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To Grasp the Unexpected

*Information Following a Prenatal Diagnosis of
Congenital Heart Defect in the Fetus*

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Abstract

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The aim was to explore experiences and needs of information following a prenatal diagnosis of congenital heart defect, and to assess the quality of publicly available information websites about congenital heart defects. Study I was a qualitative interview study that explored experiences among 11 parents to prenatally diagnosed children. Respondents tried to grasp the facts today while reflecting on the future, and personal contact with medical specialists was valued. The analysis showed that the Web contained an overwhelming amount of information. Study II was a qualitative interview study that explored experiences among 26 females and males 5-15 weeks after a prenatal diagnosis. Respondents hunted for information in a confusing reality, with a need for information about various topics and methods for information delivery. Although high satisfaction with the specialist information was described, the information was considered overwhelming and complex. Supplemental information was sought via the Web. Insufficient information about induced abortions was described. Study III was a quantitative study that explored content and quality of 67 English websites about congenital heart defects. Few websites included information about prenatal aspects, such as pregnancy termination. The overall quality was poor, especially reliability and information about treatment choices. Study IV was a mixed methods study that explored the quality of 10 Swedish websites about congenital heart defects, from the perspectives of 9 assessors with personal experience of a prenatal diagnosis. Quantitative Likert scale assessments were followed by written open-ended questions and focus group discussions. Quantitative assessments represented unfulfilled quality criterion for treatment choices, and partially fulfilled quality criteria for appearance, details, relevance, suitability and overall quality. Websites had significantly different scores for all investigated quality criteria. Various issues were highlighted in the responses to the open-ended questions and during the discussions, including inappropriate advertisements, biased information, poor illustrations, complex language and poor trustworthiness. In conclusion, expectant parents faced with a prenatal diagnosis of congenital heart defect in the fetus try to grasp the unexpected, an attempt that involves difficulties in relation to information. These are present during the consultation with health professionals and when searching for web-based information.

Keywords: Congenital Heart Defects, Consumer Health Information, Internet, Popular Works, Prenatal Diagnosis, Website Quality

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List of papers

This thesis is based on the following papers, which are referred to in the text by their Roman numerals.

- I Carlsson, T., Bergman G., Melander Marttala U., Wadensten, B., Mattsson E. (2015) Information following a diagnosis of congenital heart defect: Experiences among parents to prenatally diagnosed children. *PLoS One*; *10*(2):e0117995.
- II Carlsson, T., Bergman, G., Wadensten, B., Mattsson, E. (2016) Experiences of informational needs and received information following a prenatal diagnosis of congenital heart defect. *Prenatal Diagnosis*; *36*(6):515-22.
- III Carlsson, T., Bergman, G., Karlsson, AM, Mattsson, E. (2015) Content and quality of information websites about congenital heart defects following a prenatal diagnosis. *Interactive Journal of Medical Research*; *4*(1):e4.
- IV Carlsson, T., Melander Marttala, U., Wadensten, B., Bergman, G., Axelsson, O., Mattsson, E. (2017) Quality of Patient Information Websites About Congenital Heart Defects: Mixed-Methods Study of Perspectives Among Individuals With Experience of a Prenatal Diagnosis. *Interactive Journal of Medical Research*; *6*(2):e15.

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Background

Prenatal diagnosis of a fetal anomaly

Congenital heart defects

During pregnancy, fetuses may develop congenital heart defects, defined as malformations of the heart and great vessels. Congenital heart defects are the most common of all congenital anomalies,^{1,2} with a reported global incidence between 4 to 50 cases per 1,000 live births.^{3,4} There is a wide range of congenital heart defects, spanning from small lesions that heal spontaneously to complex malformations that require surgical interventions and lifelong treatment.^{5,6} The reported incidence of the severe types of defects that require expert cardiologic care is approximately 2.5 to 3.0 per 1,000 live births.³ There is a known association between congenital heart defects and chromosomal anomalies.³ Approximately 12 percent of all cases have an associated chromosomal anomaly.⁴ Congenital heart defects may be detected with routine obstetric ultrasound examinations, which are integral parts of antenatal care in many countries,⁷ and prenatally diagnosed with fetal echocardiography, a diagnostic tool that evaluates the function and structure of the heart and great vessels of the fetus.⁸ In Europe, approximately one in five cases are prenatally diagnosed. However, this number varies depending on the severity of the defect, from 64 percent in the most severe types to 9 percent in the least severe.⁴ Prenatal detection rates have increased over the years, most likely due to a gradual introduction of routine screening of fetal hearts with the four-chamber view at the second-trimester obstetric ultrasound examination.^{9,10} Univentricular defects, tetralogy of fallot, and transposition of the great arteries are the most common types of prenatally diagnosed congenital heart defects.¹¹

If a congenital heart defect is detected during pregnancy, expectant parents, together with specialist health professionals, have time to plan for the birth and postnatal management.¹² A prenatal diagnosis may positively influence postnatal morbidity of children born with birth defects. Studies have shown that prenatally diagnosed newborns suffer less preoperative acidosis and organ compromise, in comparison to their postnatally diagnosed counterparts. Moreover, they are less likely to require inotropic support, fluid therapy, ventilatory support, and emergency surgery or preoperative catheterization.¹³ Research also indicates that newborns with prenatally diagnosed

hypoplastic left heart syndrome are put on prostaglandin infusion more readily after the birth and suffer from fewer neurological complications, in comparison to postnatally diagnosed newborns.¹⁴ Although it is possible that a prenatal diagnosis may improve postnatal mortality, there is an overall lack of sufficient research to draw firm conclusions.¹² Research indicates that, when adjusting for comparable anatomy and parental wishes concerning postnatal treatment, prenatally diagnosed newborns are significantly less likely to die in the preoperative time period.¹⁵ Among infants diagnosed with transposition of the great arteries, those with prenatal diagnosis may suffer from less pre- and postoperative mortality.¹⁶ When a prenatal diagnosis is made, the birth may be planned to take place in proximity to a specialized cardiac centre, where appropriate surgical treatment is available. This, in turn, has been shown to improve the outcomes for newborns with congenital heart defects.¹²

Experiences of pregnancy and prenatal screening

The journey towards parenthood is a process of a life-transforming transition for pregnant persons,¹⁷ involving both physical and psychological changes as the pregnancy progresses.¹⁸ Parental identity and attachment to the fetus is a growing process during the course of pregnancy, with increased awareness and attachment during the second trimester.^{19–22} Worries about the health of the expected child are common, and expectant parents consider these thoughts to be a normal part of the process of expecting a child.²³ Research has shown that expectant parents who are partners of the pregnant person move through a process of involvement and psychological adaptation during the course of pregnancy.²⁴ When obstetric ultrasound examinations in the second trimester of pregnancy are offered routinely, the vast majority of expectant parents accept and find the decision to attend the examination easy to reach,²⁵ consider the decision an obvious choice, and suppress fears of adverse findings.²⁶ Furthermore, they have optimistic expectations of the examination, viewing it as a confirmation of the health of the fetus and an enjoyable social event.^{27–33} They regard and value the examination as a tool that allows them to hear the heartbeat of their expected child, see their expected child move in the uterus, and gain knowledge about the biological sex of the expected child.³⁴ Expectant parents who are partners of the pregnant person want to be included in pregnancy-related activities³⁵ and consider the obstetric ultrasound examination as an important step towards parenthood.^{35–37} However, conflicting results have been presented about the effect the examination may have on prenatal attachment, as some studies suggest increased attachment^{30,38} while others report no difference in comparison to controls.²¹ According to qualitative studies, obstetric ultrasound examinations contribute to the realizations of the pregnancy and parenthood,^{26,39}

evoking thoughts about the expected child, life situation, parenthood, and childbirth.³⁹

Experiences following a prenatal diagnosis of fetal anomaly

Many expectant parents attend the obstetric ultrasound examination without knowledge regarding the medical purpose of the examination.^{27,40} Thus, they are often unprepared for a prenatal detection of a fetal anomaly.^{30–32,34,41–43} A prenatal diagnosis of a fetal anomaly is as a traumatic life event for expectant parents,³⁰ and involves various psychological consequences, such as acute grief reactions,^{44,45} anxiety,^{46,47} depression,⁴⁷ confusion,³¹ and psychological distress.^{31,44,48–51} It entails a number of potential personal losses, including loss of the prospect of a healthy child and loss of joy over the pregnancy.^{30,42} Relatively few studies have investigated the psychological reactions of expectant parents who are partners of the pregnant person carrying a fetus with a prenatally diagnosed anomaly.^{37,44,45,50,52–54} Research indicates that they experience high levels of psychological distress and depression when faced with the news.^{37,50,53,54}

A number of decisions are set in motion following a prenatal diagnosis, the most immediate being whether to continue or terminate the pregnancy.³⁰ The legal availability of pregnancy termination varies greatly worldwide. In 2011, approximately half of the world's countries permitted induced abortions due to a fetal anomaly.⁵⁵ In Europe, the number of terminated pregnancies due to a fetal heart defect is approximately 31 percent for cases without associated chromosomal anomaly and 48 percent for cases with associated trisomy 21.⁴ Various aspects have been identified that influence the decision to continue or terminate the pregnancy. Identified aspects related to the expected child include severity of the anomaly,^{4,56–58} prognosis,³⁰ possible postnatal pain,⁵¹ and presence of associated chromosomal anomalies.^{57,58} Identified aspects related to pregnant persons and their families include gestational age at diagnosis, country of origin,^{57,58} socioeconomic considerations, religious background, maternal age, difficulties to conceive,⁵⁶ availability and acceptability of legal pregnancy termination, perspectives on the ability to parent a disabled child, as well as the effect on other children, marriage, or family life.³⁰ The decision may involve ethical dilemmas of life and death.⁵⁹ In order to reach a decision, individuals faced with a prenatal diagnosis often have to confront their values regarding disabilities, parenthood, and induced abortion. Expectant parents who are partners of the pregnant person perceive the decision as the rights and responsibility of the pregnant person, and tend to agree with their decision.³⁰

The decision is regarded as very difficult among pregnant persons who terminate the pregnancy,^{56,60} who report the decision as being significantly more difficult than those who continue the pregnancy.⁵⁶ However, most of those who terminate believe that they reached the right decision in retro-

spect.^{44,56,61,62} These persons experience high levels of psychological distress at the time of the diagnosis^{44,49} and regard the abortion as an emotionally painful experience.⁶²⁻⁶⁴ Studies indicate high levels of symptoms for post-traumatic stress, depression, similar grief reactions to those of spontaneous perinatal losses,⁴⁴ and psychological distress months to years after the abortion.^{61,65,66} Pregnant persons who terminate a pregnancy due to a fetal anomaly describe a long process of personal loss and keep longing for a child that was never born.^{62,67}

Few studies have investigated the psychological situation of expectant parents who continue the pregnancy after a prenatal diagnosis.⁴⁴ Among Swedish pregnant persons with a prenatal diagnosis of fetal anomaly and continued pregnancy, 37% show depressive symptoms and many experience major worries.⁶⁸ On the other hand, many describe that the diagnosis prepared them for the birth.⁶⁹⁻⁷¹ During the remainder of the pregnancy, expectant parents deal with a continuous flow of information and express fears of the possibility of a pre- or postnatal loss of the expected child. They also express intensified parental feelings and duties towards the unborn child.⁴²

Decision-making and communication following a prenatal diagnosis

Reaching informed health-related decisions

The decision to continue or terminate a pregnancy following a prenatal diagnosis of a fetal anomaly differs from other types of health-related decisions,³⁰ as it also involves considerations and implications related to the moral status of the fetus, its potential rights, viability, and whether or not it should be regarded as a patient. Such considerations may be put against the autonomy of the pregnant person.⁵⁹ Respect for autonomy of the pregnant person and offers of adequate information are stressed as essential aspects in the clinical encounter, in order to strive for and achieve informed decisions following a prenatal diagnosis.⁵⁹ In countries such as Sweden,⁷² pregnant persons have the legal rights to decide upon pregnancy termination until certain limits in gestational age. It is the responsibility of the health professionals to protect their rights and help them reach an informed decision that is grounded in their own preferences.⁵⁹ Moreover, expectant parents who are partners of pregnant persons may wish to be involved in the decision-making and could be in need of professional support.^{37,50,53,54} The majority of pregnant persons faced with a prenatal diagnosis report that their partners influenced their decision,⁵⁶ illustrating the importance of including such persons when offering information. In this thesis, 'patient information' refers to information directed towards all expectant parents faced with a prenatal diagnosis of a congenital heart defect in the fetus.

