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Stillbirth and risk factors: an evaluation of Irish and UK websites

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ABSTRACT

Background: Research indicates that the internet is used to source health-related information, including pregnancy-related information. The aim of this study was to examine websites targeted at the pregnant population and to assess the content therein relating to stillbirth and modifiable risk factors.

Methods: The study was limited to websites hosted in Ireland and the UK, and results organized by provider and topic. A codebook was designed to record the information found on the websites. Data were collected on different website characteristics, and a search was undertaken for basic information related to stillbirth (prevalence, causes, procedures, consequences, etc.), and information relating to modifiable risk factors (smoking, alcohol/drug use, medicines use, sleep position, attendance at antenatal care, and weight management).

Results: 92 websites were included in the study, of which 39.1% ($n = 36$) contained basic information about stillbirth and 29.3% ($n = 27$) contained information related to modifiable risk factors. Only one website (1.1%) contained all the information that was sought. Websites hosted by charities were more likely to contain basic information related to stillbirth, (39.3%, $n = 11$ of the 28 websites hosted by charities) whereas the commercial sites were more likely to contain information about modifiable risk factors (53.3%, $n = 8$ of the 15 commercial sites).

Conclusion: The results of this study illustrate that websites directed at the pregnant population are a poor source for information related to stillbirth. Some stillbirth risk factors are modifiable; therefore, it is crucial that women and stakeholders can avail of reliable sources of information to make informed decisions.

KEYWORDS

Stillbirth; Behavioural risk factors; Websites; Online health information; online health information seeking; stillbirth information seeking

Introduction

Pregnancy represents a transition period for women into motherhood; for many, this can be a transition to the unknown [1]. Due to having to cope with the uncertainty of being pregnant for the first time, many women and their partners draw upon the internet for information [2]. This information can influence their health-care related decisions [3].

Previous studies have concluded that around 80% of internet users use the Internet to find health-related information [4,5]. Andreassen et al. [6] conducted a questionnaire-based study to explore the internet information seeking behaviours of the general population. From a sample of 7934 people from seven different European countries, 44% reported that they had used the internet for health purposes, with respondents from northern Europe (German, Denmark and Norway) more likely to use the internet to seek health information compared to southern countries (Portugal and Greece).

Many women also use the internet as a source of information during their pregnancy [3,7–9]. Sayakhot & Carolan-Olah [10] conducted a systematic review to describe use of the Internet as source of information for pregnant women. They concluded that around 90% of the women who participated in the studies had accessed the internet for information, while factors such as having higher education levels, being married, being employed or being a first-time pregnant woman were associated with increased use. Similarly, a recent study conducted by Jacobs et al. [11] found that 96% of women in their Dutch sample used the Internet as an information source before or during their pregnancy.

Lagan et al. [3] conducted a questionnaire-based study that confirmed that all women had used the internet to search for health information during their pregnancy. In their sample, 13% of women stated that the internet was the only source of information they used. Although more than 95% used general search engines to find the information, less than half reported trusting that information. Government sites were cited as the least used, yet rated as the most trusted.

The internet has the potential to serve as a tool to empower and inform users in healthcare-related issues and in supporting patient choices [12]. There is

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evidence that interventions aimed at primary prevention have been delivered successfully online [13–15]. Previous research on internet use by people with different health conditions has shown that finding health-related information on the internet clarified many of their concerns and broke the feelings of isolation [16,17]. The same authors also concluded that finding this information online motivated discussions between these patients and their healthcare professionals [16,17]. In the aforementioned study by Lagan et al. [3], around 50% of pregnant women reported that the Internet helped them be better prepared for their next antenatal appointment and feel more involved in the decision-making process.

However, not all types of pregnancy-related topics are uniformly represented online. Globally, there are 2.6 million cases of stillbirth every year [18]. Most of these stillbirths occur in low and middle income countries, where preventive strategies focus on improving care during labour and birth [19]. In high-income countries, the rate of stillbirth (after 28 weeks of gestation) varies from 1.3–8.8 per 1,000 births depending on the country. In Ireland, a stillbirth is defined as an infant born weighing 500 grams or more or at a gestational age of at least 24 weeks who shows no signs of life [20], with a rate of 3.8 per 1,000 births in 2017 [21].

