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Exploring the Needs and Expectations of Women Presenting for Hysterosalpingogram Examination Following a Period of Sub Fertility: - A Qualitative Study

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Abstract

This grounded theory study sought to explore women's experience of healthcare following referral for hysterosalpingography (HSG) after a period of sub fertility. These otherwise fit and healthy women enter the healthcare system and their only problem is a failure to become pregnant. They find themselves trying to negotiate a system designed for sick people. Previous research in this field consists mainly of studies comparing HSG to other diagnostic studies. An HSG is an invasive procedure involving the administration of intrauterine radio opaque contrast via a catheter inserted transvaginally. The demonstration of this contrast within and spilling out of the fallopian tubes determines patency. Ten women were interviewed using 12 core questions just prior to their HSG examination. Each woman needed a diagnosis of primary sub fertility. Each was asked how they were coping with the uncertainty of their fertility. They were asked about their expectations of the HSG examination, the importance of HSG and what methods were available to them to reduce any anxiety experienced. Data analysis was undertaken after each interview. Presently HSG is seen by healthcare providers as a routine out patient examination at the start of sub fertility investigations. In contrast to this, it was discovered at interview that HSG was seen by the women as a defining moment that would signpost their future treatment options to become pregnant. Women reported receiving little support from health care providers and that written information given did not fulfil all of their Often written information alone heightened anxiety and this written needs. information needs to be tailored to a specific set of circumstances. The literature review noted that anxiety can lead to mental health issues but that properly focused, correctly given, timely information can reduce anxiety. The implications of the

findings are that if anxiety relating to treatment at this early stage can be managed effectively it could minimise the possible physical and emotional trauma to the woman as her sub fertility journey continues, thus at the same time preventing future anxiety related illness.

What is already known about the topic?

Current literature mostly focuses on the process of HSG as a procedure and how it compares to other diagnostic tests.

Little is known about the emotional needs of the patient or the levels of anxiety HSG generates.

What does this article add?

Women need access to professionals to discuss HSG at the earliest opportunity. Recognition that written information meets only part of the information needs of women.

Sub fertility investigations are rated important amongst women. Service providers need to address a possible miss match in perception.

Methods of reducing anxiety prior to HSG to reduce possible later mental health issues.

Nurse Practitioners can use the role to enhance education and communication.

Introduction

HSG provides an assessment of both Fallopian tube and uterine causes of infertility (Thurmond 2003). It is performed in a Radiology department under the direction of a team led by a doctor or suitably trained nurse or radiographer. Additionally there is a nurse to look after the patient and a radiographer in the team. In recent years HSG has been undertaken by nurses or radiographers who are in a position to influence the quality of the patient experience. The nurse practicing at this advanced level can use that position to improve communication leading to an enhanced patient experience and a seamless episode of care.

Despite advances in the treatment of sub fertility, semen analysis, hormone determination and HSG are still seen as leading diagnostic investigations before any fertility treatment is decided upon. (Smith et al 2003). At present women are seen in Gynaecology Out Patients' Clinic and at this appointment are referred for some or all of the above investigations. At the same time written and verbal information is given by nursing and medical staff. How well women cope following this initial out patient appointment can depend upon their ability to absorb this information. Variables can exist that include the experience of the referring clinician, whether the attending nurse has specialist knowledge and any previous patient experience within healthcare.

For some years now nurses have increasingly been taking the lead role in HSG and contributing to the increasing numbers performed, more than doubling at Gateshead Health NHSF Trust between 2003-09. Review of the online information surrounding HSG for many hospitals shows the patient is told that the procedure is quite likely to be carried out by a nurse. This is the case in Gateshead Health NHSF Trust and is a natural progression of the advanced nursing role and is seen as appropriate in most quarters. Regardless who performs the procedure the clinical question about

continuity of care is; 'do we address patient anxiety and do we provide a seamless episode of care from the out patient appointment to the completion of the HSG?'

A previous medical study, by Tyrell et al in 1993, sixteen years ago, asked about emotional issues for the women surrounding the HSG examination. One aim of this study is to see if time has changed any of those issues. Nurses working as independent practitioners performing HSG examinations can support their work by contributing to the body of qualitative knowledge in this way.

