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The public awareness of stillbirth: An Irish population study

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Running Title: The public awareness of stillbirth

Abstract

Objective To evaluate the general population's awareness of stillbirth.

Design A cross sectional telephone population survey.

Setting A nationally representative sample of the Irish adult population.

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Sample 999 members of the Irish population selected by random digit dialling.

Methods Data were analysed using descriptive and inferential statistics. Binary logistic regression was used to assess the odds of identifying risk factors for stillbirth.

Main outcome measures Public knowledge of incidence, risk factors, causes and social awareness about stillbirth.

Results

Only a minority, 17%, of respondents correctly identified the incidence of stillbirth. Men and those aged over 45 were more likely to say they did not know when a stillbirth occurs. Over half, 56% of respondents were unable to identify any stillbirth risk factors. Half of respondents, 53%, believed that the cause of stillbirth was due to a problem with the baby, 39% a problem with the mother, while 31% believed stillbirth occurred as a result of the care provided to the mother. The majority, 79%, believed that all stillbirths should be medically investigated, although women were more likely to suggest this (82% v 76.4% p=0.043). Stillbirth had been represented in traditional and online media for 75% of respondents and 54% said they personally knew someone who had a stillbirth.

Conclusions

There is a lack of public knowledge concerning the incidence, risk factors and causes of stillbirth. Improved public health initiatives and antenatal education are warranted to increase awareness of stillbirth risk factors and to improve care and monitoring during pregnancy.

Funding No funding was granted for this study.

Keywords Stillbirth, stillbirth risk factors, Irish population survey, antenatal education, public health.

Tweetable abstract Irish population study shows low public awareness of stillbirth incidence, risk factors and causes.

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Lay summary

This study aimed to find out what the general public know about the risk factors associated with stillbirth and whether stillbirth can be prevented. Many stillbirth risk factors can be identified and when they are, healthcare professionals can monitor pregnancy and hopefully reduce the possibility of a baby dying before birth. A sample of 999 people from the Irish population was surveyed by a professional telephone polling company for this study.

The results of this study found that most people did not know how common stillbirth was and also believed that only a minority could be prevented. Most people were not able to identify any risk factors that can lead to stillbirth. Most people knew someone who had a stillbirth and likewise most people believed that all stillbirths should be investigated to find a cause.

It is possible that some people do not know the difference between stillbirth and miscarriage and this question was not asked in this study. Six people did not complete the interview as the topic of stillbirth was too sensitive. It is possible that these people had experienced a stillbirth themselves and so their results are not included.

This study highlights the importance of increasing public awareness about stillbirth by providing clear information to women and their partners that there are risk factors associated with stillbirth that can be identified and monitored. The results of this study suggest that these risk factors could be highlighted in antenatal preparation classes and public health campaigns.

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Introduction

There has been a renewed global focus on stillbirth as a public health concern where the decline in stillbirth rates has remained static in the developed world.[1-6] The economic, social, emotional and professional burden of stillbirth is well documented in the literature.[1, 7-11] In addition, stillbirth in many parts of the world has been an unacknowledged grief with an associated lack of public discourse compounding the grief experience for bereaved parents and limiting public awareness of the prevalence of stillbirth as a possible outcome in pregnancy.[12, 13]

Most studies about stillbirth knowledge have focussed on bereaved parents and healthcare professionals.[8-11, 14, 15] These studies highlighted the considerable and enduring trauma of stillbirth where existential questions and strong feelings were raised, especially where bereavement care had been deficient.[9, 16] A recently published metasynthesis confirmed that bereaved parents would like increased public awareness and prioritisation of stillbirth care.[17]

Coupled with advances in global stillbirth classification systems and data collection, stillbirth is increasingly recognised as an important public health metric.[5] However, the low awareness of stillbirth in public discourse is likely to impact negatively on initiatives to identify risk factors in high risk populations. There is also a challenge to communicate the importance of recognised modifiable risk factors for stillbirth in the general population for whom the possibility of stillbirth may not have been considered. The early identification of risk factors, both modifiable and non-modifiable, for example maternal obesity, diabetes, smoking and early identification of fetal growth restriction, has been shown to contribute to the prevention of stillbirths, most especially in normally formed singleton pregnancies.[18-20] In Ireland, where this study was conducted, stillbirth is defined ‘a child born weighing 500 grammes or more or having a gestational age of 24 weeks or more who

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shows no sign of life.'[21] The incidence of stillbirth in Ireland is 1 in 238 births.[22] This rate compares favourably with other high-income countries.[2]

Public health campaigns in the area of stillbirth have to date focussed mainly on reduced fetal movements during pregnancy.[19] The AFFIRM interventional trial in the United Kingdom is one such example where the provision of a standardised antenatal care bundle and raising awareness of reduced fetal movements to reduce stillbirths is being tested.[23]. The public awareness of risk factors associated with stillbirth is not known.