Patients regard information as a key aspect of their care, and place great value on the information received from health professionals.⁷³⁻⁷⁶ They consider health professionals experts, who they feel are able to provide them with full explanations. Patients desire to be involved in mutual discussions concerning health-related decisions related to their situation.⁷³ Supportive and patient-centered communication between patients and health professionals leads to greater patient satisfaction,⁷⁷⁻⁸¹ recall of information provided,⁷⁷ and psychological adjustment.^{81,82} However, discouraging findings have been reported concerning communication between patients and health professionals, calling attention to the various issues related to patient information. Patients report difficulties communicating with health professionals,⁸² may misunderstand the information provided during medical consultations,⁸³ are at risk to feel insufficiently informed,^{84,85} and may have incorrect knowledge concerning their health conditions or treatments.⁸⁶ Health professionals can overestimate how well patients understand them,^{83,84,86} and may fail to address the topics related to individual preferences, needs and values of their patients.^{84,87} Poor communication with health professionals is an identified complaint among patients,⁸⁸ and is associated with malpractice claims.^{89,90}

As a response to the growing interest in patient communication, enactments and policies have been implemented in many countries around the world, with the purpose to promote informed decisions.⁹¹⁻⁹³ Informed decision-making concerns the possibilities for patients to act independently and reach a decision based on free choice.⁹⁴ Sufficient information and successful exchange of information are central aspects.⁹⁵ Informed decisions relies on offers of information and use of interventions that support the internal processes associated with the decision-making.^{94,96} Such decisions foster acceptance of uncertainty, patient empowerment, and trust between health professionals and their patients.⁹⁷ Because of the preference-sensitive nature of reproductive health decisions and necessary efforts to optimize patient satisfaction, informed decisions are key aspects in obstetric practices.⁹⁸

Health literacy involves the skills to access, process, and interpret information to make health-related decisions.⁹⁹ Low health literacy is associated with less health-related knowledge, more hospitalisations,¹⁰⁰⁻¹⁰² and poor ability to understand health messages.¹⁰⁰ According to information processing theories, all humans have a restricted capacity to take in and store information presented to us. Because of the immense amount of information presented to us, our brains automatically sort, ignore, and lose information through its natural processes.^{103,104} Information processing can be enhanced by repetition,¹⁰³ dividing information into smaller segments, and presenting it in various formats.¹⁰⁴ However, there is a limitation to the capacity of storing information through rehearsal. Eventually, memory is either decayed, or moved to the long-term store, which holds memories in a more permanent state.¹⁰³ Research has shown that people have difficulties recalling the in-

formation provided during consultations with health professionals within several fields, such as oncology,⁷⁶ primary care,¹⁰⁵ and paediatrics.¹⁰⁶

Communication barriers may act as a hindrance to informed decisions. Barriers related to patients may involve sociocultural background,^{94,107,108} previous knowledge,¹⁰⁹ language competency,¹⁰⁸ as well as their psychological^{107,109} and physical state.¹⁰⁷ Barriers related to interactions between health professionals and patients may involve differences in culture,^{107,109,110} education, and experience,¹⁰⁷ as well as possible power structures.¹⁰⁹ Barriers related to health professionals may involve use of medical jargon or other difficult language,^{109,111} poor communication skills with less focus on holistic care, non-disclosure of information, discouragement of patient collaboration,¹¹² reluctance to discuss certain topics,^{112,113} lack of empathic attitude, failure to address patient concerns,¹¹¹ lack of eye contact,¹¹⁴ and poor use of non-verbal communication.¹¹⁵ The environment in which the encounter takes place may serve as a barrier,¹⁰⁷ as patients may feel unaccustomed to hospital settings.¹⁰⁹ Institutional barriers may also affect communication, such as insufficient time and lack of private rooms.¹⁰⁸ Typically, communication barriers exist in complex combinations, closely related to the circumstances associated with encounters between health professionals and patients.¹⁰⁷

When a health-related finding is identified, such as a prenatal diagnosis of fetal anomaly, health professionals need to break the bad news to their patients, defined in the literature as ‘any information likely to alter drastically a patient’s view of his or her future’.¹¹⁶ As such, the severity of the news depends greatly on how it is perceived by the person receiving the news.¹¹⁷ Initiatives have been launched with the purpose of providing health professionals with recommendations of how to communicate bad news, stressing the importance of offering sufficient information in clinical encounters with patients.^{118,119} Breaking bad news entails a balancing act of offering information while still sustaining a sense of hope¹⁰⁸ and avoiding exacerbating possible discomforts associated with receiving the news.¹¹⁷ Health professionals who work with breaking bad news stress the importance of communication, in order to adequately assess patients’ current knowledge, wishes and needs.^{108,117,118} Thus, they need to adjust their communication depending on the emotional reactions patients experience when told about the news, a task which many consider difficult.^{108,118}

Information following a prenatal diagnosis

Following the initial psychological shock when faced with a prenatal diagnosis of fetal anomaly, expectant parents move to a phase of trying to gain meaning and knowledge.^{28,43,52} They seek information to reach, affirm, and come to terms with a decision of whether to continue or terminate the pregnancy, as well as to learn about or verify the diagnosis.³⁰ Information through counseling sessions with health professionals becomes a key component to support expectant parents in their efforts to understand their unfamiliar situation.¹² According to Allan and Huggon, the four aims of counseling in connection to a prenatal diagnosis of congenital heart defect in the fetus are to establish an accurate diagnosis, offer clear and truthful information about the prognosis, present management and available treatment choices, and help them reach a decision concerning which option is best for them.⁵ Health professionals who work with counseling expectant parents faced with a prenatal diagnosis of fetal anomaly regard their role as bearers of information, and stress the importance of supporting the decision reached by the expectant parents.¹²⁰

Expectant parents regard both the content of the information and the methods of information delivery as important aspects at the time of diagnosis.^{121,122} However, it has previously been observed in Swedish settings that expectant parents faced with a prenatal diagnosis feel ignored concerning their informational needs. Further, they express that their emotional state is not taken seriously enough by health professionals.³¹ Research has identified differences in individual preferences for information following the diagnosis. While most are information seekers with great needs of information to maintain emotional control, others try to avoid information, accept the situation without a felt need to ask questions,^{28,34,123} and experience anxiety when presented with more information than what they feel able to handle.^{34,123} Therefore, tailoring information to accommodate individual coping styles may be required in order to promote patient-centered care.^{123,124}

Conflicting results have been reported regarding the satisfaction with information offered in consultations following a prenatal diagnosis of fetal anomaly. Some research indicates that most expectant parents consider that they had enough time to reach a decision⁵⁶ and are satisfied with the information provided during the initial consultation.^{49,69,122,125} On the other hand, other research indicates that expectant parents consider one consultation insufficient to gain a complete understanding of the anomaly,^{42,57} and that they experience difficulties in comprehending the information offered during the consultation.¹²⁶ In addition, studies show that pregnant persons feel a need for more information than what they received during their consultations,^{47,125} and that one quarter of those who terminate their pregnancy regard the information as insufficient to reach an informed decision.⁵⁶ A possible explanation of the difficulties related to informational uptake may be

that emotional reactions causes confusion.^{31,51,126} Studies have shown that counseling after a prenatal diagnosis of fetal anomaly reduces anxiety^{127,128} and increases the expectant parent's confidence in their health professionals.³⁴

Overall, there is a lack of research that explores appropriate techniques for counseling following a prenatal diagnosis of congenital heart defect in the fetus.¹² Thus far, much of the work in clinical settings is based on basic principles, as well as the personal experience and training of the counselor.¹² In summary, these principles suggests that counselors should offer timely information in an empathetic and sensitive manner, with honest, detailed and straightforward information about the anomaly and available options.³⁴ Prompt, high-quality information is considered of great importance after the diagnosis.¹²² Information provided on the same day as the diagnosis may help expectant parents to cope with the situation, and those who experience a delay in time between diagnosis and information may feel neglected by their health professionals.³⁴ Expectant parents faced with a prenatal diagnosis desire honest information, as uncertainty increases their anxiety further.³¹ Clinical guidelines recommend that expectant parents faced with a prenatal diagnosis should be informed about the prognosis, the possibility for pregnancy termination, as well as available postnatal palliative care. Moreover, these guidelines recommend that the focus of the counseling should be to offer unbiased information, so as to support the expectant parents' own rights to reach an informed decision regarding which alternative best suits their situation and preferences.¹² Expectant parents regard the language used by the counselor as an important aspect in the clinical encounter,¹²² giving great significance to phrasing and words.^{34,122,129} Written supplemental information is suggested as a beneficial way to improve the communication.³⁴

Web-based information following a prenatal diagnosis

Access, use, and structure of the Web

The Internet makes it possible for people to participate in communication and partake in information at a global scale.¹³⁰ The World Wide Web, or 'the Web' for short, is a part of the Internet that contains a great amount of various websites, defined as a collection of linked web pages.¹³¹ Research indicates that the Web is used as a source of supplemental information among parents to children with congenital heart defects^{132,133} and among persons faced with a prenatal diagnosis of fetal anomaly.^{134,135} Current clinical guidelines in fetal cardiology recommend that health professionals acknowledge the Web as a potential source of information, and that they are prepared to answer questions concerning web-based information.¹² However, research

indicates that parents of children with congenital heart defects rank the importance of information about websites higher than cardiologists rank providing such information.¹³⁶

Worldwide, the Web has grown to become a large and commonly used source of health-related information.^{137,138} The majority of the population in developed countries use the Web to search for health-related information.^{137–}

¹³⁹ Europe has seen a significant growth in the use of the Web for health purposes, and many people in the European population view it as an important source of health-related information.¹³⁸ The use for health-related information is especially high among young adults.¹³⁹ Reasons for using the Web to find health-related information vary. Many use it as an initial source for health-related information, to gain knowledge about a specific health condition and decide whether or not it requires professional attention.¹³⁷

Others use it because they consider the communication with their health care providers as insufficient, or in order to verify and disprove the information received from health professionals. Web-based health-related information is used in the everyday lives of laypersons, as a way for them to immerse themselves in a great volume of available information and gain control of their own health circumstances.¹⁴⁰ The use of the Web to find health-related information is greater among people with high education and income. Furthermore, more males than females use it for general purposes, while more females than males use it for health-related purposes.^{137,138} Pregnant persons frequently use the Web as a source for information about fetal development, pregnancy complications, and antenatal care.¹⁴¹ A Swedish study conducted in 2004 observed that the large majority of pregnant persons have access to the Web and use it up to 62 times in a month to find pregnancy-related information on a variety of topics, the most common topic being fetal development.¹⁴² Considering the introduction and expansion of handheld devices connected to the Web,^{137,139} it is reasonable to assume that the use will continue to increase further. While the physical access and use of the Web is increasing, the skills to search for and interpret the information found may vary within the population. Consequently, the attention has shifted from physical access to digital skills.¹⁴³

The Web contains various potential sources for health-related information. For example, websites may be affiliated with hospitals or clinics, governments, pharmaceutical companies, or independent information websites. Moreover, the information available on a website may be written by a named and verified author, such as a medical professional or a journalist, or by an anonymous author. Information consumers come in contact with commercial websites, which may aim to sell products, as well as open-access scientific journals with peer reviewed scientific reports.¹⁴⁰ The vast amount of available web-based information from various types of sources imply a risk of disorganization on the Web.¹⁴⁴ Because of its great size and volume, laypersons may be faced with difficulties searching for and sorting

out the available information. Most commonly, people use search engines to search for and identify health-related information,^{137,145} Search engines are tools that index a large number of available websites, with the purpose of helping users navigate the Web and identify websites related to the topic of interest.¹³¹ There is great variation in the skills needed to search for health-related web-based information, and users show sub-optimal search strategies. Studies indicate that many users do not look beyond the first page of search hits,^{146,147} implying that a limited amount of sources may be used by the intended consumers.

