A Questionnaire Survey of Health Care Professionals Regarding Their Knowledge of Congenital CMV Infections in Pregnant Women

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Aims

Active CMV infections in pregnant women whilst not particularly common can have long term debilitating effects on the child after birth. This project involves interviewing health care professionals, in particular those routinely involved in pregnancy care, in order to investigate the degree of their understanding pertaining to the risks, effects and management of CMV infections in pregnant women. This is to establish whether more needs to be done in the field to further improve care.

The results from this questionnaire will also be used as part of a proposal to the RCOG for the establishment of new CMV-related training for relevant health care professionals.

Methods

The means of data collection in this study was a questionnaire. However, to increase the specificity of this study, three different questionnaires were prepared in order to target three specific groups, namely; specialists in Obstetrics & Gynaecology and/or Fetal Medicine, midwives, and GPs. This was done to ensure more accurate responses from a demographic sampling perspective, the majority of the questions pertaining to CMV were similar, with the exception of a few which were amended slightly to allow for job appropriate responses.

As this was a study conducted within the country and did not involve patient contact or details, no additional approval was sought from a Research Ethics Committee.

Introduction

A congenital cytomegalovirus (cCMV) infection occurs when an infected mother passes CMV to the fetus through the placenta (1). Though not always the case, the most likely cause is when a woman is infected with CMV for the first time (primary infection) during her pregnancy (2).

In individuals who are infected post-utero, symptoms can be so mild that the individual does not even realise they are unwell. They also usually carry no long term effects (1). However, children born with congenital CMV unfortunately have increased risks of severe developmental problems. 15% of children born asymptomatically have an increased risk of developing partial or total hearing loss over time. Some children are born with obvious signs and symptoms such as petechiae, jaundice, hepatomegaly and splenomegaly. These children have increased risks of developing problems such as developmental delays, visual and/or hearing loss, physical and/or motor impairment and autism (3). Additionally, there is no accurate means of predicting the effect of the infection on the child either in-utero (if the infection is picked up then) or post delivery (3). Serological screening is currently not advocated by the NHS due to its low specificity and negative predictive values (4). When compared to other congenital infections of similar status, most commonly listeriosis, toxoplasmosis and Down's syndrome, congenital CMV actually significantly outranks them in both incidence and severity of complication (1). It has an incidence of 1000/year compared to 750 for Down's syndrome. Both Listeriosis and Toxoplasmosis have incidence rates of below 50 per annum. This is partially attributable to the high rate of transmission of active CMV to the foetus, which is estimated to between 33% and 40% (5).

Despite its obvious severity, there is evidence to suggest that there is a lack of knowledge on the part of health care professionals when it comes to CMV care.

A study conducted by Harrison GJ, likened CMV infections to an "elephant in the living room" due to its major public health impacts that continues to be unrecognised and unaddressed to this day (6). He argues that irregardless of various different healthcare institutions acceptance or dismissal of CMV diagnostic tests (there are pros and cons to both he says), there is much more that can be done in the field of prevention, which then reduces the importance of diagnostic test. He emphasises the importance of a CMV "knowledge vaccine" that he says negates the fact that there is currently no licensed vaccine for CMV. A 'knowledge vaccine" he says, is composed of an ounce of CMV awareness and three simple precautions", which despite being established by various bodies such as the CDC in America, is significantly under-utilised and unrecognised in a practical healthcare setting.

Additionally, a 2014 survey of medical students and doctors at an American institution revealed a overall baseline lack of knowledge compared to what was predicted. It found that whilst knowledge and awareness did gradually increase according to the seniority of the individual, "In contrast to how commonly it occurs, physicians and medical students have little knowledge of CMV" (7). The highest positive response rate of knowledge of the diseases and treatment approaches was measured at individuals with between 3-5 years of being a doctor (the highest group that was surveyed). Whilst that was to be expected, the rate itself was only 72% which was argued as being insufficient for doctor's of that experience. In fact, the findings of the study argue that this insufficiency of knowledge held true for all the demographics surveyed, with the exception of one (7). This further reemphasises the fact that knowledge pertaining to congenital CMV is lacking in health care professionals.

As such, based on the above and in line with my previously stated aims, a research hypothesis may be formed for this study:

Research hypothesis: Health care professionals regularly involved in the care of pregnant women lack sufficient knowledge when it comes to the facts, procedures and management of congenital CMV infections.

A total of 37 specialists, 79 midwives and 55 GPs responded to the questionnaire. Listed below is a summary of the most relevant responses.

1) Respondents demographics:

	Specialists/Specialist trainees	Midwives	GPs
<5 years	5	24	17
5-10 years	11	27	11
10-15 years	7	11	6
15-20 years	10	7	7
>20 years	4	10	14

Doctor's were also asked as to their respective training levels e.g ST4, consultant, GP registrar. The breakdown is as follows: 48.6% consultants, 37.8% senior specialist trainees (ST 4+), 13.6% junior specialist trainees (SHOs, ST1-3).