Although not all stillbirths can be prevented, a systematic review published in the Lancet Stillbirth series found that a large proportion of stillbirths in high-income countries are associated with factors that are avoidable [22]. The authors of this systematic review also argue that increased clinical and community awareness of the risk factors associated with stillbirth might improve management and lower stillbirth rates. Despite some existing controversies regarding the modifiable risk factors associated with stillbirth, there is strong evidence suggesting that smoking, high amounts of alcohol drinking, illicit drug use, high BMI, certain sleeping positions, and poor attendance at antenatal care, are associated with a higher risk of stillbirth [23].

Pregnancy could be a teachable moment to motivate women to adopt healthy behaviours and reduce risk-taking [24]. Teachable moments give healthcare professionals an opportunity to inform their patients and utilize the intrinsic motivation associated with them to promote health and wellness [25]. However, information relating to stillbirth is not widely available in general, and healthcare professionals do not tend to discuss stillbirth as a possible outcome of pregnancy with their patients [26], letting this teachable moment pass.

In a national cross-sectional study conducted by Nuzum et al. [27], 56% of participants within the Irish population were not able to identify a single risk factors for stillbirth, demonstrating a lack of public awareness of the prevalence of stillbirth, or potential risk factors associated with it. Nevertheless, 88% of the respondents felt that the possibility of stillbirth should be included in antenatal education programmes [27]. This issue is in keeping with a qualitative study conducted by Kelley and Trinidad [28] which concluded that parents who had experienced stillbirth had no prior knowledge or expectations of stillbirth as a potential occurrence. The women in this study with high-risk pregnancies were concerned about prematurity, but not about stillbirth; they reported that they had never been informed about stillbirth. The authors suggest that the lack of information about stillbirth online could be explained by the taboo and stigmatization surrounding stillbirth with the awkwardness and discomfort that this topic produces in others.

This fact not only hinders possible prevention strategies for stillbirth, but also leaves parents bereaved by stillbirth feeling very isolated. In a qualitative study conducted by Pollock et al. [29], bereaved parents felt that they would have preferred to live with some fear, to be prepared and aware of the risks, rather than have to face the shock and isolation surrounding their loss.

To be able to make informed decisions, women who are planning a pregnancy or are already pregnant need to have access to updated high quality information [3], and, as shown in previous research, the Internet is a source of information commonly chosen by pregnant women. Expectant parents should be aware that stillbirth is a possibility in order to be able to recognize the warning signs, and seek medical attention, before it is too late [30].

Geller, Psaros, & Kerns [31] conducted a study where they systematically assessed several websites targeted at people who had experienced a pregnancy loss. They selected eight high quality websites that were acceptable for women and professionals to use. However, this previous work was neither focused on stillbirth, nor on risk factors for it. In our study, we do not only focus on websites addressed to people who have experienced a pregnancy loss, but also on websites that target the pregnant population in general, and hence can have some influence on the prevention of stillbirth.

The aim of this research was to examine websites targeted at the pregnant population to assess whether or not they had content in relation to stillbirth, and maternal modifiable risk factorsthat are associated with an increased risk of stillbirth. Our research questions were as follows:

(a) How many websites directed at pregnant women, or women who have had a pregnancy loss, contain information about stillbirth?
(b) How many websites directed at pregnant women, or women who have had a pregnancy loss, contain

information about modifiable risk factors for stillbirth?

(c) What are the differences between the different types of websites (e.g.: UK vs. Ireland, General vs. Specialized, type of provider, etc.) in terms of the information provided?

Methods

Context of the study

This study was focused on websites targeted at pregnant women in the Republic of Ireland and the UK, based on the similarities among the antenatal care systems of both countries. In Ireland, all pregnant women and their babies are entitled to access a free programme of care with their General Practitioners (GP) and antenatal hospital services under the Maternity and Infant Care Scheme [32]. This programme includes eleven visits during a woman's pregnancy, which are alternated between visits to the maternity unit/hospital and GP. The care of the women is midwifery-led in cases of normal risk, and a combination of midwifery and obstetrician care is provided in higher risk cases [33]. Similarly, the National Health Service in the UK offers 10 pregnancy appointments to all pregnant women. The care is also midwifery-led combined with GP appointments in normal risk cases, and obstetrician-led care in higher risk cases.