Literature Review

A review of the literature showed that very little work had been undertaken looking at the issues of HSG since 1993 when patient's perceptions were examined by Tyrell. All of the studies focused around the emotions of patients or their satisfaction level with the total package of infertility treatment including IVF. (Souter, Penney, Hopton & Templeton 1998) (Oddens, Tonkelaar & Niewenhuyse.1999). Oddens study found that infertility as a 'life event' was seen as severe. Given that HSG is part of the sub fertility investigations we wanted to consider the severity of this event to the women during the specific time covering HSG examination. It was previously discovered that at the time of HSG anxiety levels associated with this examination were high. (Tyrell 1993) Sub fertility is shown to be a cause of grief as well as stress from the start of the process.

In all walks of life the literature shows that stress occurs during life events even if the individual does not recognise it at the time, possibly giving an indication for the future episodes of anxiety, as described by Shevrin (2001) Van Den Hout (1995) Kemp-Wheeler (1987). Long before IVF is considered there are many questions that need to be answered. (Smith et al 2003) Some couples will progress to be offered IVF treatment. Cassidy & Sinttrvani (2008) recommended stress reduction interventions for these couples.

Ramezanzedeh et al (2004) looked at a group of 370 women infertile for between 1 and 20 years. Results showed that 40% of women had depression and 86% had anxiety. Depression was most common after 4 to 6 years of infertility and severe depression in years 7 - 9 years. The study concluded that attention should be given to women's psychological health and 'treating them properly' was a great advantage to their mental health.

When looking at the psychological and emotional effects of sub fertility Hamdieh et al (2009) showed a correlation between information giving and reduced anxiety. Following a session of face to face information giving along with a provision of written information at follow up, there was a 'significant' reduction of anxiety. This duel strategy is supported by Timmins (2006). Information giving was seen as vital by Timmins who showed that written information is not sufficient for a full understanding of an invasive procedure. It showed a women's natural coping mechanism is to seek out information in response to a specific problem. Written information alone is not enough. Successful information giving requires the input of nursing and medical staff personally to support written and other material.

Malin, Hemminki, Raikkonen, Sihvo& Perela (2001) report that the most positive treatment experience was 'respectful, empathetic and personal care from the doctor'. A higher percentage of dissatisfaction with treatment was found in this study group than in the general population. The most common cause for dissatisfaction was found to be negative treatment experiences. The authors state that this dissatisfaction could

reflect the relatively young healthy women's assertive attitude towards infertility care services and the vulnerability and intimacy associated with childlessness. These women's only reason to be in healthcare is the inability to become pregnant.

Anxiety reducing strategies at the time of procedure have been researched by radiographers and showed that music can reduce anxiety during a HSG. (Agwu and Okoya 2007). In this study patients were asked to bring music of their choice. In the experimental group of women, music reduced the physiological and cognitive responses of anxiety. It was found that the blood pressure and pulse rate of women in the control group was higher than that of women in the group listening to music. Women's willingness to return for repeat procedures was also more positive in the experimental group. The specific radiology literature in most parts goes no further than describing an HSG (Jones 2006) or the merits of HSG as compared with other forms of imaging. (Fatum 2002)

As regards the psychosocial impact of sub fertility, Covington and Hammer Burns, (2000) show sub fertility to be a taboo subject, not easily discussed. Sub fertility is an experience that alters an individual's identity and sense of self. This is caused by feelings of deficiency, hopelessness and shame. In society it is seen as a failing to fulfil personal and societal roles. (Unruh and McGrath 1985)

As part of the 'medicalization of infertility' (Newton. Et al 1992) healthy, yet childless, women become patients and undergo HSG. Due to the increasing number of women having to submit to this process, it was decided to investigate as a follow up to the 1993 Tyrell study what is uppermost in the minds of women attending for an HSG and if their anxiety level has increased or decreased since that study. These previous papers help to focus the work of this study questioning; do the documented problems with anxiety and anxiety related illness still occur? How early in the infertility pathway are these symptoms present? Can they be addressed at an earlier stage in women's care, and how?

Aims of the study

- To understand the specific needs of this group of women at this point in their care.
- To add to the knowledge within the field of sub fertility treatment.
- Discover the underlying issues and anxieties that women have at the start of sub fertility investigations
- Raise awareness of the need for research by nurses in areas where they are practicing at an advanced level.