The objective of this study was to evaluate the general Irish population's understanding about stillbirth and to identify knowledge gaps about causes and risk factors for stillbirth.

Methods

A cross-sectional telephone survey was conducted to ascertain public awareness regarding stillbirth. The survey was facilitated by IPSOS MRBI, which is a commercial omnipoll survey company who collect a representative national sample of Irish adults aged fifteen years and above, with state census derived quota controls,[24] on a fortnightly basis. The data were collected during a two-week period in January 2017. Participants were contacted using random digit dialing to ensure that both listed and unlisted telephone numbers had the same probability of being contacted. Interviews were conducted with participants using both landline and mobile phone contacts.

The questionnaire was designed by the research team and covered the following ten areas: (i) timing of stillbirth (ii) incidence of stillbirth in Ireland (iii) perception about stillbirth prevention (iv) perceived reasons for stillbirth (v) whether all stillbirths should be medically investigated (vi) personal knowledge of someone who has had a stillbirth (vii) media coverage of stillbirth (viii) legal registration of stillbirth (ix) inclusion of stillbirth in antenatal education (x) awareness of

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stillbirth risk factors. All questions were asked of all participants. Oral consent to participate was given at the beginning of each interview.

Ethical approval for this study was granted by the Clinical Research Ethics Committee of the Cork Teaching Hospitals (Ref. No: ECM 4 (k) 06/12/16).

Sample

There were 1,005 participants in the study drawn from a nationally representative sample of the Irish adult population in line with known demographics form the Central Statistics Office.[24] However, the data from six participants were removed from the dataset as they were unable to fully complete the telephone survey due to difficulties with the sensitivity of the subject matter. The final sample was 999 participants.

Analysis

Data were analysed using descriptive and inferential statistics. Associations were assessed using chi-square tests. Binary logistic regression was used to assess the odds of identifying risk factors for stillbirth. Adjusted odds ratios with 95% confidence intervals are reported for these analyses. The data were weighted in line with the known profile of the Irish population according to the latest national census data.[24] All analyses were conducted using IBM SPSS Statistics version 23.0.

Results

There were 999 participants in the study of which 51% (n=510) were female and 49% (n=489) were male. Of these, 48.6% (n=486) were from professional socioeconomic grades and 51.4% (n=513) from manual socioeconomic grades; 33.6% (n=336) had children under 18 years old. Table 1 lists

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the sample characteristics illustrated by age, gender, socioeconomic status, employment status and whether respondents had children aged under 18.

General awareness of stillbirth

Over half, 54% (n=540) of the total sample stated that they personally knew someone who had a stillbirth. Women were more likely than men to know someone who had experienced a stillbirth (61.6% v 49.2%; p=0.049). Respondents who had children under 18 were also more likely to know someone who had a stillbirth (63.7% v 51.1%; p<0.001) and likewise those from professional socioeconomic grades (61.7% v 49.3%; p<0.001).

Incidence of Stillbirth:

Seventeen percent of respondents were able to correctly identify the stillbirth rate (n=174). Half the population believed that stillbirth was more common, believing that the rate was between 1 in 50 and 1 in 100 births. Women were more likely than men to state that stillbirth occurred in 1 in 50 births (29% v 19%; p<0.001) and 1 in 100 births (24% v 22%; p<0.001). Those aged under 45 were also more likely to state that stillbirth occurred in 1 in 50 births (30.6% v 18.3%; p<0.001) and 1 in 100 births (26.3% v 19.6%; p<0.001). Similarly, those with children aged under 18 were more likely to think that stillbirth is more common; 1 in 50 births (30% v 22%; p<0.001) and 1 in 100 births (25% v 22%; p<0.001). Those who personally knew someone who had a stillbirth were also more likely to state that stillbirth was more common.

