



Severe hyperemesis gravidarum increases rates of termination of pregnancy and suicidal ideation: results from a UK questionnaire completed by >5000 participants

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How the study came about...

- Georgie Bevan (investigative journalist)
 - 'I developed an interest in hyperemesis after listening to a compelling interview on BBC 5 live'
- Collaboration with PSS
- Development of a questionnaire
- Aim: to gain further insight into the experience of those suffering with HG
- BBC News coverage across the UK:
 - Results
 - Patient stories
 - UK genomics study

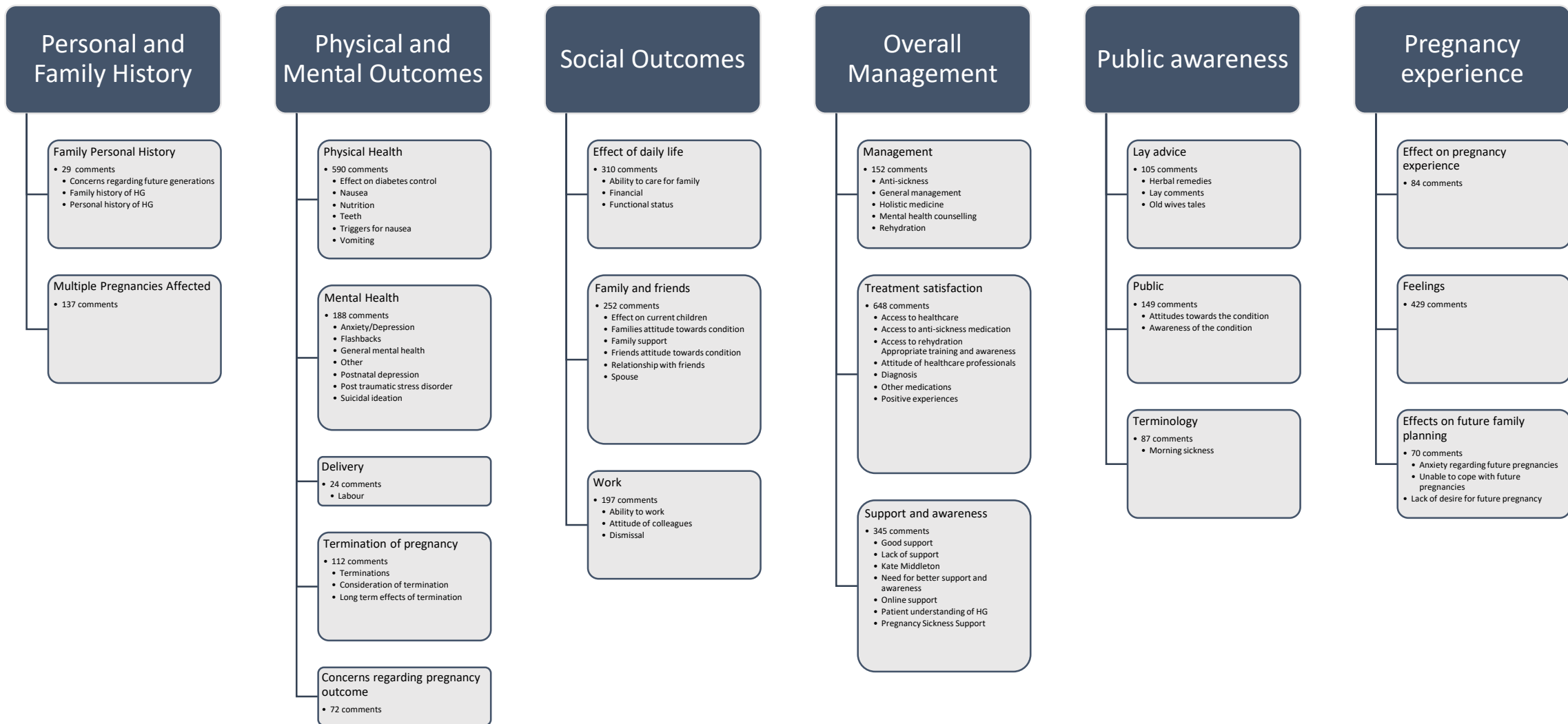


Topics covered in the survey

- Basic demographic information
- Impact on functional status
- Patient perception of advice/treatment received
- **Termination**
- **Suicidal ideation**
- Long term effects

Methods

- 14 item anonymous online questionnaire
- Circulation to members of the Pregnancy Sickness Support (PSS) charity
- 22nd March – 15th April 2019
- **Quantitative analysis:** geographical locations, current pregnancy status, impact on function status, treatment regimen and patient satisfaction, suicidal ideation, consideration of termination due to HG
- Statistical analysis using SPSS
- **Qualitative analysis:** inductive thematic approach using NVivo
- Free text comments for 2500 participants analysed
 - Coded, categorised and reviewed for emergent themes