2)Please rank the following in order of frequency. ***(Specialists and Midwives only)***

	Down's Syndrome	CMV infection	Rubella infection	Toxoplasmosis infection	Listeria infection
1	9	11	4	3	17
2	2	11	14	7	2
3	3	1	11	17	3
4	0	9	6	8	11
5	23	5	2	2	4

Specialist/Specialist trainees, 1=not common at all, 2=very uncommon,3= neither common nor uncommon, 4=rather common, 5=very common

	Down's Syndrome	CMV infection	Rubella infection	Toxoplasmosis infection	Listeria infection
1	4	18	26	12	19
2	40	31	35	40	35
3	25	25	17	21	18
4	10	5	1	6	5
5	0	4	0	0	2

Midwives, 1=very uncommon, 2=rather uncommon, 3=rather common, 4=very common, 5 = I don't know

3) Please rank the following in order of severity ***(Specialists and Midwives only)***

	Down's Syndrome	CMV infection	Rubella infection	Toxoplasmosis infection	Listeria infection
1	0	0	0	0	0
2	5	1	2	0	1
3	21	23	22	29	14
4	11	13	13	8	22

Specialist/Specialist trainees, 1=not serious at all, 2=not very serious, 3=rather serious, 4=very serious

	Down's Syndrome	CMV infection	Rubella infection	Toxoplasmosis infection	Listeria infection
1	0	0	1	1	0
2	12	4	1	3	3
3	47	53	41	45	39
4	16	22	36	30	36

Midwives, 1=not serious at all, 2=not very serious, 3=rather serious, 4=very serious

4)Would you feel confident answering a woman's questions about diagnosis, transmission and treatment of congenital CMV? ***(Doctors only)***

	Specialists/Specialist trainees	GPs
Yes	23	24
No	14	25
Don't know	0	6

5) Do you feel confident advising women on how to prevent a CMV infection? ***(Doctors only)***

	Specialists/Specialist trainees	GPs
Yes	22	22
No	15	28
Don't know	0	5

6)Do you counsel pregnant women about preventing cCMV? ***(Doctors only)***

	Specialists/Specialist trainees	GPs
Regularly	5	3
Occasionally	12	17
Rarely	16	24
Never	4	11

7) Do you think pregnant women should be given advice about preventing CMV infection?

Specialists - Yes **(36)**, No **(0)**, Don't know **(1)**
Midwives - Yes **(77)**, No **(2)**, Don't know **(0)**
GPs- Yes **(47)**, No **(0)**, Don't know **(8)**

A short passage was written regarding the facts of CMV including describing its effects on the developing foetus, how common it is compared to other similar diseases, how it is transmitted and how to prevent its transmission. Following which, respondents were asked the question on the left:

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Discussion

The discussion will link back to each previously listed question and relate it to the aims of this study, that is to investigate the degree of understanding pertaining to the risks, effects and management of CMV infections in pregnant women and establish its degree of suitability. It is split into 5 main areas of inquiry.

1) Assessing the factual baseline knowledge of CMV

This is done based on the responses to question number 2. This therefore assesses the degree of knowledge pertaining to the incidence of CMV.

The answer's from question 2 show that the largest proportion of specialists (29.7%) categorised cCMV infections as 'not common at all' and 'very uncommon'. This shows a clear belief that cCMV is an uncommon condition. In fact, CMV had the highest proportion of specialists categorising it as either not common at all or very uncommon, this figure was 59.5%, the next highest was Listeriosis at 51%. At the other end of the spectrum, 37.8% of specialists categorised it as rather or very common, placing it third highest behind Down's syndrome (62.2%) and Listeriosis (45.5%). This spread of answers shows uncertainty as to the true prevalence of cCMV.

For midwives, 62% categorised cCMV as very or rather uncommon, with 5.1% choosing to utilise the 'I don't know' option, which was not done for any other condition. However 39% categorised it as wither rather or very common, again showing an uncertainty as to its true prevalence. With that, cCMV ranked as the second most common amongst midwives at 39%, only behind Down's syndrome at 45.5%.

Literature however states that cCMV is actually the most common amongst the five listed conditions. cCMV has an estimated 1000 births per year in the UK (1). This is compared to 750 for Down's syndrome, and below 50 for Listeriosis, Toxoplasmosis and Rubella (1,8). As such, both groups under-appreciated the prevalence of cCMV with specialists being outperformed by the midwives who ranked it second most common, compared to their third.

2) Assessing the knowledge of management of cCMV

This is done based on the responses to question number 4. This therefore assesses the knowledge of diagnosis, transmission and treatment of cCMV by way of their confidence in answering questions pertaining to the matter.