Quality of Web-based information

The Web has the potential to offer highly accessible, interactive and tailored health information that corresponds to patient needs. However, concerns have been raised about different aspects related to the information available via the Web.¹⁴⁴ The information found may lack peer review or other types of regulatory activities, increasing the risk that information consumers will come in contact with information of poor quality.^{144,148} The majority of the studies included in a systematic review concluded that quality is an issue on the Web.¹⁴⁹ In recent years, an increasing number of studies have been published that investigate the quality of information websites for reproductive health issues such as caesarean sections,¹⁵⁰ induced abortions,^{151,152} screening for trisomy 21,¹⁵³ circulating cell free DNA testing for aneuploidy,¹⁵⁴ and noninvasive prenatal testing.¹⁵⁵ These studies report issues with inaccuracies,^{151–153,155} poor readability,^{154,155} and lack of content.^{150,151,153–155}

There are many aspects of website quality, and various ways to judge it. Core information quality criteria involve the content of the information and include aspects such as accuracy, bias, completeness, and currency. Proxy criteria involve aspects that indicate quality of the production of the information, such as authorship disclosure, sponsorship, and use of references. Site or interaction quality criteria involve the quality of the function and design of the website, such as navigation, aesthetics, and accessibility.¹⁵⁶ Accuracy, completeness, content, readability, design, disclosures, and provided references are the most common quality criteria for assessing web-based information.¹⁴⁹ Numerous tools to assess quality have been produced, with the overall purpose of raising awareness of the quality of web-based health-related information and guide website development. User guides or checklists aim to help information consumers to judge the quality of available websites by themselves.^{156,157} While these tools may empower consumers in their searches, the method has received critique for placing the responsibility and burden on the intended consumers.^{156,158} Although a great number of such tools are available, few are considered practically usable,¹⁵⁹ and many consumers do not feel confident in their ability to evaluate a website's quality by themselves.¹⁵⁶ Thus, concerns have been raised regarding the

actual possibilities and benefits to judge the quality of web-based information.¹⁶⁰ Attention has been called to the diversity of health issues and patient populations,¹⁶¹ illustrating the difficulties of generalization and need for descriptive studies within specific health-related fields.

Most published studies investigating the quality of websites about topics within the field of gynecology and obstetrics have used professionals, i.e., researchers or health professionals, as assessors of website quality.^{162–170} Very few, on the other hand, have used lay persons or the intended consumers as assessors.¹⁷¹ Research has identified differences in perspectives between professionals and laypersons,^{172,173} indicating that their preferences on information materials may differ. Previous research suggests a need for information developers of written patient information to involve the intended consumers when producing the material.¹⁷⁴ Taken together, such reports call attention to the need of research that uses the intended consumers as assessors of website quality, to reach representative and patient-centered conclusions concerning website quality. Moreover, a review of the literature calls attention to the need for studies that employ mixed methods of quantitative and qualitative approaches. According to the review, such methods are promising ways to assess website quality, as they present an opportunity for researchers not to be constricted by a set number of quality criteria in instruments, as well as to more appropriately address the multimodal and interactive structure of web-based information.¹⁶¹

While some expectant parents faced with prenatal diagnosis view the Web as a useful source of information,¹³⁵ others do not,^{135,175} experience a struggle with finding specific and current information,¹⁷⁵ and get confused by the information found.¹⁷⁶ There is a scarcity of research that explores websites about congenital heart defects. This implies difficulties in drawing conclusions about the quality of such sources, and calls attention to the need of descriptive studies.

Rationale

Research indicates that persons faced with a prenatal diagnosis of congenital heart defect in the fetus may be confronted with challenges related to information, as to feel sufficiently informed about the finding. These possible challenges warrant research that addresses how to most appropriately offer information following the diagnosis. Inductive research that specifically explores experiences and needs of information following a prenatal diagnosis of congenital heart defect in the fetus is scarce. Moreover, research indicates that the Web is used as a source of information among expectant parents faced with the diagnosis. However, the inherent structure of the Web includes a risk for contact with information of poor quality, due to the disorganization and lack of peer review or other regulatory activities. Little is known about the quality of publicly available patient information websites about congenital heart defects. The primary rationale behind this thesis is that steps need to be taken towards gaining knowledge about what information expectant parents need and come in contact with following a prenatal diagnosis of congenital heart defect in the fetus.

Aims

The overall aim of this thesis was to explore experiences and needs of information following a prenatal diagnosis of congenital heart defect (Studies I and II), and to assess the quality of publicly available patient information websites about congenital heart defects (Studies III and IV).

The specific aims of the included studies were to explore:

- I** Parental experiences and need for information following a prenatal diagnosis of congenital heart defect.
- II** Experiences of informational needs and received information following a prenatal diagnosis of congenital heart defect.
- III** Central subjects of content and assess the accessibility, reliability, usability, and quality of written information on publicly available information websites about congenital heart defects following a prenatal diagnosis.
- IV** Patient information websites about congenital heart defects from the perspectives of individuals with personal experience of a prenatal diagnosis of congenital heart defect in the fetus.

Methods

Design of the included studies

The studies in this thesis were explorative and descriptive, and included qualitative as well as quantitative methods (Table 1). Explorative studies aim to discover new knowledge related to unfamiliar or unexplored subjects, and descriptive studies aim to provide results that portray certain investigated details concerning the population.¹⁷⁷ Qualitative approaches were used in Studies I and II, and a quantitative approach was used in Study III. In Study IV, both quantitative and qualitative approaches were used, with the aim to utilize the strengths and offset the weaknesses of each singular approach.¹⁷⁸

Table 1. *Summary of the design of the included studies.*

Study	Data collection	Sample	Data analysis
I	Face-to-face interviews	Parents to prenatally diagnosed children (n=11)	Inductive qualitative content analysis of manifest and latent content
II	Telephone interviews	Persons with recent experience of a prenatal diagnosis (n=26)	Inductive qualitative content analysis of manifest and latent content
III	Website assessments	English patient information websites about congenital heart defects (n=67)	Descriptive statistics, inductive quantitative content analysis of manifest content
IV	Website assessments, focus group discussions	Swedish patient information websites about congenital heart defects (n=10), assessed by persons with experience of a prenatal diagnosis (n=9)	Kendall's coefficient of concordance W, Mann-Whitney U test, Friedman's test, Wilcoxon-Nemenyi-McDoland-Thompson test, inductive qualitative content analysis of manifest content

Study context

Studies I, II, and IV were conducted in Uppsala and Stockholm, two counties in central Sweden. In Sweden, all pregnant persons are offered a routine obstetric ultrasound examination at approximately at 16-20 weeks of gestation. If a congenital heart defect is suspected in the fetus, expectant parents are referred to a consultation with a pediatric cardiologist specialized in fetal cardiology for further investigations. If the fetal cardiologist detects a heart defect in the fetus, information is offered regarding a number of different topics. The information is usually provided both orally and through illustrations of the heart defect. No standardized written information is currently offered to those faced with a diagnosis, but recommendations are occasionally provided regarding appropriate websites and search terms to use in web-based search engines. Those who have not reached 22 completed weeks of gestation are presented with the alternative to terminate the pregnancy.

When a decision is reached to continue the pregnancy, fetal cardiology follow-up is offered every 4-6 weeks in addition to the fetal medicine program, to monitor the progression of the congenital heart defect, as well as to prepare and optimize planning for the delivery and treatment of the child. In Sweden, the alternative to terminate the pregnancy is a legal option. The Swedish Abortion Act states that pregnant persons are free to decide to terminate the pregnancy up until 18 completed weeks of gestation. At later gestations, they may apply for approval from the National Board of Health and Welfare.⁷² Social workers offer psychosocial support and fill out the application to the National Board of Health and Welfare. Typically in Sweden, induced abortions beyond 13 weeks of gestation involve medically induced labor and vaginal delivery, and very few abortions are performed after 22 completed weeks.¹⁷⁹

At the end of 2015 in Sweden, there were 27,327 registered children between 0 and 18 years of age diagnosed with heart defects. Of the 22,910 cases with a registered time for the diagnosis, 884 were prenatally diagnosed.¹¹ The prenatal detection rate of major heart defects, i.e., heart defects in need of surgical intervention within the first year after birth, rose from under 10 percent before 1998 to 40 percent in 2004. Over 75 percent of univentricular heart defects were prenatally diagnosed during the period between 2002 and 2004.⁹

During the last two decades in Sweden, there has been a great increase in access to the Web. In 2016, approximately 93% of the total population and almost all of those younger than 45 years had access to the Web. The availability of information is the most reported best aspect of the Web, while the content of the available information is the most reported worst aspect.¹⁸⁰

Sample

The samples consisted of parents to prenatally diagnosed children (n=11), persons with recent experience of a prenatal diagnosis of congenital heart defect in the fetus (n=26), English patient information websites (n=67), and Swedish patient information websites (n=10). Persons with experience of a prenatal diagnosis were purposefully (Study I) and consecutively (Study II) recruited in clinical settings. Patient information websites were identified through systematic searches in web-based search engines (Studies III and IV). In Study IV, persons with experience of a prenatal diagnosis were used as assessors (n=9). Assessors were purposefully recruited. Figure 1 presents an overview of the recruitment of respondents (Studies I and II), searches for included websites (Studies III and IV), and recruitment of assessors (Study IV).

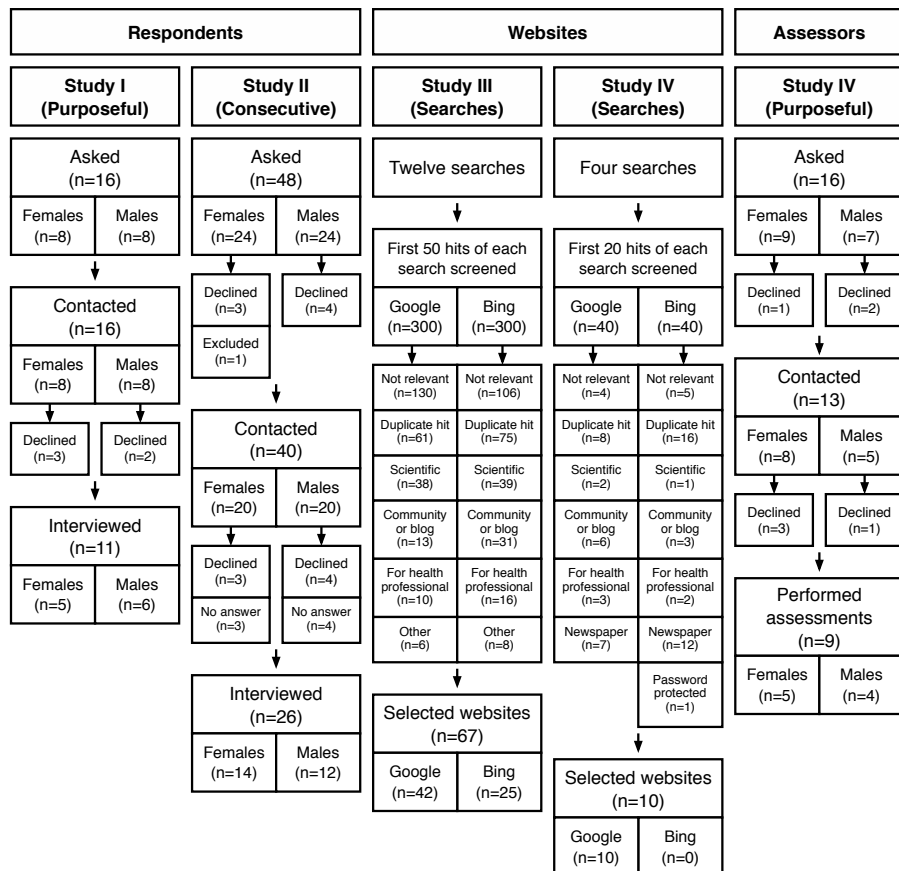


Figure 1. Recruitment of respondents (Studies I and II), searches for included websites (Studies III and IV), and recruitment of assessors (Study IV).