Both antenatal care systems have a similar scheduling for the antenatal visits: first booking visit is recommended between 8 and 12 weeks of gestation; the dating scan is performed from weeks 8–14 in the UK, and 10–14 in Ireland; a fetal anomaly ultrasound scan is offered between weeks 18–22, and monitoring gets more intensive after week 28.

Furthermore, both health services use several modes to communicate their findings; through the publication of reports and reviews (e.g.: the HSE National Reports on Women's Health or the NHS National Maternity Review) and through public health campaigns that can include posters, leaflets and social media messages. (e.g.: the HSE campaign on Fetal Alcohol Spectrum Disorders or the NHS 'Health b4 pregnancy' campaign). Finally, both services direct the pregnant population to their institutional websites which they use to disseminate pregnancy-related information.

Table 1. Website classification categories with definitions.

Category	Value	Definition
Provider	Professional bodies	Websites from official professional organizations
	Charities and voluntary organizations	Websites from public organizations that are registered as charities
	Support groups	Websites created by groups of parents or affected people not registered as charities
	Commercial websites	Websites provided by private companies not including private health providers/insurers.
	Health service websites	Websites from national health providers
	Private health websites	Private websites with the purpose to offer a service or provide information
Country	Republic of Ireland	
	United Kingdom	
Topic/Target audience	General	Websites where the main topic is pregnancy/maternity and which target all pregnant women
	Specialized	Websites where the main topic is pregnancy loss and which target those who have experienced a pregnancy loss
	Other	Websites that do not fit in any of the previous categories, for example, general bereavement support services

Research design

We conducted a quantitative content analysis to answer our research question. Quantitative content analysis provides the researcher with a systematic way of gathering and analyzing text, which can be anything written, visual or spoken, and serves as a means of communication [34]. For the purposes of this study, quantitative content analysis has been used to descriptively examine the content of pregnancy-related websites. The key steps in quantitative content analysis include: developing the research questions and conceptualization of hypothesis, sampling, developing a coding scheme, collecting and coding the data, testing for reliability, and exposing findings and conclusions [35].

Selection of websites and data collection method

One researcher compiled a list of websites from different sources: (1) internet searches; (2) discussions with stakeholders, such as obstetricians, bereavement specialist midwives, allied healthcare professionals, and researchers; (3) links provided in National Bereavement Standards [36]; and (4) hand searches of included websites. All authors also included suggestions after examining the compiled list of websites. Websites were only included if they were in the English language and hosted in the UK or Ireland. The following keywords, used in different combinations, were used to search for relevant websites: 'pregnancy', 'stillbirth', 'stillbirth support', 'stillbirth Ireland', 'stillbirth UK' and 'pregnancy loss'.

Websites were classified into different categories according to: provider, depending on what type of group or organization created the website; hosting country, depending on where the website was created; and topic/target audience, depending on the main focus of the content of the website (Table 1). For more information on what websites were included in each category, please refer to Supplementary Table 1.

A codebook was developed to assign coding values to the different categories of interest (see Supplementary Table 2). Availing of a codebook allows the process of the data coding to be systematic and replicable [35]. The categories included in the codebook were; name and link of website, date websites were accessed, main topic of website (General vs. Specialized), website provider, target audience, hosting country, presence of advertisement, and accreditation from official organizations. In addition, the website content pertaining to basic information about stillbirth was searched for and recorded, including prevalence rates, procedures (e.g. legal procedures after stillbirth, post-mortem examination, etc.), medical or psychological consequences (including; bereavement process, physical changes, health-related associated issues, etc.), and support for parents. Information relating to modifiable risk factors for stillbirth was also included and recorded, specifically that relating to risk factors with a behavioural component (smoking, alcohol and drug use, medicine intake, sleep position, attendance to antenatal care, and weight management). Information about other types of risk factors for stillbirth (e.g.: fetal growth restriction, high blood pressure, placental insufficiency, etc.) was recorded in a general variable, since the focus of this study were modifiable risk factors. Data were considered as absent when no information explicitly linked to stillbirth was found. Information about other types of pregnancy loss, or when risk factors were mentioned without reference to stillbirth, was not included.

