviously if I was in that much pain it could probably have been there for a while... the pain that I’ve had, is that because I’ve had it a long time?”*

Secondly she constructed a link between longevity and infertility on the basis of anecdotal information.

*“It really worried me, not being able to have children, it really did ..... because my mum said, oh, this woman’s been on the telly, she’s had it for 12 years and she can’t have children.”*

These factors provided the basis of a retrospective assessment of the damage caused by infection. However they were used as the basis of two oppositional constructions. For those who considered that they had had a long and or severe infection they formed the basis of anxieties surrounding infertility whilst for those who considered themselves to have had a short or mild infection they were used as a means of relieving anxiety.

### **Catching it in time**

A number of the respondents equated the value of diagnosis with the opportunity to receive treatment and eliminate the infection. Several described this as ‘catching it in time,’ the implication being that the treatment and cure served as a safeguard against tubal damage.

*“I’m glad that I’m getting it treated and not to leave it because if not I would be infertile ... in time to come if I ever want children if I don’t have it treated I’ll not be able to have any.” (Kate)*

Treatment provided the means by which to protect oneself from damage in contrast to those case studies portrayed in the media; the women who had not been afforded this opportunity with the apparently inevitable consequences of not being treated. This perspective focused on the potential damage prevented as a result of treatment

rather than on the unquantifiable and unalterable damage that may already have occurred. It represents positive action, a means by which to manage uncertainty through reclaiming control and re-establishing the predictability of a body-self threatened by the presence of infection (Frank 1995).

### **The professional perspective**

When confronted by the diagnosis of infection and the consequent uncertainties surrounding infertility, asking questions and seeking information constitutes a response to that uncertainty. The health professionals who are concerned with treatment and management of the infection have an essential role as a source of information and support for those emotionally traumatised by the infection experience (Piercy 2006). They also represent a safe and expert potential source of knowledge. Several of the respondents sought a definitive test that could provide unequivocal information;

*"I did ask them when I came last time, I said is there anything that can, any way that you know [that I can become pregnant], and they said no, you can't test for it can you?" (Michelle)*

This reflects a mechanistic paradigm of medicine in which diagnostic testing is the link between cause and effect. However in this situation there are no technological procedures available to provide such information, no tests that can unequivocally resolve the uncertain issue of fertility. The only way that someone can definitively determine their fertility is by becoming pregnant. This leaves medical opinion as the only source of information on this matter, an opinion which occupies a largely unquestioned position of dominance by drawing upon both common sense and technical explanatory models (Oakley 1984).

### **Communication of risk**

The communication of risk on an individual basis is a common aspect of medical practice, however it is intrinsically problematic. A discussion of percentage probabilities that relates to a group of people has little relevance for the individual who wants to know specifically about their own life chances. People are generally considered to apply a bimodal model of risk in which they see themselves as either high or low risk which bears little relevance to the mathematical models used by doctors (Misselbrook and Armstrong 2002). In communicating risk, the challenge is to provide understandable information that has personal relevance and reflects the probable health effect in a comprehensible form.

Whilst the way that information is presented is highly relevant in this respect, arguably the way that it is received is of greater concern. The specific terminology and approach of the health professionals are important. However, an individual's beliefs influences how they interpret health messages and assimilate them into a wider understanding of the infection. It is the 'take home message' that they glean from that consultation, and the extent to which it either reinforces or extends their own interpretation of the situation which is of particular relevance in this respect.

The respondents reported a health professional viewpoint that largely mirrored their own although with an emphasis on the importance of treating and eliminating infection. In answer to the central question 'am I infertile?' all the respondents reported a non committal response that neither confirmed nor rejected the possibility. The question of fertility and conception was one for the future, to be answered at some later indefinite time.



*“she told me just to forget about it for now because what worried me the most was when later on, if I want to have children and that’s the one thing that’s really worrying me, but she said just to forget about it and when the time comes and you want to try, she said you’ll just have to keep trying, that’s what worried me the most.” (Jacky)*

In several accounts, the way that the health professionals’ viewpoints were recounted suggests that they were largely optimistic, suggestive of a favourable outcome. It is no more possible for a health professional than for a patient to be sure that damage has not occurred. Optimism is arguably the most pragmatic approach to adopt on the basis that statistically, the majority will not have problems. However if there are unanswered questions, such as the duration of a particular infection episode, that the professional judgement does not appear to take into account, the extent to which the professional opinion is considered reassuring is questionable.