Recruitment of respondents

Study I

Swedish-speaking parents to children with a prenatally diagnosed major congenital heart defect, defined as a congenital heart defect in need of surgical intervention within the first year after birth, were recruited between April and May 2013 from the unit for fetal cardiology at Uppsala University Hospital, Sweden. Purposeful recruitment¹⁸¹ was used to achieve variations with regard to cultural and socio-demographic backgrounds. The second and last authors were responsible for the recruitment from their clinical networks. In total, 16 parents were asked to participate. Of these, 11 consented and were interviewed (females n=5, males n=6).

Study II

Swedish-speaking females and males with experience of a prenatal diagnosis of major congenital heart defect in the fetus were consecutively recruited between March 2014 and November 2014 from the units for fetal cardiology at Uppsala University Hospital and Astrid Lindgren Children's Hospital, Sweden. In total, 48 potential respondents were asked to participate. One was excluded due to language difficulties and seven declined participation. Consequently, 40 consented to be contacted via telephone within 5-15 weeks after the diagnosis. When called, seven were unavailable and seven declined participation. Following oral and written consent, 26 were interviewed (females n=14, males n=12).

Search strategy to identify websites

Study III

In October 2013, the following search terms were entered into Bing and Google, the two most used search engines on the Web:¹⁸² '*congenital heart disease*', '*congenital heart defect*', '*ultrasound heart disease*', '*ultrasound heart defect*', '*pregnancy heart disease*', and '*pregnancy heart defect*'. To be eligible for inclusion, the websites had to be written in English and provide patient information about congenital heart defects. The first 50 hits for each search were screened for inclusion (n=600). Hits leading to virtual communities or blogs, video materials, websites for health professionals, and scientific articles were excluded. In total, 397 (66%) hits were excluded, leaving 67 (11%) websites for inclusion after adjusting for duplicate hits (n=136, 23%).

Study IV

In May 2015, the Swedish terms for the search terms '*heart defect*' and '*fetus heart defect*' were entered in Bing and Google. The first author decided which search terms to use. After the data was collected, the assessors were

asked which search terms they preferred to use when searching for patient information websites about congenital heart defects in connection to the diagnosis. The most commonly reported words in these search terms were '*heart defect*' (29 times mentioned) and '*fetus*' (11 times mentioned). To be eligible for inclusion, the websites had to be written in Swedish and provide patient information about congenital heart defects. The first 20 hits for each search were screened for inclusion by the first author (n=80). Nine hits led to websites not relevant to the subject of congenital heart defects. Hits leading to newspaper websites, virtual communities or blogs, websites for health professionals, scientific articles, and password-protected websites were excluded. In total, 46 (58%) hits were excluded, leaving 10 (12%) websites for inclusion after adjusting for duplicate hits (n=24, 30%).

Recruitment of website assessors

The assessors in Study IV were purposefully recruited, to strive for variation with regard to country of birth, educational level, and age. The last author was responsible for recruitment of parents to prenatally diagnosed children from her clinical network. Eight potential assessors were identified and asked to participate in the study. Of these, two declined as they feared that participation would rekindle emotionally difficult memories, one declined because of lack of time, and one declined as she felt it was enough with one parent from the family. Thus, four (females n=2, males n=2) participated as assessors. One of the males had previously participated in Study I. The first author was responsible for recruitment of assessors with experience of pregnancy termination following a prenatal diagnosis. Respondents in Study II who terminated the pregnancy were asked for participation. In total, eight were purposefully selected and asked to participate. Of these, two declined due to lack of time and one declined due to lack of interest. Thus, five (females n=3, males n=2) participated as assessors.

Sample characteristics

Table 2 presents the characteristics of the included respondents in Studies I and II, as well as the assessors in Study IV. In Study I, four of the parents had a child younger than one year, six had a child between one and two years, and one had a child older than two years. Two had a child who awaited surgical intervention, while nine had a child with one or two interventions. In Study II, eleven respondents had no previous children, while fifteen were parents to at least one child. In Study IV, assessors with continued pregnancy had children with congenital heart defects who were two (n=2 assessors) and three (n=2 assessors) years old. Those with terminated pregnancy had experienced induced abortion 20 (n=1), 24 (n=2), 27 (n=1), and 38 (n=1) weeks before the assessments took place. Four assessors with con-

tinued (n=2) and terminated (n=2) pregnancies were couples, thus with experience of the same diagnosis.

Table 2. *Characteristics of the respondents in Studies I (n=11) and II (n=26), and the assessors in Study IV (n=9).*

Characteristic	Study I, n	Study II, n	Study IV, n
Age			
20-29 years	2	9	3
30-39 years	7	12	2
>39 years	2	5	4
Country of birth			
Sweden	7	24	6
Other	4	2	3
Highest education			
Junior high school	1	-	-
Senior high school	4	9	2
University/college	6	17	7
Prenatal diagnosis			
Tetralogy of fallot	3	6	-
Atrioventricular septal defect	4	3 ^{T21}	2 ^{T21}
Critical aortic stenosis	-	4	2
Tricuspid atresia	-	4	-
Double inlet left ventricle	-	3	-
Coarctation of aorta	1	2	-
Hypoplastic left heart syndrome	-	2	-
Ventricular septal defect	2	-	2
Combination of transposition of great arteries, ventricular septal defect and pulmonary stenosis	-	-	2
Combination of pulmonary atresia with ventricular septal defect and major aortopulmonary collateral arteries	1	1	-
Ebstein's anomaly/tricuspid dysplasia	-	1 ^{MESM}	1 ^{MESM}

^{MESM}Multiple extracardial structural malformations, ^{T21}Prenatal diagnosis of trisomy 21

Most of the included websites were affiliated with independent information websites, charities/private organizations, or government/hospitals/clinics (Table 3). The information on the websites in Study III were written by anonymous authors (n=51, 76%), medical professionals (n=10, 15%), journalists (n=2, 3%), and authors of other backgrounds (n=4, 6%).

Table 3. *Affiliations of the included patient information websites in Studies III (n=67) and IV (n=10).*

Affiliation	Study III, n(%)	Study IV, n(%)
Independent information website	25(37)	2(20)
Government/hospital/clinic	21(31)	3(30)
Charity/private organisation	17(25)	3(30)
Medical/pharmaceutical company	1(2)	2(20)
Other	3(5)	0(0)

Data collection

Interviews (Studies I and II)

The interviews were conducted between April and June 2013 (Study I), and between April 2014 and February 2015 (Study II). In Study I, the parents were given the option to either be interviewed separately or together in a face-to-face setting, resulting in five individual interviews and three joint interviews. All respondents in Study II were interviewed individually via the telephone. The interviews in Studies I and II lasted between 20 and 89 minutes, and were conducted with the aid of a semi-structured interview guide (Table 4). Clarifying questions were asked, such as ‘*can you please describe that in more detail*’, ‘*do you have any examples to share*’, ‘*how come*’, ‘*what*’, ‘*in what way*’, ‘*how was it*’, and ‘*how did you experience that*’. A summary was given at the end of the interviews, and the respondents were asked if they wanted to correct or add anything. All interviews were digitally recorded and transcribed verbatim. However, one interview in Study I was not recorded because of a respondent’s wishes. Handwritten notes were kept during all interviews.

Table 4. *Interview guide in Studies I and II.*

Topic	Questions
Initial question	1. Could you tell me what it was like for you to be told about the heart defect?
Informational needs	2. Can you describe what information you experienced that you needed when you received the diagnosis? 2.1. What topics do you think are particularly important to get information about at the time of the diagnosis? 2.1.1. Did you receive answers to these questions? 2.2. In what way would you have preferred to get information? 2.2.1. Did you receive any information in that way?
Information received	3. Can you describe how you experienced the information from the health professionals? 3.1. Who gave the information? 3.2. Was the information easy or difficult to understand? 3.3. Were you given any written information? 3.4. Was any information particularly useful? 3.5. What information was missing? 3.6. Was any information superfluous? 3.7. Did you get answers to your questions? 4. Can you describe if and how you looked for information yourself? 4.1. What methods did you use to look for information? 4.2. What did you find? 4.3. How did you experience what you found? 4.3.1. Did you experience any information especially useful? 4.3.2. Did you experience any information especially poor?

Patient information websites (Studies III and IV)

English patient information websites (Study III)

The websites were separately evaluated using two standardized instruments: the DISCERN instrument¹⁸³ and the Minervation validation instrument for health care websites (LIDA tool).¹⁸⁴ The DISCERN instrument is a reliable and valid instrument¹⁸⁵ for assessing the quality of written consumer health information, independent of previous knowledge.¹⁸³ It consists of 16 questions divided into three sections: 1) reliability (8 questions), 2) information about treatment options (7 questions), and 3) overall quality (1 question). Each question is rated from 1 (No, serious shortcomings) to 5 (Yes, minimal shortcomings), resulting in a total score from 16 to 80.¹⁸³

The LIDA tool assesses accessibility, reliability, and usability of health care websites. Accessibility includes an automated test of website code (score range 0-54), and subscales about browser compatibility (1 question) and registration requirements (1 question). Usability includes four subscales that measure clarity (6 questions), consistency (3 questions), functionality (5 questions), and engagability (4 questions). Reliability includes three subscales that measure currency (3 questions), conflicts of interest (3 questions), and content production (3 questions). Each question is rated from 0 (never) to 3 (always) resulting in a total score from 0 to 141.¹⁸⁴ The overall score is calculated as a percentage, where scores greater than 90 percent represent good quality and less than 50 percent represent poor quality.¹⁸⁶

Swedish patient information websites (Study IV)

The assessors performed individual written assessments in 2015 for each included website. For the quantitative assessments, a quality assessment tool was developed, inspired by the work in Study III (Table 5). The tool included six questions concerning appearance, details, relevance, suitability, information about treatment choices, and overall quality. The assessors rated each question on a five-point Likert scale ranging from 1 (lowest possible score) to 5 (highest possible score). In addition, each question was supplemented with an open-ended question asking whether the assessor had any additional comments. Assessors were also asked to leave written comments regarding their perspectives on the positive and negative aspects related to each of the included websites. Nine assessments for each of the ten included websites resulted in a total of 90 assessments. Eight assessors completed the written assessments during a four-hour workshop, and one assessor completed the assessments at his home since he was unable to attend the workshop. They were instructed to assess each of the included websites separately, and assess the sections they found relevant in relation to the topic of congenital heart defects when faced with a prenatal diagnosis.

Table 5. *Quality assessment tool (Study IV).*

Question	Scale
1. Is the appearance appropriate for the target audience?	1 (No) to 5 (Yes)
2. Is the level of detail appropriate for the target audience?	1 (No) to 5 (Yes)
3. Is the content of the website relevant?	1 (No) to 5 (Yes)
4. How suitable is the website as a source of information following a detection of congenital heart defect in the fetus?	1 (Very unsuitable) to 5 (Very suitable)
5. Is it clear that more than one treatment choice exists?	1 (No) to 5 (Yes)
6. How is the overall quality of the website as a source of information following a detection of congenital heart defect in the fetus?	1 (Low) to 5 (High)

A follow-up focus group discussion was held with the assessors with continued and terminated pregnancy, respectively. Websites were accessed from a computer connected to a projector, and discussions were digitally recorded with audiovisual screen recordings. Assessors were encouraged to freely discuss aspects perceived as relevant to them. The discussions lasted 55 minutes for assessors with continued pregnancy and 46 minutes for assessors with terminated pregnancy. The recordings were transcribed verbatim.