Data extraction and analysis

An excel sheet was used to record the information obtained through the data collection process. Required information was searched for in each of the different websites, and recorded as per the codebook in the excel sheet. If the information was explicitly expressed in the body of the website, it was coded as present. However, if the data were not found after utilizing the website's own navigation panel and the website's search box (when available) with the terms stillbirth, stillborn, pregnancy loss, and loss, it was then marked as absent. The data were recorded by the main author between May 2019 and July 2019. Given the nature of websites, content can be updated regularly. Therefore, screenshots of the information on the date websites were accessed were taken, and stored in NVivo V12. The second author reviewed the Nvivo V12 file, including the screenshots, for consistency, and any discrepancies were discussed. Data were analysed using descriptive statistics and the analysis was conducted using SPSS statistical software v.25.

Results

A total of 92 websites were included in this study, of which 39.1% ($n = 36$) websites were hosted in the UK and 60.9% ($n = 56$) in the Republic of Ireland. The websites were divided into the following categories of websites, depending on the provider: professional bodies' sites (8.7%, $n = 8$), charities and voluntary organizations sites (30.4%, $n = 28$), support groups sites (13%, $n = 12$), and commercial sites (16.3%, $n = 15$), health services sites (14.1%, $n = 13$) and private health sites (17.4%, $n = 16$) (See Table 2). Regarding the classification per topic or targeted audience, the websites were divided as follows: specialized websites (32.6%, $n = 30$), general websites (63.0%, $n = 58$), and other (4.3%, $n = 4$) (See Supplementary Table 1).

At least one positive result relating to basic information about stillbirth was present in 39.1% ($n = 36$) of the included websites, with information about support for families (30.4%, $n = 28$) and prevalence (25.0%, $n = 23$) being the most common topics. Almost 12% ($n = 11$) of the 92 websites contained all the basic information about stillbirth that was sought. Information regarding modifiable risk factors was found in 29.3% ($n = 27$) of the websites, with smoking being the most common risk factor mentioned (26.1%, $n = 24$), followed by illicit drug intake (15.2%, $n = 14$) and sleep position (14.1%, $n = 13$).

Only one of the 92 websites contained all the information that was sought pertaining to basic information about stillbirth and associated modifiable risk factors (see Figure 1).

When examining the websites by provider, as outlined in Table 2, websites classified as charities were more likely to contain basic information about stillbirth (39.3%, $n = 11$) than any other provider, followed by commercial sites (53.3%, $n = 8$) and support groups sites (58.3%, $n = 7$). Support for families was the most common topic, regardless of the provider. Websites hosted by support groups and commercial sites were the most likely to report on emotional or physical consequences after a stillbirth (41.7%, $n = 5$ and 46.7%, $n = 7$ respectively). On the other hand, charities and support groups focused on reporting stillbirth prevalence (32.1%, $n = 9$ and 41.7%, $n = 5$ respectively). Only two (25%) of the eight professional bodies' websites contained some basic information about stillbirth, focusing equally on prevalence, causes, consequences and support for families (12.5%, $n = 1$). Seven (53.8%) of the health services websites contained some basic information about stillbirth focussing mostly on offering support for families (46.2%, $n = 6$); and only one (6.3%) of the private health sites contained some basic information about stillbirth, also giving information on support for families.

When looking specifically at information about modifiable risk factors for stillbirth by provider,

Table 2. Information depending on provider.