Timing of stillbirth:

The majority of respondents, 58% (n=580), stated that stillbirth can occur at any stage in pregnancy. Women were more likely than men to say that stillbirth occurs before 24 weeks gestation (32.5% v 26.4%; p=0.001), after 24 weeks gestation (41.2% v 31%; p=0.001) and during labour (32.5% v

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24.2%; p=0.004). Men were more likely than women to state that they did not know when a stillbirth occurs (24.4% v 10.9%; p<0.001). Those aged over 45 years were more likely to state that they did not know when a stillbirth occurred (20.1% v 13.3%; p=0.005), were less likely to think that a stillbirth can occur at any stage in pregnancy (52.7% v 63.3%; p=0.001) and less likely to state that stillbirth occurs after 24 weeks gestation (32.8% v 39.2%; p=0.035). Those with children under 18 years were less likely to state that they did not know when a stillbirth occurs (11.3% v 19.5%; p=0.005). Those who knew someone who had a stillbirth were more likely to think that a stillbirth could happen at any stage in pregnancy (67.8% v 46% p<0.001).

Causes, prevention and investigation of stillbirth

Causes of stillbirth:

Most respondents, 87% (n=873) stated that there were reasons for a stillbirth. Over half of respondents, 53% (n=528) believed that the cause was related to something being wrong with the baby; 39% (n=390) believed it was something wrong with the mother, while 31% (n=309) believed that it was related to the care provided to the mother. One in three, 29% (n=285) reported that the cause is usually unexplained.

Prevention of stillbirth:

A minority, 10% (n=100) of the total sample believed that all stillbirths can be prevented and 21% (n=208) were unsure whether all stillbirths could be prevented. Men were more likely than women to respond that all stillbirths can be prevented (11.1% v 8.2%; p=0.004) and were also more likely to respond that they did not know whether all stillbirths can be prevented (24.4% v 17%; p=0.004). Likewise, those without children aged under 18 were more likely to respond that all stillbirths can

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be prevented (11.3% v 7.4%; p=0.017) or to respond that they did not know if all stillbirths could be prevented (22.35 v 17.6%; p=0.017).

Investigation of stillbirth:

The majority, 79% (n=789), of respondents believed that all stillbirths should be medically investigated. This was represented across all demographics. Women, however, were more likely than men (82% v 76.4%; p=0.043) to state that all stillbirths should be medically investigated. Those from professional socioeconomic grades were more likely to think that stillbirth should not be investigated (16.5% v 10.9%; p=0.049).

Risk factors and education

Half of respondents, 56% (n=559), were unable to identify a risk factor for stillbirth. Of those who could identify at least one risk factor, 28% (n=275) identified alcohol, 22% (n=222) identified smoking, 16% (n= 158) identified drug/substance abuse, 4% (n=41) identified stress, 4% (n=41) identified diet and 3% (n=31) identified the general health/lifestyle of the mother. Only 2% (n=24) stated that genetics was a risk factor and two respondents stated reduced fetal movements as a risk factor for stillbirth. As indicated in Table 2 professional grades were less likely to identify smoking, alcohol and drugs as risk factors in stillbirth than those in manual grades (see Table 2)

A majority of respondents, 88% (n=882) felt that the possibility of stillbirth should be included in antenatal education programmes.

Social awareness of stillbirth

A majority of respondents, 75% (n=750), had seen or heard stillbirth represented in the media. Those aged over 45 were more likely to report that they had seen stillbirth represented in non-online

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sources such as newspapers and magazines and those under 45 more likely to report social media sources such as Twitter, Facebook, Instagram and online pregnancy fora, websites and blogs.

Discussion

Main findings

This study demonstrates that while there is general awareness concerning the existence of stillbirth as an outcome of pregnancy, there is a lack of public knowledge about incidence, causes and risk factors for stillbirth. While over half of respondents were personally aware of someone who had a stillbirth, these results raise important concerns in terms of public health awareness in the efforts to reduce preventable stillbirth. The data, particularly relating to risk factors and causes of stillbirth, highlight the need for an improved public health information campaign and antenatal education.