*“I just said, I said to her that I’d heard it could stop you having children and she said oh that’s only if it’s gone on for a very long time but I didn’t know how long I’d had it for or anything.” (Liz)*

### **Distancing the problem**

Although women made their own assessments of damage or sought information from health professionals, they did recognise that ultimately they had no means by which to obtain definitive information. This effectively limited their ability to reduce uncertainty. Distancing themselves in temporal terms enabled them to manage the continued uncertainty. In so far as pregnancy was a matter for the future, so too were the potential problems associated with it. The most common response, as summarised by Jill, was to wait and see, to deal with the matter as and when it occurred

*“I suppose the major thing was, you know, I hope I don’t become sterile, but again, as I’ve said I’m not going to know for another 10 years and so it’s a waste of energy to worry about stuff like that now.”*

However, when that time does come the uncertainties around fertility may well re-emerge and cause considerable anxieties, particularly if they have unrealistic expectations about the length of time that it may take to conceive as Jane identified.

*“I know if I think we’ll try for a baby, I know roughly when and if I don’t get caught then I think first month I’ll panic and second month I’ll panic even more and the third month I don’t know what I’ll do.”*

When respondents did reflect on the possibility of future fertility problems, the New Reproductive Technologies (NRT’s) were envisaged as a solution to their potential problem. The proliferation of these technologies represents a medical industrialised approach to the problem of infertility where new techniques reconstruct an unachievable pregnancy as a not yet achieved pregnancy. Although this belies the reality that for many this is beset by unattainability, enormous personal cost and frequent failure, the image of endless possibilities is portrayed in the media which reinforces the authority of biomedicine (Whiteford and Gonzalez 1995). It is unsurprising therefore, that respondents identified NRT as the solution, a means by which to overcome the uncertainty of infertility. NRT offers a means by which to fulfil the social desire to have a child, a way in which to bypass infertility (Shildrik 1997). Reproduction in these terms is a technological process, produced and sanctioned by the authoritative knowledge of biomedicine. NRT’s offer a degree of control over those life choices and cultural expectations that are threatened by a susceptible and potentially damaged body. If technology cannot provide definitive answers at present

to the central question of fertility, it does promise a resolution to the uncertainty that chlamydial infection creates by bypassing the problem of infertility.

### **Conclusion**

Concerns about fertility are a source of considerable anxiety for women diagnosed with chlamydial infection. These anxieties are reflected in and reinforced through the health promotion literature which presents a view of women defined in terms of their reproductive capabilities. In the absence of definitive information, women draw on a range of physical indicators and social comparisons and use them as information sources in order to try and reduce their resultant uncertainty. These pieces of information provide benchmarks against which they estimate the likelihood of tubal damage. Assessments of severity and duration of infection are particularly significant in this respect. Pain is commonly taken as an indication of both severity and duration and is therefore viewed as considerably more sinister than other symptoms. These indicators are used in a similar way by health professionals.

These techniques appear to be effective in reducing the anxieties associated with infertility that occur around the time of infection. However their effectiveness is inevitably limited and may well be challenged when circumstances change and women attempt to conceive. An alternative approach was to accept continued uncertainty and reduce current anxieties by postponing any fertility considerations although anxieties may well re-emerge when women attempt to conceive.

The number of women diagnosed with chlamydial infection will continue to increase as a result of increasing incidence rates and increased testing and screening activity. Consequently the number of women who are required to face uncertainties about their fertility will also increase. Implementation of the national screening programme in England (ref) will result in increased detection of asymptomatic infection. The extent to which this will impact on fertility anxieties is a matter for speculation. Overall however, the collective emotional burden on women, and those health professionals who support and care for them, seems set to increase and should not be underestimated. The ramifications of these anxieties are likely to extend well beyond initial diagnosis and treatment of infection and may affect women throughout the rest of their reproductive lifespan.

### **Questions for reflection**

1. To what extent do you consider that health promotional messages which link chlamydia to infertility impact upon sexual behaviour, initiating health protective behaviours?
2. In what ways might women's fertility anxieties, subsequent to chlamydial infection, influence their contraception and conception behaviours?
3. Consider how this may impact upon their use of sexual health service provision.

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