Qualitative analysis - emergent themes



Results: Demographics

- 5071 participants completed the questionnaire
- 14 regions across the UK
- 940/5071 (18.6%) currently experiencing symptoms
- 2217/5071 (43.7%) had 1 pregnancy affected, remainder >1



Results: impact on functional status

- 3432/5071 (67.7%) reported being bedridden as a result of HG
- 1547/5071 (30.5%) able to function most of the time but needing extra support

Social Outcomes

Effect of daily life

- 310 comments
- Ability to care for family
- Financial
- Functional status

Family and friends

- 252 comments
- Effect on current children
- Families attitude towards condition
- Family support
- Friends attitude towards condition
- Relationship with friends
- Spouse

Work

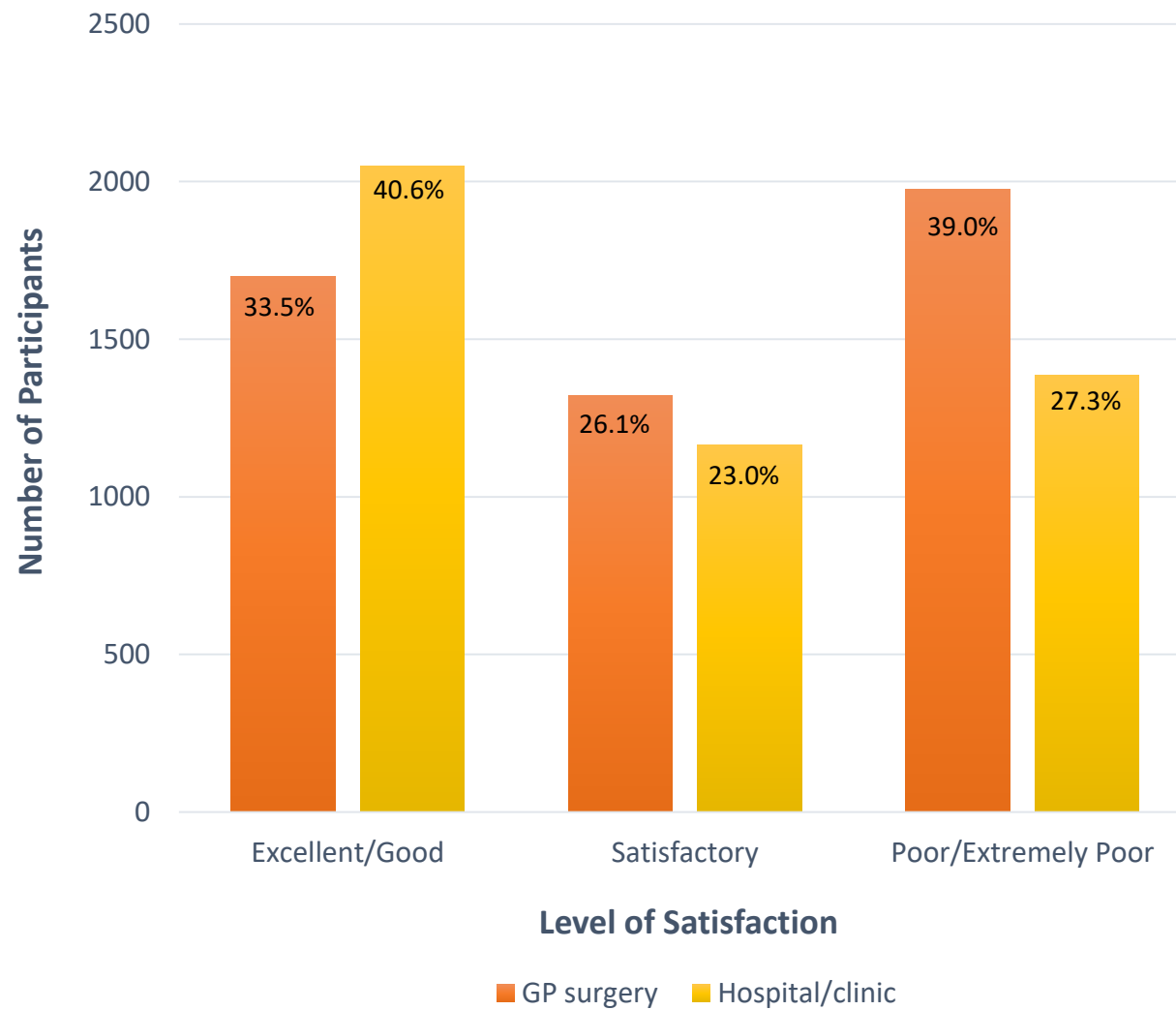
- 197 comments
- Ability to work
- Attitude of colleagues
- Dismissal

Emergent themes...