Data analysis

Content analysis

Text-based materials from the included studies in this thesis were subjected to inductive content analysis, a method used to describe patterns in, and summaries of, such data.^{187,188} There are various approaches available when analyzing data with content analysis. Quantitative approaches draw on positivist reasonings and uses statistics to provide summaries of the data. Qualitative approaches draw on naturalistic reasonings and seeks to describe material in ways that moves further into the domain of interpretation.^{177,187–189} Generally, content analysts strive to stay close to their collected material, with an overall goal of providing straightforward and comprehensive summaries of the content.¹⁸⁸ According to Sandelowski, content analysis is the least interpretive of the forms of qualitative analyses, which makes it a fitting approach in studies that aim to provide straight descriptions.¹⁸⁸ Inductive content analysis produces findings that originate from the collected material, rather than existing theory and literature.¹⁹⁰ Inductive approaches are appropriate when conducting descriptive and exploratory studies that seek to describe content grounded in the collected material.¹⁷⁷

Qualitative content analysis (Studies I, II and IV)

Inspired by the outline presented by Graneheim and Lundman,¹⁹¹ the analytic steps in Study IV involved manifest qualitative content analysis, while Studies I and II involved manifest and latent qualitative content analysis.

Manifest content concerns the visible and obvious content, while latent content is geared towards an interpretation of the underlying meaning, representing a deeper level of abstraction.¹⁹¹ As a first step, the transcribed material was read repeatedly to familiarize with it. Meaning units were identified, defined as words, sentences or paragraphs containing aspects related to each other through a common content and context. These units were subjected to condensation, a process where the unit is shortened, while still retaining the core, i.e., its central content and context. The condensed units were labeled with a descriptive code, i.e., a label that describes the meaning unit, used to understand and interpret the data in new ways.¹⁹¹ Table 6 presents examples of the analytic process of identifying meaning units, condensing the meaning unit, and labeling it with a descriptive code.

Table 6. *Examples of the analytic process of defining a meaning unit, condensing it, and labeling it with a descriptive code (Study II).*

Meaning unit	Condensed unit	Code
1.1. We didn't know anything. We only knew that something was wrong with the heart. We didn't know anything more than that. So it was a very difficult weekend...	1.2. We didn't know anything. So it was a very difficult weekend.	1.3. Difficult wait in uncertainty
2.1. Then we supplemented by reading on the Web very much	2.2. Supplemented by reading on the Web	2.3. Supplemented with web-based information

The identified codes were aggregated into categories, defined as collections of codes that share a commonality. Categories are mainly regarded as descriptive of the manifest content, typically homogeneous at the internal level within a category while retaining a heterogeneous external level between categories. Due to the complex and intertwined features of human experiences, it is not always possible to separate the categories into perfectly independent and externally heterogeneous collections.¹⁹¹

Themes refer to the latent content of the material, and represent the interpreted underlying meaning of the material. In contrast to categories, themes do not necessarily have to be exclusively externally heterogeneous, as material can have multiple meanings.¹⁹¹ The analysis moved forward as more material was included, moving back and forth between the data, codes, the manifest content, and the latent content. Discussions were held with others in the research group to gain an understanding of the data from various perspectives. Table 7 presents examples of the analysis of codes to categories and themes. The data collection and analysis in Studies I and II were continued until saturation was considered achieved,¹⁸¹ which was defined as the point when new interviews did not deepen or challenged the findings. Nvivo for Mac version 11.4.0 was used to organize the codes into categories in Studies II and IV.

Table 7. *Examples of categorization and thematization (Study II).*

Code	Category	Theme
1.1. Difficult wait in uncertainty 1.2. The uncertainty made it confusing 1.3. Left hanging when professionals did not provide any information at the routine ultrasound examination	1. A confusing situation because of unspecific initial information	Hunting for information in a confusing reality
2.1. Searched the Web for information 2.2. Supplemented with web-based information 2.3. Searched the Web out of curiosity	2. Supplemental online information	

Quantitative content analysis (Study III)

In Study III, a manifest quantitative content analysis¹⁰⁶ was performed to identify the central subjects of content of each website. Initially, websites were accessed and read repeatedly to gain an understanding of its structure and content. Meaning units were identified and structured into categories of central subjects of content, defined as collections of meaning units that shared a common topic, i.e., the manifest content. After an initial analysis, the websites were read again and subcategories were identified. The number and percentage of websites in each category and subcategory was counted.

Reflexivity

My professional background is that I am a registered nurse, a specialist intensive care nurse, and a registered midwife. During the course of the data collection and analysis, I was a midwifery student. I have worked clinically in the fields of hematology and neurointensive care, and have no professional background in prenatal care. My personal background is that I am a male with no children, nor any personal experiences of prenatal diagnoses. To strive towards gaining insights into my preconceptions, I kept a reflective journal¹⁸¹ during the course of data collection and analysis.

Statistical analysis

In Study III, means, standard deviations, and distributions were calculated. In Study IV, Kendall's coefficient of concordance W was used to determine inter-rater reliability, which checks for similarities and inconsistencies in assessment scores.¹⁹² Concordances were determined as $W \geq 0.21$ representing fair, ≥ 0.41 moderate, ≥ 0.61 substantial, and ≥ 0.81 almost perfect.¹⁹³ The Mann-Whitney U test was used to compare the ranks of the median assessment scores from the groups of assessors who continued and terminated the pregnancy. Friedman's test was used to compare the assessment scores of the included websites, which gave an indication of overall differences in the ranks of websites. The Wilcoxon – Nemenyi – McDonald –

Thompson test was used as a post hoc test. P-values < .05 were considered statistically significant. The analyses were performed with R version 3.2.2.

Ethics

The Regional Ethical Board in Uppsala and Stockholm approved the studies that involved persons as research subjects (Studies I, II, and IV), approval numbers 2012/553/2 and 2014/504/1. All eligible participants were informed orally and in writing about the study, that participation was completely voluntary, and that it could be terminated at any time. Oral and written informed consent was obtained from all participants before enrolment. Information was given that their participation or decline to participate in the study would not affect any future care or communication with the unit for fetal/pediatric cardiology. The senior researchers who worked at the unit (EM and GB) recruited the respondents and assessors. It could be speculated that the respondents and assessors might have felt pressured to give their consent. However, they were given repeated information about the study when I contacted them via telephone, and presented with the option to decline participation. Permission to audio record the interviews was collected, and when one respondent expressed a preference not to be recorded, this was respected.

Only the researchers involved in the studies had access to the collected data. The collected data was stored in a password-protected computer. During data collection, care was taken not to intrude on the privacy of the respondents. They were encouraged to share as much or little as they wanted. While some respondents seemed emotionally affected when talking about sensitive subjects, no one described that the interview caused them harm.

The data in Study III was publicly available websites. The study did not include any persons as subjects of research. According to current Swedish law,¹⁹⁴ there is no need for ethical approval of such studies. No data was registered or saved regarding specific details of authors of the information on the websites, to protect their anonymity.

Primary findings

Parental experiences and need for information (Study I)

Three themes represent the experiences related to taking in, accessing, searching for, understanding, interpreting, and judging the information offered by the health professionals and available on the Web.

The first theme was *'grasping the facts today while reflecting on the future'*. The emotional shock experienced at the time of diagnosis resulted in difficulties sorting, understanding and remembering the information. Consequently, repeated information was considered to be of great importance, and illustrations of the heart defect facilitated comprehension. Respondents described a need for early and detailed information about various topics related to the situation at the time of the diagnosis and the postnatal future. Those who would consider pregnancy termination valued information about the possibility to undergo induced abortion. Worries about the postnatal future were described, and respondents expressed a desire to relate to families with similar experiences.

The second theme was *'personal contact with medical specialists who give honest and trustworthy information is valued'*. It concerns the value of contact with specialists, and being presented with honest information that portrays a truthful picture of the impact of the heart defect. Overall, respondents were satisfied with the information offered at the consultation following the diagnosis. Personal contact with specialists was considered the best way to receive trustworthy information. The importance of continuity of care was emphasized, which facilitated comprehension and reduced anxiety.

The third theme was *'an overwhelming amount of information on the Web'*. Use of the Web varied, as some used it extensively for supplemental information, while others chose not to use it at all. Those who used it and who were able to find relevant websites considered it a good source of supplemental information. However, difficulties were described related to finding relevant websites and understanding the language used in the websites. Respondents expressed that they did not trust the information found via the Web, and described that reading web-based supplemental information resulted in worries about the postnatal situation of their child. To deal with these difficulties, respondents desired professional's recommendations on appropriate and reliable websites.

Informational needs and received information (Study II)

The theme '*Hunting for information in a confusing reality*' represent the attempts to search for and find information while in a state of confusion. Six categories were identified: '*informational methods*', '*informational content*', '*a confusing situation because of unspecific initial information*', '*specific information from a specialist clarifies the situation*', '*supplemental online information*', and '*insufficient information about termination of pregnancy*'. The diagnosis was an unexpected emotional shock, which made it difficult to comprehend and remember information. The situation was clarified with specific information at the specialist consultation, generally described to be of high quality. However, some respondents experienced this information as complex and overwhelming. Various needs concerning the methods of delivery and content of information were mentioned (Table 8).

Table 8. *Identified needs for informational methods and content (Study II).*

Identified needs	Illustrative quote
Informational methods	
Available	<i>What made it easier, was that we got a direct telephone line to everyone. We felt that we could get in touch and that was very positive.</i>
Detailed	<i>You want to know everything in the greatest detail.</i>
Early	<i>You want to find out about it as early as possible.</i>
Honest	<i>It's better that they say precisely what they think.</i>
Illustrations	<i>He drew it [valve] closed and then you understood more, when you sat and looked at the healthy heart and then the one with closed valve and so on. It became an easier way to take in the information, if you see how it's supposed to look and then how it's not supposed to look.</i>
Mother tongue	<i>And that was a very good illustration. It was in English, because there were not many available in Swedish. So maybe that would have been better, if we could have received it in Swedish.</i>
Objective	<i>If someone [health professional] had been for it [one of the alternatives to continue or terminate]... then you couldn't have made a choice.</i>
Repeated	<i>We met them several times as well, so then we remembered everything.</i>
Specialist information	<i>First we wanted it confirmed with their instruments, so that it really was this defect. And to get a statement, a verdict, from a heart specialist.</i>
Written	<i>This need for a brochure or an Internet site or something.</i>
Informational content	
Anatomy	<i>I thought that it was good that he... he explained how the heart looks.</i>
Associated anomalies	<i>It was all that about Down's syndrome. Um... I wanted more information regarding that.</i>
Causes	<i>We asked, tried to get an answer, is it [because of] our lifestyle.</i>
Postnatal situation	<i>We were very interested how life would be for our child... with a univentricular heart.</i>
Previous cases	<i>I think that it helps to hear that others... have gone through it [pregnancy termination]. [...] I don't know, you feel that you aren't alone.</i>
Professional psychosocial support	<i>She asked me why don't you talk to someone in the meantime, and I just, I didn't know that it was even possible.</i>
Statistics	<i>I would have liked statistics.</i>
Termination	<i>Extra important that they explain how a pregnancy termination is done.</i>

While some avoided the Web, others used it for supplemental information. Searching for web-based information had been difficult, but respondents who received recommendations on websites or search terms described that this helped them identify relevant sources. Websites were considered to be of poor quality, with complex, insufficient or unspecific information occasionally biased against induced abortions. The Web was also used to read stories of others, criticized as an unreliable and biased source of information. Simultaneously, respondents also described that it was comforting to read these stories. Among respondents with terminated pregnancy, insufficient information about induced abortions was described, both that available on the Web and that offered from health professionals. This resulted in worries, unanswered questions, and unpreparedness. However, some were satisfied with the preparatory information offered by health professionals.