Strengths and limitations

The strengths of this study were that it established a baseline of knowledge about incidence, risk factors, causes and social awareness of stillbirth from a representative sample of a general population using a robust sampling methodology. The limitations of this study were that the sensitivity of the subject may have prevented participation from the general population, however only six respondents failed to complete the survey for this reason. The absence of this data is a limitation.

Interpretation

It is noteworthy that 47% of the general population believed that stillbirth was more common than the actual rate; this was particularly the case with women, those aged under 45, those with children under 18 and those who personally knew someone who had a stillbirth. From a public health perspective, this belief may have a protective health benefit where stillbirth is considered as a

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possible outcome of pregnancy. In turn this may lead to a potentially increased likelihood of identifying risk factors and receiving antenatal care and surveillance following the detection of non-modifiable risk factors. The results of this study suggest that the public awareness of stillbirth as a possible outcome of pregnancy is at least higher than the public awareness of the incidence of miscarriage although the incidence of miscarriage is considerably higher.[25]

The fact that 58% of respondents believed that stillbirth could occur at any stage in pregnancy would also suggest that there is general confusion between the understanding of miscarriage and stillbirth. This was particularly the case with men and those aged over 45. When considered with the results concerning the incidence of stillbirth and the numbers of respondents who personally knew someone who had a stillbirth, these data suggest that there is public confusion between miscarriage and stillbirth which deserves further research to establish if this is in fact the case. While only a minority of respondents, 10% (n=100), believed that all stillbirths can be prevented, the data suggests that respondents do not know how it can be prevented.

One in three respondents in this study stated that the cause of stillbirth is usually unexplained, whereas the latest Irish perinatal data from the National Perinatal Epidemiology Centre records that the number of stillbirths in Ireland classified as unexplained has now reduced to sixteen percent.[22] Further, most respondents stated that there is usually a cause for stillbirth, where just over half stated that the cause is usually with the baby and 39% believed it was caused by something wrong with the mother. The latest Irish perinatal data reports that 38% of stillbirths are attributed to causes with the baby and 16% attributed to maternal causes.[22] This strengthens the importance of developing comprehensive antenatal care pathways for those in higher risk groups. For those who have had a stillbirth, robust maternal, placental and fetal investigation is important to identify and minimise risk in subsequent pregnancies.[22, 26]

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The attribution of the role of care provided to the mother as a cause for stillbirth by one in three respondents suggests that the respondents in this study attribute blame to healthcare staff for stillbirth. From the perspective of healthcare staff, this finding is consonant with other studies where healthcare providers experience feelings of guilt, sadness and anxiety contributing to the personal and professional burden that can be experienced by healthcare staff following adverse perinatal outcomes such as stillbirth.[8, 11] Attribution of blame and suspicion concerning care is also increasingly expressed by the public both in traditional media and on social media platforms., where public confidence in safe maternity care following adverse obstetric events can diminish.[27]

While a majority of respondents believed that stillbirth should always be medically investigated, it is noteworthy that higher socioeconomic groups were less likely to believe that stillbirth should be medically investigated. This is contrary to the global trend in recent years to improve complete investigation and classification of stillbirth.[22]

The majority of respondents were unable to identify any risk factors for stillbirth. Given that the literature suggests that modifiable risk factors are present in up to 56% of stillbirths,[18] the lack of knowledge about risk factors highlights the need for increased public health information to address this gap in knowledge. While previous studies have focussed on the higher risks for stillbirth amongst lower socio economic grades,[2, 28] it was significant that professional grades in this study were less likely to identify stillbirth risk factors and also less likely to state that stillbirth should be medically investigated even though they were more likely to state that they knew someone who had a stillbirth.

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The identification of modifiable risk factors such as maternal obesity and smoking have been recognised as important targets by Flenady et al in the drive to reduce stillbirths in high-income countries.[29] Although smoking, alcohol and drug use were the top three risk factors identified by respondents in this survey, there was very little awareness of maternal obesity, reduced fetal movement or genetics as risk factors for stillbirth. As reduced fetal movements is the focus of much global attention in high income countries as a stillbirth risk factor, the lack of knowledge in this sample is concerning.[19] The data from this study supports the importance of monitoring pregnant women to enable early detection of well-established modifiable and non-modifiable risk factors for stillbirth.[18-20, 22] The data also supports the provision of public health campaigns for women of child-bearing age have an important role in addressing modifiable lifestyle risk factors such as obesity, drug and alcohol use. Although there was lack of knowledge about risk factors, a large majority felt that the possibility of stillbirth as an adverse pregnancy outcome should be included in antenatal education.