Themes	Categories	Frequency of Comments	Representative quotations
Social Outcomes	Effect on daily life	310	'Unable to do basic things like shower or even sit up, left me in absolute despair'
	Family and Friends	252	'It almost ruined my relationship and the bond with my first child as I barely saw her due to being in hospital so much for a lot of the pregnancy'
	Work	197	'Now my baby is 9 months old I'm making arrangements to go back to work, and they are making it difficult for me and trying to push me out. I feel this is due to the length of time I had to take off sick. I've now had to move to another lower paid role'

Patent perception
of
advice/treatment
received

Perceived satisfaction with care services



Overall Management

Management

- 152 comments
- Anti-sickness
- General management
- Holistic medicine
- Mental health counselling
- Rehydration

Treatment satisfaction

- 648 comments
- Access to healthcare
- Access to anti-sickness medication
- Access to rehydration
- Appropriate training and awareness
- Attitude of healthcare professionals
- Diagnosis
- Other medications
- Positive experiences

Support and awareness

- 345 comments
- Good support
- Lack of support
- Kate Middleton
- Need for better support and awareness
- Online support
- Patient understanding of HG
- Pregnancy Sickness Support

Emergent themes...

Themes	Categories	Frequency of Comments	Representative quotations
Overall Management	Treatment Satisfaction	648	'Hardest thing after 11 admissions was midwife saying 'You ladies with HG take up so much of my time' she was rude and made me feel so uneasy and low I cried a whole 12 hours due to her behaviour towards me, but I was too scared to complain'
	Management	152	'Measuring for ketones would have indicated that I wasn't unwell even when I was extremely dehydrated. Thankfully I was generally assessed and given appropriate treatment'
	Support and Awareness	345	'I definitely don't think there is anywhere near enough support, or knowledge on this condition'.

Results: termination and suicidal ideation

- 249/5071 (4.9%) reported terminating their pregnancy as a result of HG
 - A further 1268/5071 (25.0%) seriously considered termination due to HG
- 1582/5071 (31.2%) reported suicidal ideation during pregnancy as a result of HG

Results: termination and suicidal ideation

		Termination				Suicidal ideation			
		Yes	No	% yes	p value	Yes	No	% yes	p value
Bedridden	Yes	223	3209	6.5	<0.001	1304	2128	38.0	<0.001
	No	26	1613	1.6		278	1361	17.0	
Admission for rehydration	Yes	181	2609	6.5	<0.001	1047	1743	37.5	<0.001
	No	68	2213	3.1		535	1746	23.5	
Poor/very poor support from GP	Yes	152	1824	7.7	<0.001	762	1214	38.6	<0.001
	No	97	2998	3.1		820	2275	26.5	
Poor/very poor support from hospital	Yes	127	1258	9.2	<0.001	557	828	40.2	<0.001
	No	122	3564	3.3		1025	2661	27.8	

Physical and Mental Outcomes

Physical Health

- 590 comments
- Effect on diabetes control
- Nausea
- Nutrition
- Teeth
- Triggers for nausea
- Vomiting

Mental Health

- 188 comments
- Anxiety/Depression
- Flashbacks
- General mental health
- Other
- Postnatal depression
- Post traumatic stress disorder
- Suicidal ideation

Delivery

- 24 comments
- Labour

Termination of pregnancy

- 112 comments
- Terminations
- Consideration of termination
- Long term effects of termination

Concerns regarding pregnancy outcome


- 72 comments

Emergent themes...

Themes	Categories	Frequency of Comments	Representative quotations
Physical and Mental Outcomes	Physical Health	590	'My partner recalls being able to see my bones protruding through my skin due to weight loss.'
	Concern Regarding Pregnancy Outcome	72	'I took the medication and my baby was born visually impaired. We don't know whether it was coincidental or not, but I will always blame myself'
	Mental Health	188	'led to long term depression and attempted suicide'
	Termination of Pregnancy	112	'At the point of termination, it was either an abortion or suicide' 'I had no other option if I was going to be able to look after my existing child'
	Delivery	24	'I knew I would vomit during the labour but not to the extreme extent that I did'



Conclusion

- HG exerts a significant burden on physical and mental health
 - Termination rates and suicidal ideation are very high in affected women
 - Rates are high in those who perceive that they have poor care
 - Urgent attention must be paid to improving the services delivered across primary and secondary care for the patient and their family
 - Ongoing need for improved awareness and education
 - Insight gained into patient experience by listening to their stories
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Acknowledgements

Patients

Georgie Bevan

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Harriet Boulding, Florence Tydeman and Kimberley Kavanagh





Thank you for listening

Any questions?

Management and patient perception of advice/treatment received

- 4303/5071 (84.9%) reported taking medications to reduce extreme sickness
 - 51.9% 'quickly offered prescribed medication and took it'
 - 48.1% 'took prescribed medication but had to request it'
- 2790/5071 (55.0%) reported being admitted to hospital for rehydration therapy
 - A further 862/5071 (17.0%) reported receiving OPD rehydration therapy

Perceived satisfaction with care services