		Websites $n = 92$ (%)	Professional bodies $n = 8$(8.7)	Charities $n = 28$ (30.4)	Support groups $n = 12$ (13.0)	Commercial websites $n = 15$(16.3)	Health services $n = 13$ (14.1)	Private health websites $n = 16$(17.4)
Basic information about stillbirth	Prevalence	23(25.0)	1(12.5)	9(32.1)	5(41.7)	5(33.3)	3(23.1)	0(0.0)
	Causes	16(17.4)	1(12.5)	8(28.6)	2(16.7)	3(20.0)	2(15.4)	0(0.0)
	Procedures	16(17.4)	0(0.0)	7(25.0)	3(25.0)	3(20.0)	3(23.1)	0(0.0)
	Consequences	22(23.9)	1(12.5)	7(25.0)	5(41.7)	7(46.7)	2(15.4)	0(0.0)
	Support families	28(30.4)	1(12.5)	10(35.7)	4(33.3)	6(40.0)	6(46.2)	1(6.3)
Information about behavioural risk factors	Smoking	24(26.1)	1(12.5)	7(25.0)	1(8.3)	7(46.7)	5(38.5)	3(18.8)
	Drug use	14(15.2)	1(12.5)	6(21.4)	0(0.0)	3(20.0)	3(23.1)	1(6.3)
	Medicine intake	4(4.3)	0(0.0)	1(3.6)	0(0.0)	2(13.3)	0(0.0)	1(6.3)
	Sleep position	13(14.1)	1(12.5)	6(21.4)	0(0.0)	5(33.3)	1(7.7)	0(0.0)
	Antenatal attendance	9(9.8)	0(0.0)	5(17.9)	1(8.3)	1(6.7)	2(15.4)	0(0.0)
	Alcohol	17(18.5)	1(12.5)	6(21.4)	0(0.0)	6(40.0)	3(23.1)	1(6.3)
	Weight	14(15.2)	1(12.5)	4(14.3)	1(8.3)	5(33.3)	3(23.1)	0(0.0)

websites hosted by commercial sites were the most likely to contain information about at least one risk factor (53.3%, $n = 8$), followed by the sites hosted by charities (28.6%, $n = 8$). Only two (25%) websites hosted by professional bodies and one (8.3%) website classified as a support group contained information regarding at least one modifiable risk factor for stillbirth. Most websites focused their content on smoking (25%, $n = 7$ for charities; 46.7%, $n = 7$ for commercial sites; 38.5%, $n = 5$ for health services sites and 18.8%, $n = 3$ for private health sites). Medicines intake was the least represented risk factor.

When comparing the websites by country, websites hosted in the UK were more likely to report basic information about stillbirth than Irish websites (55.6%, $n = 20$ vs. 28.6%, $n = 16$, $p = 0.010$). Websites hosted in the UK were also more likely to contain information about modifiable risk factors (41.7%, $n = 15$ vs. 21.4%, $n = 12$, $p = 0.037$). Regarding other types of risk factors, there were no differences between the UK websites and the Irish websites (36.1%, $n = 13$ vs. 23.2%, $n = 13$, $p = .180$). (see Figure 2). As mentioned previously, the websites were also categorized by topic. Specialized websites (websites targeting people who have experienced a pregnancy loss) were more likely to contain basic information about stillbirth compared with general websites (46.7%, $n = 14$ of 30 vs. 36.2%, $n = 21$ of 58), however, this difference was not statistically significant ($p = 0.533$). On the other hand, there were differences observed between the groups of websites when examining information regarding modifiable risk factors (13.3%, $n = 4$ of 30 vs. 39.7%, $n = 23$ of 58, $p = 0.015$) (See Figure 3).

A large proportion of the websites contained external links to either professional guidelines, patient information leaflets, or other websites. External links providing basic information about stillbirth were present in 43.5% ($n = 40$) of the websites, whereas external links containing information about modifiable risk factors were present in 21.7% ($n = 20$). Only 13 (23.2%) out of 56 websites not containing any basic information about stillbirth provided external links with this information. Seven (10.8%) out of 62 websites without information about any modifiable risk factor provided external links with this information.

Most of the external links provided redirected the user to other websites for both types of information (30.4%, $n = 28$ in the case of basic information about stillbirth, and 13%, $n = 12$ in the case of information about modifiable risk factors (see Graph 2)). However, clinical guidelines were frequently linked when providing information about risk factors (6.5%, $n = 6$), whereas patient information leaflets were linked when providing basic information about stillbirth (8.7%, $n = 8$) (see Figure 4).