1. Research Design and Method

This exploratory study used a qualitative methodology to examine if women had sufficient information prior to HSG examination to meet their needs at this time. Grounded theory methodology was appropriate given the sensitive nature of the topic. (Glazer & Strauss 1967). This research approach allows information to develop inductively and for common themes to emerge as the data is collected and analysed.

A proposal was submitted to the Research and Development Committee of Gateshead Health NHS Foundation Trust and the local Research Ethics Committee for validation of ethical standards.

Data was collected through semi-structured interviews. A set of 12 core questions were devised that would allow the use of semi structured interviews. The questions guided the researchers to gain information in the following areas. Firstly the background to the woman's sub fertility history, secondly the expectations of the women and finally the importance of HSG, and the availability of both health service support and informal friend and family support. Each interview was analysed and common themes emerged and were identified. Interview data was coded and analysed until data saturation had been achieved. When each interview had taken place and been analysed, it was then assessed as to whether any new information had been obtained. After eight interviews it became clear that there were no new themes. To consolidate an additional two interviews were conducted. At the end of ten interviews it was evident that the data collection could stop. Now it was certain that no new theme would emerge the researchers could argue that data saturation had been achieved. (Ashworth et al 1986)

2. Sampling and recruitment

The study was carried out within the Radiology Department at Gateshead Health NHSF Trust. Referrals for HSG were received from Trust Consultants. All referrals were screened by the senior nurse to assess suitability for inclusion in the study. Prospective candidates were required to have a diagnosis of sub fertility. All women identified as meeting the criteria were sent an information pack explaining the proposed research. The information pack contained a patient information sheet and consent forms.

Within seven days the prospective candidate was contacted via telephone. If further information was required this was then given. Recruitment proved more difficult than expected. The participants in the study were women between the ages of 27 and 39 years. The status of women in the target group is otherwise young and healthy. They all had employment and busy lives. During the day it was difficult to reach them by phone in a situation in which private conversation could take place. On occasions it proved impossible to make contact with the patient in the short space of time before they presented for HSG.

When a woman agreed to an interview it had to be at a time and a place convenient to the women. This required evening and weekend interviews. Most women looked for a time when the partner was not present. No partners were present at any of the interviews. For the purpose of this study only the women were approached. 16 women were contacted to take part and 10 women were eventually interviewed. Although two women did not go on to have HSG because they fell pregnant naturally, at the time of interview these two women had no knowledge that they would not need to progress to HSG. It did not become apparent that they were pregnant until they failed to menstruate. Therefore these two interviews were valid and were not excluded from the sample.

Women declined for a number of reasons. These included the number of hours they were working, not thinking 'it was for them' and other family issues resulting in little free time. The lack of research in this area may suggest that others have also found this group of patients difficult to engage. It is therefore a challenge to the health service to look at ways of resolving this. Overall the women who were contacted were extremely positive about the research, commenting that although this research would not benefit them personally, it would "benefit women in the future".

Table 1 Candidate Histor

Candidate History					
Candidate	Age	Length of wait for HSG from referral (in menstrual cycles)	Length of sub fertility		
1	36	1 st Cycle	12 months		
2	30	2 nd cycle	11 years		
3	36	1 st Cycle	12-18 months		
4	33	1 st cycle	3 years		
5	39	2 nd Cycle	18 months		
6	38	1 st cycle	2 years		
7	34	1 st cycle	2 years		
8	26	2 cycles	18 months		
9	38	No HSG	15 months		
10	27	No HSG	4 years		

3. Data collection

When women agreed to take part, arrangements were made for a researcher to visit them at their home or suitable location. Allowing the women to choose a location for the interview was found to be the favourable strategy as women tended to relax in their chosen environment. 9 interviews were conducted in the home and one interview was conducted within the hospital. Interviews lasted for approximately 60 to 90 minutes.

For continuity all interviews were carried out by the same researcher. The interviews were tape recorded and transcribed as soon after interview as possible. Brief memo notes were also taken during the interview and immediately after each interview to contextualise circumstances that may prove important when data analysis took place.

At the end of each interview the women were given a card with contact details of the researcher. Women were told that they could contact the team with any additional information they wished to give or if they needed to discuss any issue.