English patient information websites (Study III)

Content analysis revealed 25 categories (Table 9). Few included illustrations of the cardiovascular system (n=29, 43%) and heart defects (n=28, 42%).

Table 9. *Categories of central subjects of content (Study III).*

Category	n	%
Care and treatment of children with congenital heart defects	59	88
Causes of congenital heart defects	59	88
Symptoms of congenital heart defects	57	85
Prevalence of congenital heart defects	54	81
Potential complications of congenital heart defects	50	75
Prenatal diagnostic/screening methods	48	72
Specific congenital heart defects	48	72
Associated anomalies	47	70
Normal cardiovascular system	46	69
Postnatal diagnostic methods	45	67
Long-term outlook and care	44	66
Prognosis of congenital heart defects	41	61
Risks of treatment of congenital heart defects	25	37
Common feelings following prenatal diagnosis of congenital heart defects	18	27
Postnatal quality of life	18	27
Examples of previous cases that continued the pregnancy	16	24
Precision of prenatal diagnosis of congenital heart defects	16	24
Delivery/childbirth	14	21
Postnatal coping with the diagnosis	13	19
Risks of congenital heart defects in future pregnancies	10	15
Fetal interventions	8	12
Presentation of the multidisciplinary team in care of the child	8	12
Termination of pregnancy	4	6
Care during pregnancy	3	5
Information specifically directed at partners	1	1

Overall, the mean DISCERN scores were low, especially for reliability and information about treatment options (Table 10). All DISCERN questions had a mean score below 3.0, indicating serious shortcomings for all aspects covered in the instrument. Questions concerning explicit aims, aims achieved, explicit sources, explicit date, areas of uncertainty, risks with treatment, effect of no treatment, effects on quality of life, all options described, and support for shared decision had mean scores below 2.0. The mean scores for LIDA subscales varied. One subscale had a mean score above 90 percent, indicating good quality concerning registration requirements. Six subscales had a mean score between 50 and 90 percent, indicating moderate quality concerning automated source code test, browser compatibility, clarity, consistency, functionality, and conflicts of interest. Three subscales had a mean score below 50 percent, indicating poor quality concerning engagability, currency, and content production.

Table 10. Means, standard deviations, and ranges of the quality assessments (Study III). [Maximum achievable scores in brackets]

	Mean	SD	Range (min - max)		
DISCERN					
Reliability [40]	14.7	5.2	8	-	30
Treatment options [35]	11.1	4.9	7	-	25
Overall rating [5]	2.1	1.0	1	-	4
Total [80]	27.9	9.7	16	-	53
LIDA					
Accessibility [60]	50.7	5.3	37	-	59
Usability [54]	32.5	7.1	19	-	48
Reliability [27]	8.9	5.4	0	-	22
Total [141]	92.3	13.1	61	-	127

Swedish patient information websites (Study IV)

Inspecting all of the assessment scores (n=90), the highest proportion of the lowest score (1) was found for treatment choices (n=35, 39%). The highest proportion of the highest score (5) was found for relevance (n=16, 18%). The inter-rater reliability for all assessors ranged between 0.18 and 0.40 for the six questions in the quality assessment tool. With the exception of treatment choices, which had a median total score of 2.0, all questions had a median total score of 3.0 (Table 11). The Mann-Whitney U test revealed no significant differences between the ranks of the median scores of the assessments from assessors with continued and terminated pregnancy. Figure 2 presents the distributions of the assessment scores for each of the included websites. No website had a median score of 5.0 for any of the questions in the quality assessment tool. Median scores of 1.0 were found in questions about treatment choices (n=4 websites), details (n=2 websites), suitability

(n=1 website), and overall quality (n=1 website). One website (website 10, which was affiliated with a clinic) had median scores of 1.0 across four of the total six questions. Friedman’s test revealed significant differences between websites for all six questions in the quality assessment tool. The post hoc test revealed that website 10 had significantly lower scores in comparison to other included websites for appearance, levels of details, relevance, suitability, and overall quality. For levels of detail, websites 6 and 9 had significantly lower scores than websites 1 and 2.

Table 11. *Inter-rater reliabilities (IRR), medians (Med), and interquartile ranges (IQR) of the quality assessments (Study IV).*

	Continued pregnancy			Terminated pregnancy			Total		
	IRR ¹	Med	IQR	IRR ¹	Med	IQR	IRR ¹	Med	IQR
Appearance	0.36	3.0	2	0.34	3.0	2	0.23	3.0	2
Details	0.60	3.0	3	0.42	3.0	2	0.38	3.0	3
Relevance	0.54	3.0	1	0.32	3.0	1	0.31	3.0	1
Suitability	0.66	3.0	2	0.42	3.0	1	0.40	3.0	2
Treatment choices	0.43	3.0	2	0.32	2.0	2	0.18	2.0	2
Overall quality	0.57	3.0	2	0.29	2.5	1	0.31	3.0	1

¹Kendall’s coefficient of concordance W

The qualitative analysis generated six categories: ‘*advertisements*’, ‘*comprehensiveness*’, ‘*design*’, ‘*illustrations and pictures*’, ‘*language*’, and ‘*trustworthiness*’. Advertisements made it difficult to recognize relevant information, were considered inappropriate, and made the websites feel less serious. Generally, medical anatomical information was considered to be of good overall quality. However, websites were considered to lack information about the postnatal situation for families and included irrelevant topics, which reduced the impression of the overall quality. Assessors appreciated stories of previous cases, but reacted negatively when websites lacked stories about cases that terminated the pregnancy. Information was considered belittling regarding the consequences of severe heart defects, portraying an overly optimistic view. Moreover, balanced information about the alternatives to continue or terminate pregnancy was considered lacking. Assessors with terminated pregnancy described insufficient and simplistic information about induced abortions. Clean, easily navigated interfaces were appreciated. However, disorganized designs resulted in unnecessary clicks and hindered information uptake. Easy-to-read illustrations of anatomy were appreciated, and website quality was considered poor when websites lacked them. Assessors described other types of used illustrations and pictures as irrelevant, unsuitable, and complex. Those with terminated pregnancy mentioned that pictures of children were inappropriate, while those with continued pregnancy appreciated pictures of hospitalized children. Assessors also appreciated understandable, easy-to-read language with comprehensible explanations

and the option to read more by clicking on complex words. However, complex language with unnecessary medical terminology was described. Aspects considered to reduce the trustworthiness of websites included outdated information, affiliation with pharmaceutical companies, lack of references, and not using specialist health professionals as authors of medical content.

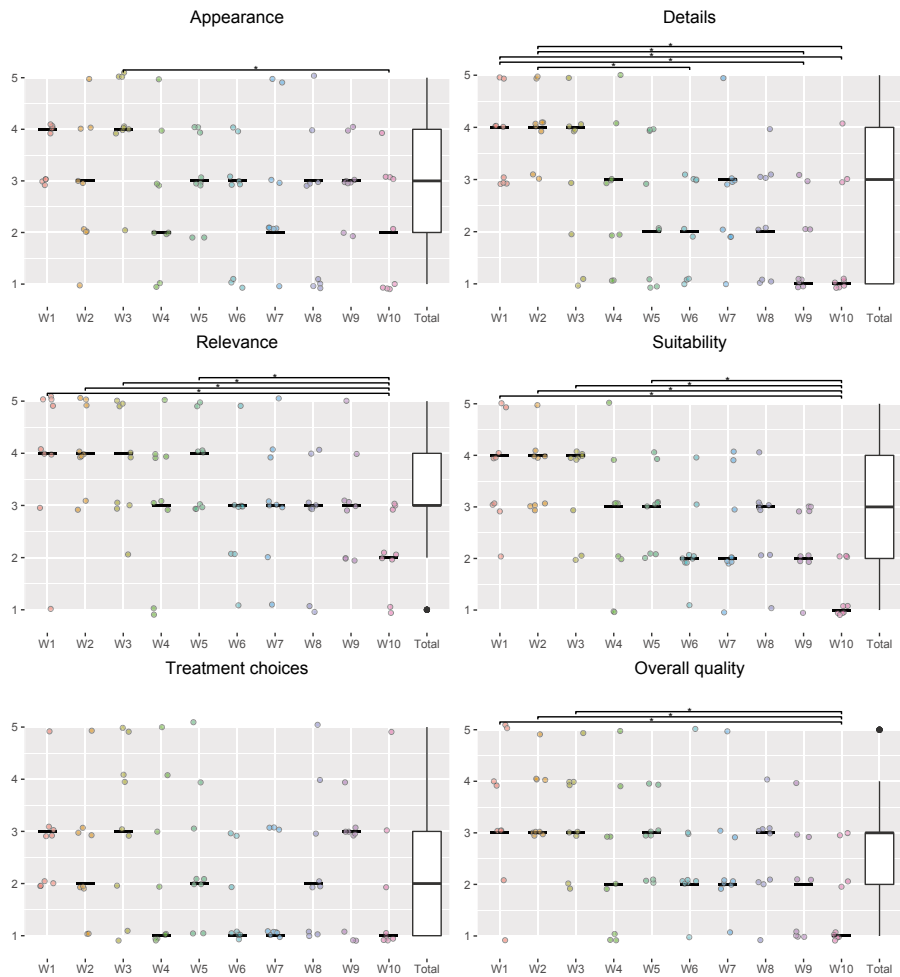


Figure 2. Distributions and medians (horizontal lines in dotplots) of the assessment scores for each of the websites included (n=10), with significant differences between websites (brackets above plots).

1=Low quality; 5=High quality; W=Website; *p < .05.

Discussion

Summary of primary findings

This thesis highlights a number of issues involving patient information following a prenatal diagnosis of congenital heart defect in the fetus. These illustrate the general difficulty persons face following the diagnosis, namely to grasp the unexpected while burdened with trying to take in, search for, understand, and interpret information. Respondents tried to grasp the facts and hunted for information in a confusing reality following the diagnosis. Consequently, they desired information about various topics, offered with methods that promote information uptake. However, the information uptake was hindered by the emotional distress experienced in connection to receiving the news of the heart defect. Professional information offered during face-to-face consultations with specialist health professionals was highly valued, but some described the information as complex and overwhelming. Thus, repeated information was desired and web-based supplemental information was sought. The Web contained an overwhelming amount of information for respondents to sort out, and they described difficulties finding relevant sources of sufficient quality. Systematic searches in web-based search engines confirmed this, as the searches for patient information websites about congenital heart defects resulted in many irrelevant hits. When systematically evaluated, English websites showed issues with regard to quality of information about treatment choices and reliability, and few of the websites included information about pregnancy-related topics, such as induced abortions. From the perspectives of laypersons as assessors, Swedish websites did not fulfill the quality criteria concerning information about treatment choices, and only partly fulfilled quality criteria concerning appearance, details, relevance, suitability and overall quality. There were differences in quality scores between the Swedish websites, illustrating variations in the online landscape. The assessors described negative aspects of the Swedish websites, including inappropriate advertisements, biased information, poor illustrations, complex language, lack of information, and poor trustworthiness.

Discussion of primary findings

The psychological distress following a prenatal diagnosis has been described in previous research,^{28,30,31,195} which was confirmed by the findings of this thesis. The emotional shock made it difficult for respondents to comprehend and remember the information offered during the specialist consultation. The importance of an empathic stance when informing patients about bad news have previously been emphasized in systematic reviews.^{108,117} The interview studies illustrate the value of what has previously been described as the balancing act, between offering enough information and consideration of the emotional state of the recipient.¹¹⁷ It can be speculated that the emotionally difficult situation experienced in connection with a prenatal diagnosis hinders effective communication between expectant parents and specialist professionals. Health professionals need to be mindful of emotional distress following a prenatal diagnosis, and plan their communication of information accordingly.