The reported high awareness of stillbirth through traditional and online media raises the potential of social media to be an important platform for the dissemination of public health information pertaining to risk factors associated with stillbirth. The growing use of social media platforms as sources of health information poses challenges for both users and healthcare providers to ensure that accurate and reliable information is provided. A 2016 study by Farrant et al of online media providing information about reduced fetal movements identified that most internet sites were providing unreliable information that was not evidence based.[30] How health providers utilise social media in this regard requires further study as does the reliability of information concerning stillbirth risks and causes that the general public access through social media and the influence such information has on health choices and outcomes.

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Conclusion

In the global drive to reduce preventable stillbirths, this study identifies that there is little awareness about incidence, risk factors and causes of stillbirth amongst the general population. These results highlight the need for increased information about stillbirth risk factors and causes in both antenatal education and public health campaigns to reduce the incidence of preventable stillbirth.

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Disclosure of Interests

The authors declare that they do not have any conflict of interest in regard to this paper. The ICMJE disclosure forms are available as online supporting information.

Contribution to authorship

KOD, SM and DN designed the study. KOD and SM assisted with data analysis. DN, SM and KOD wrote the paper

Details of ethics approval

This study received ethical approval from the Clinical Research Ethics Committee of the Cork Teaching Hospitals (Ref. No: ECM 4 (k) 06/12/16)

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Table 1: Sample characteristics

	Professionals Grades		**Manual Grades**	
	Male	**Female**	**Male**	**Female**
Age				
18-24	34(13.5)	32(13.6)	31(12.3)	30(11.5)
25-34	52(20.7)	46(19.6)	34(13.4)	30(11.5)
35-44	78(31.1)	71(30.2)	29(11.5)	35(13.5)
45-54	46(18.3)	46(19.6)	48(19.0)	38(14.6)
55-64	28(11.2)	28(11.9)	48(19.0)	41(15.8)
65+	13(5.2)	12(5.1)	63(24.9)	86(33.1)
Employment status				
Employed	209(83.3)	180(76.6)	127(50.2)	83(31.9)
Unemployed	7(2.8)	5(2.1)	24(9.5)	22(8.5)
Retired	8(3.2)	11(4.7)	80(31.6)	108(41.5)
Other	27(10.8)	39(16.6)	22(8.7)	47(18.1)
Children	113(45.0)	87(37.0)	63(24.9)	73(28.1)

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Table 2: Unadjusted (OR) and adjusted (aOR) odds ratios and 95% confidence intervals (CI) for stillbirth risk factor awareness

	Smoking				Alcohol				Drugs				Don't know			
Variable	OR	CI	aOR	CI	OR	CI	aOR	CI	OR	CI	aOR	CI	OR	CI	aOR	CI
Sex																
Male	1	(ref)	1	(ref)	1	(ref)	1	(ref)	1	(ref)	1	(ref)	1	(ref)	1	(ref)
Female	0.75	0.55-0.99	0.74	0.55-1.00	0.81	0.61-1.07	0.82	0.62-1.08	0.78	0.56-1.10	0.79	0.56-1.11	1.1	0.86-1.41	1.09	0.85-1.40
Age																
Under 45	1.34	0.99-1.80	1.19	0.87-1.62	1.35	1.024-1.78	1.17	0.88-1.56	1.59	1.13-2.24	1.47	1.03-2.10	0.76	0.59-0.98	0.87	0.67-1.13
Over 45	1	(ref)	1	(ref)	1	(ref)	1	(ref)	1	(ref)	1	(ref)	1	(ref)	1	(ref)
Social Class																
Professional	0.63	0.46-0.84	0.66	0.48-0.90	0.57	0.43-0.75	0.59	0.44-0.79	0.68	0.48-0.95	0.75	0.53-1.07	1.68	1.31-2.17	1.62	1.25-2.1
Manual	1	(ref)	1	(ref)	1	(ref)	1	(ref)	1	(ref)	1	(ref)	1	(ref)	1	(ref)

The aORs have been adjusted for all other factors in the table

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