Discussion

The purpose of the current work was to examine a list of websites targeted at the pregnant population and hosted in the Republic of Ireland and in the UK in order to assess their content in relation to stillbirth, and maternal modifiable risk factors in pregnancy that have been previously associated with a higher risk of stillbirth. The results of the study illustrate that less than half of websites contained basic information about stillbirth, and approximately 30% contained information on at least one of the modifiable risk factors examined. However, only one website contained all the information that was specifically searched for.

The websites that contained information about stillbirth predominantly provided information on the prevalence of stillbirth and supports for families who are bereaved. Providing data about the prevalence of stillbirth is very valuable as demonstrated in a previous qualitative study conducted by Kelley & Trinidad [28]; which shows that parents who had experienced a stillbirth were surprised to learn both the rates of stillbirth worldwide and also the rate in their high income country.

The fact that websites include data about the prevalence of stillbirth in high income countries can have a positive impact on pregnant women's behaviours, since it could prevent biased beliefs such as thinking

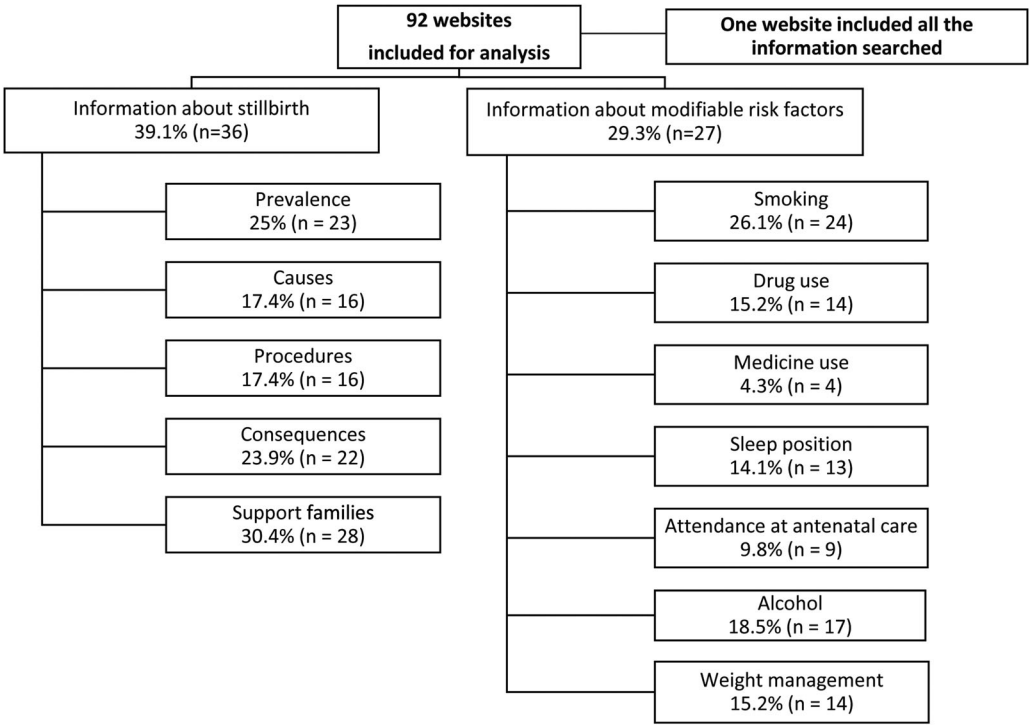


Figure 1. Information searched on the websites and prevalence of appearance. *Categories are not mutually exclusive.

that stillbirth only happens in developing countries [28]. However, providing women with this information alone is not enough, given that the most successful communication behaviour change interventions use three or four categories of communication techniques engaging participants at different levels [37]. Hence, more comprehensive communication strategies are necessary.

Research shows that there are several maternal modifiable risk factors associated with stillbirth and other adverse perinatal outcomes [23]. Our study found that these websites focus their efforts on informing the public about the risks of smoking and illicit drug use during pregnancy. Providing this information to women is very positive since there is evidence associating these behaviours with a higher risk of stillbirth and other adverse pregnancy outcomes, and considering that many women use the internet to access pregnancy-related information in the antenatal period [11]. However, as this study illustrates, there are other maternal modifiable risk factors that have also been associated with a higher risk of stillbirth which are not included in website content. For example, the evidence related to the risk of stillbirth and the intake of over-the-counter medicines, herbal supplements and/or micronutrient supplements is very limited and conflicting [23], yet this information is not present in most of the websites, leaving women potentially uniformed.