Table 2Interview Questions

- 1. How did you feel when you found you were to have a HSG examination?
- 2. Describe to me your expectations from this examination?
- 3. Do you feel that you know what will happen during the examination?
- 4. Describe to me what you think will happen after the examination?
- 5. Describe to me how importantly you would rate the importance of HSG?
- 6. What is the factor that is uppermost in your mind prior to the examination?
- 7. How are you dealing with this?
- 8. Do you have any unresolved frustrations in relation to your experiences so far?
- 9. Tell me about the formal help you received at this time. I.e. GP, hospital?
- 10. Tell me about the informal support you are receiving. I.e. family and friends?
- 11. Tell me about the background to you sub-fertility?
- 12. How do you feel about being involved in this research?

4. Data analysis

Coding started soon after the first interview was completed. As data analysis progressed coding allowed the sorting of data into manageable segments. Constant comparison of established codes with incoming data allowed for the development of new code categories or consolidation of existing categories.

Axial coding is the process of relating codes to each other. (Corbin and Strauss 2008 p.195). While coding the data, behaviours and specific acts were looked for. Axial coding soon led to a core category. This core category of anxiety soon emerged. It acted as a link entwining each category.

Kelle and Seldel (1995) states the codes act as collective pointers to the themes. The analysis of the data, as described above led to the emergence of four themes. They all link to the core category of anxiety.

Theme Emergence

- 1. HSG is seen as an important examination and a defining moment. At this time attention was focused away from conception and transferred to anxiety surrounding the HSG procedure.
- 2. A delay in gaining an appointment. We live in an 'I want it now society.'
- 3. Sub fertility was not a subject to be discussed openly. A taboo subject to be kept private.
- 4. Written information leaflets do not meet all of the needs of the women and information is often gained from family and close friends rather than healthcare workers.

Theme 1. HSG is seen as an important examination and a defining moment .At this time attention was focused away from conception and transferred to anxiety surrounding the HSG procedure.

The prominent theme that emerged with all candidates was that HSG is an important examination. All of the women rated the importance of HSG between 8 and 10. 10 on the scale rated as the most important. The women described HSG as a defining examination. Most saw HSG as important and something that had to be ".gone through" in order to ".find out what is wrong." Women felt that without knowing the results of an HSG then no progress could be made to eventual conception. (See table 3)

Most of the participants felt the HSG was the thing that was uppermost in their minds. Fear and anxiety associated with the process of the HSG shifted their focus away from the reason for the examination being required, the desire to become pregnant. All understood that in order to be able to progress to further treatment this procedure had to be endured not matter how unpleasant. When discovering the detail of the procedure one woman stated that she '*was horrified*'.

Theme 2. A delay in gaining an appointment. We live in an 'I want it now society.'

For some of the women in the sample it took an average of two cycles to actually get an appointment for their HSG. Because of the nature of the examination normal rules for waiting lists do not apply. It is important that prior to the procedure the patient is not unknowingly pregnant. Each examination needed to be carried out after menstruation has stopped but before day 10 of the menstrual cycle.

If an appointment could not be given during this window, women had to wait until their next cycle. Women who had been waiting for up to two years for answers to their sub fertility before referral for HSG found this very frustrating (table 3). The women in the study had waited for up to 4 years. Some of the women stated that if

they were given an explanation as to why they could not get an appointment this would have made the waiting easier. One woman stated her unresolved frustrations were '.getting an appointment-it's just the NHS'

Theme 3. Sub fertility was not a subject any wanted to discuss openly – a taboo subject.

This research has established that women still see sub fertility as a subject that is kept private. In their book 'Infertility Counselling', Covington and Hammer-Burns (2000) state that '...in all cultures involuntary childlessness is recognized as a crisis that has the potential to threaten the stability of individuals, relationships, and communities' It would seem that from listening to the women they experience a loss of well-being and self-confidence as a result of the loss of privacy and control of their own body (table 3).

Also they experience the anticipatory grief of the possibility of being left without a child. (Saunders 1989). Studies have shown that infertile women have feelings of defectiveness and worthlessness as well as shame and guilt. (Unrch and McGrath 1985) In our society where cancer, aids and heart disease are talked about openly, sub fertility which takes many persons by surprise has been left behind as a taboo subject for discussion.

Theme 4. Written information leaflets do not meet all the needs of the women and information is gained from family and close friends rather than healthcare workers

It soon became clear that information giving was coming to the fore as a prominent theme. Most of the women stated that they 'think they know what is going to happen.' On probing, all women had additional questions and issues that were playing on their minds as HSG drew close (table 3). Much anxiety was generated from reading the information leaflet.