In line with previous research,⁴⁹ the respondents in the interview studies were satisfied with the information offered during the consultation. Specialist health professionals were considered the best source of information, and the consultation clarified the confusing situation by providing specific information. However, respondents described information offered during the consultation as overwhelming and complex, and experienced difficulties with recollection of the information. Similar results have been reported in the fields of oncology,⁷⁶ primary care,¹⁰⁵ and paediatrics.¹⁰⁶ To confront this, health professionals may need to utilize methods that aim to promote comprehension and reduce potential intrapersonal, interpersonal and institutional barriers.^{107–115,196} Theories acknowledge that decay of human memory may be halted by repetition of information,^{103,104} which supports the concept of supplemental written information as one type of potential intervention following the diagnosis. Such interventions have been shown to increase satisfaction with care and knowledge among patients discharged from acute hospital settings,¹⁹⁷ and is a desired approach following a prenatal diagnosis.^{122,195,198–200} However, a Swedish survey shows that few patients are offered written information following hospital discharge.²⁰¹ At the units for fetal cardiology in Stockholm and Uppsala, no standardized written materials are currently offered to expectant parents faced with a prenatal diagnosis of congenital heart defect in the fetus. The findings of this thesis emphasize the importance to offer repeated and supplemental oral and written information following the diagnosis, provided by specialist health professionals. In line with what is suggested in the findings of this thesis, a small-scaled study of an educational CD-ROM that included supplemental information for expectant parents faced with a prenatal diagnosis of congenital heart defect in the fetus observed that the intervention was well received by the participants, who reported that it was a helpful tool for gaining an under-

standing of the normal cardiovascular system and heart defect.¹⁹⁸ There seems to be a need for efforts with the purpose of developing standardized supplemental written information to expectant parents following a prenatal diagnosis of congenital heart defect in the fetus.

Respondents' valued illustrations as tools to comprehend and remember the information offered during the consultation. Illustrations as supplements to oral information have previously been shown to increase information uptake,^{202,203} and are especially helpful among those with low health literacy.²⁰³ Animations may be especially suitable tools, as they reduce potential gaps in information recall between those with high and low levels of health literacy.²⁰⁴ In Study III, less than half of the websites included illustrations or animations of congenital heart defects. In Study IV, assessors appreciated easy-to-read illustrations of anatomy and regarded the quality as poor when websites lacked these pedagogic tools. Judging from the findings in this thesis, it seems reasonable to assume that there is room for improvement on the Web, so that patients that prefer visual learning²⁰⁵ are provided with illustrations and animations of the detected heart defect. Moreover, the findings emphasize that health professionals should strive towards offering these tools during consultations.

For patients with auditory learning styles, interventions that utilize hearable teaching strategies such as rephrasing and audiotapes may lead to better comprehension of health-related information.²⁰⁵ Interestingly, respondents did not mention any needs for specific auditory interventions, apart from repeated consultations. A possible inexpensive intervention that may promote information uptake is consultation audiotapes, i.e., recordings of the consultation with the health professional. Research indicates that most patients value recordings of consultations, which may have the potential to have positive effects on recall and comprehension.²⁰⁶ A randomized controlled trial among expectant parents faced with a prenatal diagnosis reported significantly less anxiety two weeks after the consultation but no improvement in information recall among those randomized to a tape recording.²⁰⁰ The described needs for repeated consultations and difficulties with information uptake calls attention to the need for studies that investigate auditory interventions following a prenatal diagnosis of congenital heart defect in the fetus.

A majority of the public access the Web to search for health-related information.^{137,138,142} The findings indicate that the Web is used as a source of information following a diagnosis of congenital heart defect in the fetus. However, the use included various difficulties related to finding relevant patient information websites, as indicated both through interviews and through web-based systematic searches in search engines. Previous studies have observed that information consumers use sub-optimal search strategies and show limited critical skills of web-based information sources.^{146,147} Similarly, parents to children with congenital heart defects experience diffi-

culties using the Web for supplemental information.^{132,133} The findings illustrate a need for health professionals to discuss which web-based search strategies that expectant parents faced with a prenatal diagnosis plan to use after the consultation. Interventions may be needed to help them identify web-based sources of high quality. A possible way could be to offer recommendations on appropriate websites and search terms, which was desired and appreciated by the respondents. However, cardiologists rank the importance of information about websites lower than parents of children with congenital heart defects,¹³⁶ and few parents receive recommendations on appropriate websites.²⁰⁷ A possible explanation for this may be that health professionals lack the time and skills needed to familiarize themselves with available web-based sources.²⁰⁸ Perhaps there is a need for interventions that aim to educate health professionals in health informatics, in order to make them feel competent to communicate about this topic with their patients.

User guides and checklists have been launched as attempts to empower patients to, by themselves, identify and use high-quality web-based sources.^{156,157} However, empowering laypersons to identify and assess web-based sources has been criticized as an overly optimistic approach²⁰⁸ and for placing a great burden on patients.^{156,158,208} Moreover, these tools do not take insufficient digital skills among patients into consideration.²⁰⁸ Considering the emotional distress experienced by expectant parents faced with a prenatal diagnosis,^{28,30,31,195} it may be reasonable to assume that many would not be up to the task of using such tools when receiving the news. Guiding expectant parents to high-quality supplemental web-based information seems to present itself as a current yet challenging task. It is possible that there is a need for efforts from overarching institutions to publish updated lists of recommendations for web-based sources.

Quality deficits of web-based information about congenital heart defects were described by interviewed respondents, which was confirmed when English and Swedish websites were assessed. An increasing amount of studies raise concerns regarding the quality of health-related web-based information.^{149–152,155} It is imperative that pregnant persons make informed decisions regarding whether to continue or terminate the pregnancy,¹² which may be hindered by biased, unreliable, and insufficient web-based patient information. The importance of current and unbiased information is stressed in the context of the field of fetal cardiology.¹² Considering the temporal changes that inherently influence the amount and quality of available websites,¹⁴⁴ one can argue that a need exists for more regulated publication of patient material. However, the unregulated nature of web-based information is a fact,^{144,148} as practically anyone with access to the Web can publish content. Health professionals and researchers need to take steps to ensure patients come in contact with the most appropriate high-quality web-based sources of information. The findings illustrate the need for improvement of the overall quality of web-based sources about congenital heart defects. There may be a need for national

or international collaborations, with the purpose to develop trustworthy web-based sources that include supplemental patient information for those faced with a prenatal diagnosis of fetal anomaly.

Preparatory information before an induced abortion is a known indicator of quality abortion care.²⁰⁹ However, respondents described unmet informational needs about induced abortions. Similar to the findings in this thesis, a previous cross-sectional Swedish study that used mixed methods found that more than half of the included participants experienced fear before induced abortion. In a follow-up interview, various strategies for information retrieval were described. This included use of the Web, which was believed to lack sufficient information.⁶³ Another Swedish qualitative interview study observed that participants lacked an understanding about the abortion process, and experienced the information provided by health professionals as high-blown.²¹⁰ It is possible that the unmet need for information described by respondents is a result of unclear guidelines regarding the informational responsibilities of the units for fetal cardiology and gynecology. The findings illustrate that new or improved methods for information delivery might be necessary, to adequately meet the needs among those who decide to terminate the pregnancy following a prenatal diagnosis. More research is needed to investigate this topic further.

When a diagnosis of a fetal anomaly has been made, a multidisciplinary approach may be the most efficient approach to providing information and support for expectant parents.^{12,34} Such an approach may lead to patients feeling more secure and satisfied with the care.³⁴ Moreover, multidisciplinary approaches in the care for persons with perinatal losses have the potential to promote implementation of standardized procedures, and may lead to holistic, comprehensive, care.²¹¹ One such option may be to adopt a team-based strategy with nurse or midwife-led abortion counseling as a supplement to the counseling provided by physicians. Research indicates that the large majority of patients who receive midwife-led amniocentesis counseling experience the information as excellent or good, and feel they had an adequate opportunity to ask questions.²¹² Similar results have been reported for nurse-led sterilization counseling,²¹³ early pregnancy assessment²¹⁴, and preoperative assessment for gynecology surgery²¹⁵. It is possible that supplemental nurse or midwife-led counseling could increase patient preparedness for a medically induced second-trimester abortion following a prenatal diagnosis of fetal anomaly. More research is needed to investigate potential benefits of such interventions.

An evaluation of a website dedicated to information about induced abortions showed a steady increase in number of visits, reaching over 420,000 visits from 208 countries around the world.²¹⁶ Further illustrating the public demand for web-based information about induced abortions, another study found that abortion was the most common gynecology-related search term used in Google in 2013.²¹⁷ These reports call attention to the need for high

quality web-based patient information about induced abortions. However, few of the English websites included information about pregnancy termination following a prenatal diagnosis of congenital heart defect in the fetus, and the included websites received poor quality assessment scores concerning information about treatment choices. The assessors found the Swedish websites to include unbalanced and insufficient information about pregnancy termination. Inaccurate information on websites about induced abortions have previously been reported in evaluations of web-based information,^{151,152,218} further illustrating the problematic situation with poor website quality. Taken together, the findings indicate that persons who terminate the pregnancy due to a congenital heart defect in the fetus are left with unanswered questions following consultations with health professionals, which may persist or even worsen when they search for supplemental web-based information. Steps need to be taken to ensure sufficient patient information about induced abortions during counseling, and to raise the inclusion of such topics on websites about congenital heart defects, so as to adequately promote patient preparedness for the abortion process.

Methodological considerations

To address the research questions, qualitative and quantitative approaches were used. Qualitative approaches were used to inductively explore content without predetermined categories of analysis, with the purpose to gain insights and provide descriptions grounded in the experiences of persons with experience of a prenatal diagnosis. Quantitative approaches were used to investigate certain predetermined measurements of website quality, with the purpose of drawing statistical conclusions that may be generalized.¹⁸¹ Both females and males with continued and terminated pregnancy were recruited as respondents and assessors. Moreover, both English and Swedish websites were assessed. These aspects strengthen the transferability and generalizability of the findings. However, there are methodological considerations that should be taken into consideration.

Trustworthiness of qualitative findings (Studies I, II and IV)

The manner in which the interviews were carried out is an important aspect of credibility, i.e., how well the findings represent reality as seen by the respondents and how well the findings represents the phenomenon or intended focus of the study.^{191,219} Instrumental consistency refers to how consistent the interviewer has been during the course of data collection.²¹⁹ An interview guide was used in Studies I and II, which presented the possibility to stay close to the aim and ask similar questions to all respondents while allowing flexibility.^{181,220} In contrast, no discussion guide was used for the focus

group discussions in Study IV. The reasons behind this approach was to explore the native views among the assessors by allowing them to bring up topics considered important from their perspectives, and promote discussions not colored by the preconceptions of researchers. It is possible that my professional and personal background influenced the interviews and focus groups.^{221,222} For example, respondents may not have felt able to freely criticize the behaviors of health professionals. To confront this, I made sure to state that I was not involved in the clinical care at the units for fetal cardiology and that their interview would not affect any future care. Further, I stated the purpose of the interview and emphasized the value of honest descriptions. Nevertheless, it is possible that my background had an impact on the data collection.

Aspects related to the credibility of the analysis refer to the selection of meaning units, and the extent that categories or themes cover the data. Too broad or narrow meaning units imply a risk of losing the meaning of the data. Furthermore, categories or themes may not fully represent the data, leading to findings that exclude relevant parts of the data or are based on irrelevant parts.¹⁹¹ By including examples of the process of identifying, condensing, and coding meaning units, readers may gain an understanding of the analytic process. Through discussions with other members of the research team, the data could be approached with new perspectives.^{191,221} Moreover, the experience and training of the researcher is linked to the credibility of analyses in qualitative studies.^{181,221} During the course of the studies, I received training and became familiar with the analytic steps in content analyses. Nevertheless, it is possible that the analytic steps led to findings that do not fully represent the experiences of the respondents.