Another issue of concern is that only two out of the eight of the professional bodies' websites

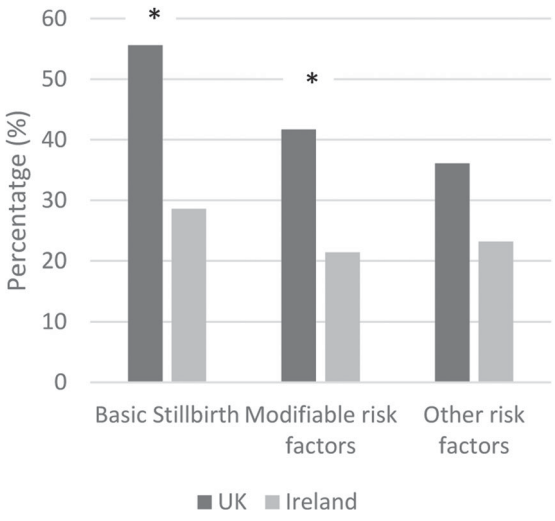


Figure 2. Information by country.

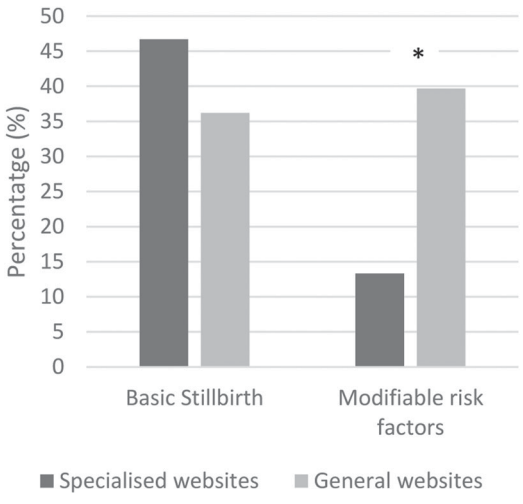


Figure 3. Information by topic.

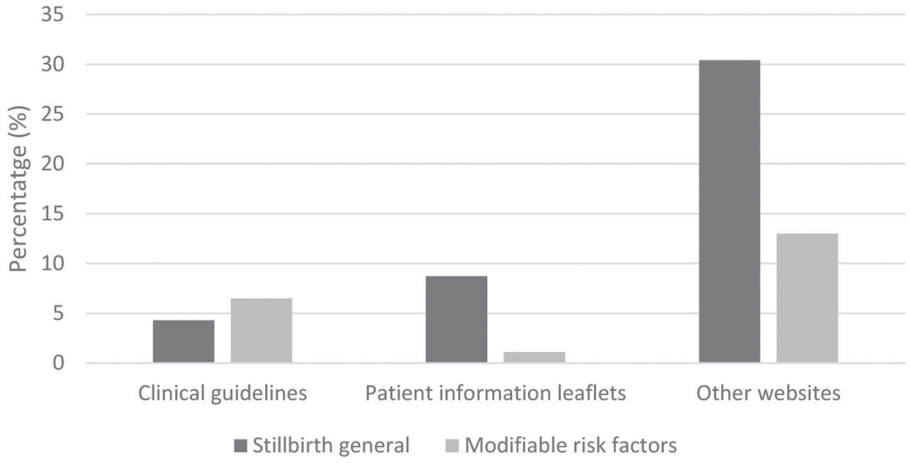


Figure 4. Types of external links used.

contained some basic information about stillbirth, and just two contained information about risk factors. These websites tend to use links to clinical guidelines instead of summarizing the information, and/or adapting it for the general public, within the body of their websites. While these guidelines may contain rich evidence-based information, they need to be up-to-date, as well as user-friendly and adapted to the general population, to be able to serve as an informative tool [38]. For other types of website sources, using links to clinical guidelines might be due to a lack of expertise in the area, resulting in them referring to appropriately endorsed guidelines and recommendations.