The women found that when they later took time to read the information leaflet that was given to them at the Out Patient visit, instead of reassuring them it raised their anxiety and gave them new questions.

One point from the leaflet states that there will be slight bleeding for some time after the procedure. It was verbalised well in this statement. '. The thought of slight bleeding afterwards? I wanted to know well, why? What has happened that is causing the bleeding a little bit afterwards? Because I thought you don't want someone to do something to you that is going to make you bleed.'

One conclusion from the Tyrell (1993) paper was for all women to be supplied with written information before presenting for HSG. It was found that most of the current participants had received written information about HSG.

It was evident that written information was often not read. Sometimes it was read but misunderstood. At the commencement of an interview the women were asked to get the packs that had been sent to them. Only a minority of participants could find the pack and most stated they had put it away after the initially reading the information. Only a minority had studied the literature.

Table 3 Women's Responses

Theme	Comment 1	Comment 2
HSG is seen as an	'I really want everything	''My worry is the fear of
important examination	to be fine and lovely, but	the unknown'
and a defining moment.	in a way I would be	
At this time attention was	disappointed in the sense	
focused away from	of what is wrong with me	
conception and	are my tubes fine?' there is	
transferred to anxiety	nothing wrong then what	
surrounding the HSG	is wrong?'	
procedure.	-	
A delay in gaining an	'At the beginning of my	'The first time I phoned up
appointment. We live in	cycle I rang and I was told	they could not do anything
an 'I want it now	that no appointments were	because they had not got
society.'	available. I think that this	the request, then when I
	was the worst bit for me	had my period they had no
	because I was so excited	appointments, so I thought
	about the fact they were	to myself will this happen
	doing something'	again on my next period?'
Sub fertility was not a	'I do not want to be the	'I had horrible thoughts
subject any wanted to	source of other peoples	about other people who
discuss openly – a taboo	gossip'	were pregnant, like you get
subject.		people saying to you 'oh
		well children are not
		everything' but shut up
		because unless you have
		been through it you don't
		know what it is like, it's
		painful'
Written information	'There is nowhere at all	'I wondered what will the
leaflets do not meet all	you can turn. If I did not	environment be like and
the needs of the women	have my friend who has	who will be there?
and information is	been through all these	
gained from family and	procedures and my	
close friends rather than	partner who has been	
healthcare workers	supportive and loving'	

Discussion

All of the women wanted to tell their own particular story. Some of the women had pent up feelings which were described as 'why me' or is this 'some kind of punishment'. This was sometimes the first opportunity that they had to voice their anxiety. Anxiety was present as each of the themes emerged. Anxiety around the procedure, the situation that the women found themselves in and anxiety about the outcomes.

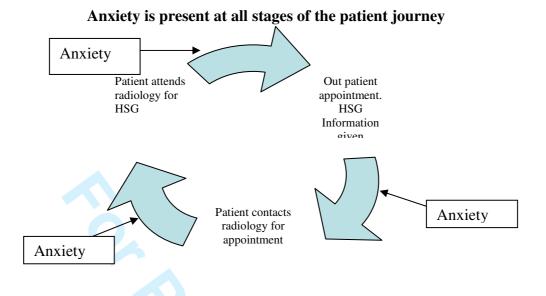
At interview it was found that the women had many misplaced worries. Some worried about privacy and dignity while others worried about the possible injection. Most did not understand the concept of the X-Ray equipment or how many staff would be required to facilitate the procedure.

As the interviews progressed it was clear that although they were asked at the Out Patient appointment if they had any questions it was difficult to verbalise specific worries at that time. They had not had the opportunity to reflect upon what had been explained to them or the time to read and digest the written information. After reading the information they found that they had new anxieties, this time around the HSG procedure itself.

It became evident that there were gaps in understanding. These gaps in understanding are the areas that previous studies have highlighted can lead to subliminal experiences of stress (Kemp-Wheeler & Hill 1987) (Van Den Hout et al 1995) If the women are not fully aware of the anxiety that is being experienced this may be a contributing factor to the episodes of depression already described..(Ramezanzedeh 2004)

Shevrin (2001) pointed out that '..aversive conditioning could be established unconsciously'. The implications are that anxieties can unconsciously act as a forerunner to depression. This can be directly related to the stress and anxiety felt prior to HSG and subsequent sub fertility treatments. Some women suffer a high degree of anxiety that can result in the episodes of depression identified by year 4 of sub fertility. (Ramezanzedeh 2004) An understanding of this process leads this research to point to anxiety reduction as a priority.