For specialists, 62.2% reported that they would be confident in addressing such concerns. This number dropped to 43.6% for GPs. Additionally, 11% of GPs were not confident enough to either affirm or disagree. Whilst 62.2% might seem like a high number, it is significantly below the reported percentage of 72% (7) in the literature. Additionally, specialists should arguably know the most pertaining to conditions within their field, and 62.2% does not quite reflect adequate knowledge. 43.6% for GPs is definitely inadequate for a group of individuals who would arguably be the first point of presentation and follow up treatment and care for the condition. Therefore it can be concluded that both specialists and GPs do not know enough regarding the management of cCMV. This is perhaps due to poor exposure to the condition or even because it is not screened for here (4), there is less impetus to know about it.

3) Assessing the knowledge of prevention of cCMV

This is done based on the responses to question number 5. This therefore assesses the knowledge of how to prevent a CMV infection by way of their confidence in answering questions pertaining to the matter.

59.4% of specialists and 40% of GPs reported being confident in this matter. Similar to the previous point, these numbers are not high enough when compared to literature and also generally as the prime personnel involved the the majority of cCMV cases.

There is also a slight trend observed that there is generally less known by both groups regarding prevention of cCMV compared to diagnosis and treatment, seen by the decrease from 62.2% to 59.4% (specialists) and 43.6% to 40% (GPs). Given the complications surrounding cCMV and the significant potential disabilities to the child later in life, it is essential that prevention is not ignored and that these statistics improve.

4) Assessing the degree of relative importance placed on cCMV

This is done based on the responses to the question numbers 3 and 6. This therefore assesses their understanding of the severity of CMV and whether if when all things considered they consider it an important enough condition to counsel patients about.

The answer's from question 3 show that the largest proportion of specialists (62.2%) categorised cCMV infections as 'rather serious' when compared to the other conditions. An additional 35.1% categorised it as 'very serious'. This shows a clear belief than cCMV is a serious condition. However this is tempered slightly by the general trend of having similar percentages ranking of all the other conditions as serious too. This leads us to belief that cCMV is on par in its seriousness to the other conditions, at least in their belief.

This general trend is also witnessed in midwives, with 94.9% categorising cCMV as 'rather serious' and 'very serious'. Again, the majority of midwives like specialists believed all the conditions to be of similar severity, with proportions only ranging between 79.7% up to 97.4% for the highest two options of severity.

Literature states that cCMV is one of the leading causes of childhood disabilities (1) and even the number one cause of child deafness and hearing loss in the UK (1). This shows a clear correlation between the responses garnered and the actual facts, showing that the respondents did in fact rank cCMV as being severe.

However, that conclusion is blurred slightly when considering the responses to question 6. Despite a clear indication of the severity of cCMV, only 13.5% of specialists and 5.5% of GPs regularly counsel pregnant women. The most common answer for both groups was 'rarely', with 43.2% of specialists and 43.6% of GPs selecting that as their answer. This worryingly shows a clear disinclination on doctor's parts to counsel their patients regarding cCMV.

5) Re-assessing (at the end of the questionnaire) the need for cCMV counselling

This is done based on the responses to the question number 7. This therefore re-assesses their opinion on whether counselling should be offered, after having read a short passage regarding the facts of cCMV. The responses show a clear difference between the responses to question 6. 97.3% of specialists (compared to 13.5%), 97.5% of midwives and 85.5% of GPs (compared to 5.5%). However, this does not take in to account certain limitations such as time constraints. Perhaps it is not a lack of desire to counsel but simply a matter of lacking time and/or the requisite knowledge to adequately do so. The reasoning for this vast gap should thus be looked into and hopefully rectified.

Limitations:

Limitations include the number of respondents, particularly in the specialist category. Having a low sample size may not accurately reflect opinions. The location of respondents should also be considered, with the majority of them being based in London, this study may not be a true reflection of UK wide health practitioners. It is also hard to assess baseline knowledge formally from questions asking about confidence. It was asked in that manner to maximise responses but it is an indirect way of assessing knowledge. However, the alternative would have meant the use of numerous open-ended questions which would result in much poorer response rates.

Future work should focus on the difference between desire to counsel and the practical reasons as to why it is not happening more frequently. Training days and adequate teaching could also be used to boost knowledge and thus sharing of said knowledge.

Conclusions

As such, based on the results of the questionnaire and when comparing them to the literature, the following conclusion may be drawn in response to the research hypothesis.

Whilst there is certainly some evidence that suggests healthcare professionals do possess certain knowledge when it comes to congenital CMV, there is much room for improvement in that respect. Health care professionals indeed do lack sufficient knowledge when it comes to the facts, procedures and management of congenital CMV infections. As evidenced in their responses, the respondents are largely inclined to agree with that as well.

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