This issue raises further questions relating to the reliability of information obtained online [39–42]. It is the official organizations' responsibility to disseminate their research efforts and provide evidence-based information. Dobbins et al. [43] conducted a review of the literature to identify any available tools that assessed reliability of websites in a quick and easy-to-use manner. The authors concluded that the tools available had poor reliability, or had not been assessed for reliability. As a result, women have few resources available to assess the reliability of the information they are obtaining, besides the reassurance of using websites provided by official institutions that follow national guidelines when providing advice. However, as per our own experience, navigating these websites and their clinical guidelines is not easy, which potentially can lead users to more attractive websites in terms of layout, ease of navigation, level of interaction, etc., but that might be providing unreliable information.

When comparing the specialized websites (those focused on pregnancy loss) to general pregnancy-related websites, there were no differences regarding the basic information provided about stillbirth. However, general websites targeting all pregnant women tended to give information about modifiable risk factors more often than specialized websites. Having specialized websites giving information about stillbirth and bereavement support is very positive. Nevertheless, by not providing information about modifiable risk factors it seems that there is a lack of recognition from these specialized websites that women who have already experienced a stillbirth have a higher risk of stillbirth in their subsequent pregnancies [44], and hence, the need to inform these women about modifiable risk factors is even more relevant.

There are some limitations to this study. The website search was done manually and limited to the United Kingdom and the Republic of Ireland. However, we consider that this kind of search simulates what an internet user would do. The search for the information in the websites was done systematically page by page. As mentioned previously, there is not a wide recognition of stillbirth, and people tend to avoid hearing or speaking about it [26]. Further, previous research indicates that people seeking health information on the internet do not have a systematic plan [45]. Hence, as per our own experience navigating the websites, and previous studies conducted in the area of online health information seeking behaviour [46,47], we can assume that it is even less likely that pregnant women accessing these websites find the information relating to stillbirth or risk factors, unless they are specifically looking for it.

The findings of our study have several implications. Firstly, maintaining the silence around stillbirth hinders potential preventive strategies. Not giving attention to the fact that stillbirth can happen, and that there are measures that may reduce the risk, not only feeds into the stigma of stillbirth [29], but also promotes an altered perception of risk or a biased belief that 'this only happens to other people' [28,48]. Knowledge and education are not enough to change behaviour; however, this is the first step in most instances. It is essential that people are educated, not only to be aware of risk factors associated with stillbirth, but also

to understand why and how behaviour change is important [49]. Hence, by not using these websites to clearly inform people about stillbirth and the relevant modifiable risk factors, the opportunity to inform and empower them is lost.

Clear and effective communication in healthcare settings and in public health is essential and can have an effect on health outcomes [50,51]. To avoid misinforming the public, it is important to use the right terms and avoid euphemisms, for example using the word 'stillbirth' instead of 'loss'. Euphemisms are often used as a way to avoid talking about a topic that the speaker would rather avoid, normally in response to taboos [52]. Previous research in the field of palliative care shows that using misleading language to avoid causing pain denies that person the opportunity to prepare for the next steps [53]. Using clear language would avoid confusion and help give visibility to the fact that stillbirth can happen and have very serious consequences. On the other hand, one of the most important things to consider is to make sure the information is not only accurate but also user-friendly. Women need to be able to find and understand relevant information easily. Use of a strategic communication framework to ensure effective communication, such as the one proposed by the WHO, could be of use [54]. This framework can be used as a resource for the development of communication strategies, based on the principles of effective communication: accessibility, actionability, credibility and trustworthiness, relevance, timeliness and understanding.

There is evidence that people use the internet to find health-related information [2]. This information can subsequently influence their decision-making [3] and can have preventive effects for certain issues [13–15]. Hence, it is important to break the silence on stillbirth and make sure women can avail of reliable sources of information to make informed decisions, not only during their pregnancies, but also when they are planning their first or subsequent pregnancy. Currently, we are not aware of what sources of information people use to educate themselves about stillbirth, so further qualitative and quantitative research is necessary to identify these sources of information and improve information provision to parents.

Ethical approval

No ethical approval was sought or necessary for the completion of this evaluation.

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