A review of the information leaflet showed that the written information consists of a set of statements. These statements are because nurses consistently aim to provide not only information, but to improve client knowledge that they assume will improve outcomes. (Nikolette et al 2003) Timmins acknowledged that the need for information is all about coping with events. Each event is unique to an individual, so the information that each individual needs has to be unique to them also. No generic leaflet can cater for all. Although written and other sources of information such as electronic data are likely to be useful the researchers found that a verbal explanation from an informed source was superior. Written information needs the support, guidance and direction of a trained professional in order for it to be beneficial (Timmins 2006).

Each woman had access to the support services, whose details were provided on the information sheet, sent with the research pack. None of the women had contacted either of the organisations. None thought that unless they were desperate they would consider phoning an anonymous help line. This gives a wider scope to the study as the NHS sees it as very necessary that patients be given written information. Many millions of pounds have been spent putting information on websites, printing and sending out leaflets etc; but is this information reducing or raising anxiety in the population? Back In 1993 during the Tyrrell study it was noted by their participants that although written information would be useful it should not replace the explanation and discussion given by the clinician.

It is important that healthcare staff remember that no matter how 'simple' the procedure, the significant meaning to the patient cannot be underestimated. Staff within the radiology department would feel that this service was a good one, particularly considering that the days available within each menstrual cycle may include a weekend when no appointments are available.

During this period of waiting most found that they gained their emotional support from partners, friends and family. In only one case was formal support offered in the form of conversation at the GP surgery. There was little NHS support offered to the women who were interviewed.

Conclusion

This research has demonstrated that at the time of the HSG, women's focus changes from conception, to anxiety about the HSG procedure itself, an invasive 'medical' procedure. Although anxious the participants saw the HSG as a very important examination in their fertility treatment. The opportunity to address women's anxiety at this early stage may help to provide women with an avenue of support and coping mechanisms for their future fertility treatments.

HSG should be seen as an important step in the whole treatment of sub fertility and not just as a diagnostic procedure. Communication between patients and professionals about waiting times and the women's expectations were also identified and provides Radiology Departments with a challenge to meet this need given the small window of opportunity to appoint these patients.

The effective use of NHS resources at an early stage to address the anxiety needs could save women from emotional distress at the time of HSG and as their treatment progresses. Anxiety reduction at an early stage may save the NHS from the financial burden of treating depression as sub fertility treatment progresses.

Previous literature and data from this study demonstrated that the use of written information needs to be supported by a verbal contact with a member of staff, which can be done via a number of methods such as pre assessment either face to face or telephone.

Despite the modernisation agenda which has undoubtedly bought vast improvements to healthcare, women's needs are often the simplest ones. It is demonstrated here that to allow women the opportunity to discuss the process of sub fertility investigations at an early stage can lead to a reduction in anxiety. Women's feelings are that sub fertility is not spoken about out with the immediate family or friends and sometimes not even with them. The Advanced Practitioner with responsibility for HSG can be the link to provide a seamless service that educates and promotes changes in practice, to ensure that sub fertility is not a taboo subject

HSG examinations are increasing in number annually, but the process of the procedure will not change dramatically. What can change for women is the situations and environment surrounding HSG. This study aims to facilitate this change.

Implications for practice

Simply stated when a woman is asked at a Gynaecological Out Patient visit "do you have any questions" she will not have had an opportunity to read an HSG leaflet. She will not know what her specific need for information will become. Practice should reflect:-

- Women need access to healthcare professionals to discuss HSG at the earliest opportunity.
- Recognition that written information meets only part of the information needs of women.
- Sub fertility investigations are rated highly important amongst women. Service providers need to address a possible miss match in perception.
- Effort should be made to meet demand for HSG during first menstrual cycle following referral.
- Ways should be found to reduce patient anxiety prior to HSG in order to reduce possible later mental health issues.
- Advanced Nurse Practitioners can use the role to enhance education and communication between all specialities involved in the sub fertility field.

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Author Contributions

Maggie Williams, Lorna Green and Karen Roberts all contributed to the concept and design, data analysis, the writing of the article.

Karen Roberts critically reviewed the article

Lorna Green conducted data collection and transcribing of data.

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