In Study I, respondents were able to choose whether to be interviewed jointly or individually. Joint interviews may result in increased participation²²³ and an enhanced interview situation.²²⁴ It has been suggested as an appropriate method when exploring complex shared practices of couples,^{225,226} such as experiences following a prenatal diagnosis. On the other hand, joint interviews may involve risks associated with interactions between respondents,²²⁶ which potentially could have impacted the findings. My own reflections are that the flexible approach promoted respondents to feel comfortable and willing to share their experiences. In contrast with Study I, Study II involved individual interviews. It is possible that interviews would have generated different findings if all interviews had been conducted in the same manner, either jointly or individually. On the other hand, these two ways to conduct interviews offered an opportunity to explore experiences with different approaches, which may have led to richer overall findings.

In relation to face-to-face interviews, telephone interviews may have the potential to increase anonymity, decrease social pressure,^{227–229} and promote respondents to feel comfortable.^{227–230} Potential disadvantages involve a

decreased opportunity to create a comfortable physical ambiance and lack of nonverbal communication.²²⁸ It is possible that some valuable data was lost due to the telephone communication in Study II. However, my own reflections are that the respondents valued the practical advantages, that the chosen method for data collection made recruitment of respondents easier, and that it encouraged the participants to freely express their experiences. When the interview ended, several expressed appreciation of the chosen method for communication and mentioned that they might have declined participation, if it had required a face-to-face interview.

Confirmability refers to the objectivity or neutrality in a study, i.e., how the researcher affects the findings and whether the findings can be confirmed by others.²³¹ In qualitative research, the researcher is considered the tool for analysis. There are multiple perceived realities and experiences, and what the researcher perceives is determined by the interaction with the respondent, as well as their own previous experiences and values.¹⁸¹ To strive towards reflection and awareness of my own preconceptions, I kept a reflective journal. This may have promoted me to be open to the experiences of respondents.^{181,232} Moreover, discussions were held in order to get feedback from members of the research team. Through these discussions, the analyses could potentially be approached with different perspectives, which may imply a richer and more nuanced representation of the data.²¹⁹ Nevertheless, the findings are products of my work and should be interpreted with this in mind.

The recruitment involved purposeful (Study I and IV) and consecutive (Study II) sampling. The attempts to include a varied sample when using a purposeful recruitment may result in nuanced and transferable findings.^{219,220} In contrast, consecutive recruitment, which lacks any such attempts, may imply limited transferability, i.e., the extent of which the findings can be transferred to other contexts.²¹⁹ It is possible that a purposeful recruitment in Study II would have generated richer findings from a more diverse sample. On the other hand, the respondents were recruited during a period of nine months from two units, which may imply transferability with regard over time and to different clinical settings. Only Swedish-speaking respondents were included. Consequently, it is possible that the findings do not represent experiences of persons who do not speak Swedish.

Data saturation deals with the richness of the data, referred to as the collection of data until the point of redundancy.^{219,220} The literature suggests that there are no clear rules or recommendations for sample size in qualitative research. When judging the meaningfulness of the findings, the richness of the data and the capabilities to capture the phenomenon may be regarded as more important than the actual sample size.^{181,220} On the other hand, the concept of data saturation has been criticized as vague²³³ and opposed to the foundations of qualitative research.²³⁴ As data was collected and analyzed, it became increasingly clear that additional interviews did not challenge the

findings. It is probable that this is an expression of the descriptive approach, in which the purpose was to provide surface descriptions, rather than in-depth interpretations.¹⁸⁸ Moreover, it is probable that additional interviews would generate new findings. In this thesis, the concept of data saturation relates to surface descriptions of the topic of research and the context in which the data was collected. No claims can be made for data saturation concerning other aspects of experiences following a prenatal diagnosis of congenital heart defects in the fetus.

Validity and reliability of quantitative results (Studies III and IV)

The included websites were identified through searches in web-based search engines, which is in line with user patterns among the public.^{137,235} The search engines used in Studies III and IV were, during the time of the studies, the most commonly used on the Web.¹⁸² Search terms believed to represent search terms similar to those used by laypersons without a background in healthcare were chosen. However, it is possible that these search terms did not produce hits that fully represent searches performed by laypersons. On the other hand, the searches yielded high numbers of duplicate hits, indicating saturation with regard to identified websites. The preferred search terms reported by the assessors confirmed the search terms used, indicating adequate representativeness. The search engines produced a range of hits, which was presented in web pages consisting of ten hits on each page. Research has observed that information seekers rarely search beyond these first ten hits.¹⁴⁶ The first 50 (Study III) and 20 (Study IV) hits of each search were screened for inclusion, indicating that the screening procedure went beyond common search patterns among the public. Moreover, I screened the hits for inclusion. It is possible that excluded websites would have been judged in another way by laypersons, had they been consulted during this process.

DISCERN instrument and LIDA tool were used to systematically assess the included English websites in Study III. It is possible that these assessments involved elements of bias related to my professional or personal background. However, research suggests that assessments are not dependent on previous knowledge of the assessor.²³⁶ The DISCERN instrument, developed and designed to help users of health information judge the quality of written information, has been found to be consistently understood and transferable to different areas.^{183,186,237,238} Nevertheless, the lack of laypersons as assessors in Study III is a limitation. Previous studies investigating website quality have, as in Study III, most commonly used professionals as assessors.¹⁶²⁻¹⁷⁰ The identified differences in perspectives of laypersons and professionals^{172,173} calls attention to the lack of assessments from the perspec-

tives of the intended consumers of patient information. These reasonings led to the chosen method in Study IV, in which persons with experience of a prenatal diagnosis of congenital heart defect in the fetus were used as assessors. Moreover, research has most often used one to four assessors,^{150,152,155,162,163} illustrating that use of nine assessors is in the larger range of what usually is seen.

Assessors of varied ages and countries of birth were purposefully recruited. However, we failed to recruit assessors with terminated pregnancy who were born outside Sweden, as well as assessors with an educational level of junior high school. Moreover, the assessors had experience of a range of different congenital heart defects, which may have reflected their assessments. It is possible that a greater variation within the group of assessors would produce more generalizable findings. On the other hand, the interrater reliability ranged between 0.18 and 0.66, with higher coefficients of concordance for assessors who shared similar pregnancy outcome. This indicates at least fair to moderate concordance between the assessors,¹⁹³ which strengthens the generalizability.

Various instruments have been launched with the purposes to assess website quality. In this thesis, user guides^{156,157} were used to assess website quality with quantitative measures in Study III. Few user guides are considered practically usable by the intended consumers, as the majority include too many elements.¹⁵⁹ This aspect was the primary reason for using an independently developed quality assessment tool in Study IV. There is a need for the development of validated quality assessment tools that are suitable and easy to use by the intended consumers. It is difficult to draw any firm conclusions regarding the reliability, i.e., the consistency,^{192,239,240} of the assessments between different assessors when using the independently developed assessment tool. However, the adequate levels of concordance suggests consistency in the assessments and indicates that the elements for assessments were well defined.¹⁹²

Non-parametric statistics, sometimes also referred to as ‘assumption-free tests’, are appropriate when the data does not comply with required assumptions for parametric statistics. Non-parametric statistics allow analyses of smaller samples and do not require normal distributions,^{241–243} which were the reasons for using it in Study IV. Such statistics focus on the ranks of data.^{242,243} Consequently, information was lost concerning the magnitude of the differences between assessment scores. If the required assumptions for parametric statistics had been fulfilled, such analyses could have potentially led to more robust results.^{242,243}

Conclusions

Expectant parents faced with a prenatal diagnosis of congenital heart defect in the fetus try to grasp the unexpected, an attempt that involves various difficulties with regard to information. These difficulties are present during consultations with health professionals, as well as when searching for and interpreting supplemental web-based information.

The following conclusions can be drawn:

- If an emotional shock is experienced following the diagnosis, it may hinder information uptake during the consultation with specialist health professionals.
- Early, honest, and trustworthy information, offered by specialist health professionals, is highly valued by expectant parents.
- The information offered by specialist health professionals may be experienced as overwhelming and complex by expectant parents.
- Supplemental written information, including illustrations of anatomy, is desired and appreciated among expectant parents.
- The Web is used by expectant parents for supplemental information about congenital heart defects following the diagnosis.
- From the perspectives of expectant parents faced with a prenatal diagnosis, the Web contains an overwhelming amount of available patient information websites about congenital heart defects.
- It is difficult to identify relevant patient information websites about congenital heart defects when using popular search engines.
- Patient information websites about congenital heart defects often lack topics which expectant parents may desire information about, such as induced abortions.
- Patient information websites about congenital heart defects are of poor overall quality, especially reliability, trustworthiness, and information about treatment choices.
- Expectant parents who decide to terminate the pregnancy may experience insufficient information about induced abortions, both from health professionals and what is found on the Web.

Clinical implications

The findings may be applicable in clinical situations when health professionals consult expectant parents faced with a prenatal diagnosis of congenital heart defect in the fetus.

The following clinical implications are suggested:

- The identified difficulties with information uptake calls attention to the possible need for repeated information through additional counseling sessions and supplemental written information.
- Illustrations of anatomy are important pedagogic tools that expectant parents desire, and should be used liberally.
- Expectant parents may need to be informed about the overall poor quality of websites about congenital heart defects.
- Expectant parents who plan to use the Web for supplemental information should be offered recommendations on appropriate search strategies and websites.
- When a decision to terminate the pregnancy is reached, health professionals should make sure that they have offered sufficient information about the process involved with induced abortions.

Suggestions for future research

The included studies all generate new hypotheses, and imply a need for future research within the context of patient information following a prenatal diagnosis of congenital heart defects. First, more research is needed concerning populations that are not represented within the included studies in this thesis, such as immigrants who do not speak Swedish and persons with low educational levels. Second, researchers should focus their work towards developing and testing interventions that correspond to the informational needs identified in this thesis, such as web-based supplemental information.

The following future research topics are suggested:

- Needs and preferences of immigrants, non-native speakers, those with low health literacy, and those with low educational levels.
- Ways to ensure sufficient information needed to promote preparedness for pregnancy termination due to a prenatal diagnosis of a fetal anomaly.
- Studies testing supplemental web-based written information as interventions following the prenatal diagnosis.

Recommendations for website developers

The findings illustrate various aspects that developers should consider when developing and maintaining websites about congenital heart defects.

The following considerations are recommended when developing websites, so that they may meet the needs of the intended information consumers:

- Include patient information concerning pregnancy-related topics such as risk of congenital heart defects in future pregnancies, induced abortions, and care during pregnancy.
- Ensure balanced information concerning pregnancy termination and possible consequences of living with a severe heart defect.
- Include statistics when possible.
- Include information about postnatal care, quality of life, as well as examples of cases with continued and terminated pregnancies.
- Raise the quality of patient information about areas of uncertainty, risks with treatment, effects of treatment, effects on quality of life, available options, and support for shared decision making.
- Raise the quality of engagability, currency, and content production.
- Develop clean and easily navigated designs.
- Do not include advertisements, and if necessary, review whether they are suitable for the context of prenatal diagnosis.
- Include clear and easy-to-read illustrations of the anatomy of the normal cardiovascular system and specific heart defects.
- Provide details concerning references, authorship, and date when the information was written.
- Strive towards continuous updates of the website, and clearly state when it has been updated.

Svensk sammanfattning (Swedish summary)

Bakgrund

Med ultraljudsundersökning av gravida är det möjligt att upptäcka medfödda hjärtfel hos foster, vilka är den vanligaste typen av missbildningar. En sådan diagnos innebär möjligheter att planera vård efter födseln och för gravida att besluta om graviditeten ska avbrytas genom medicinsk abort. Många är inte förberedda på en upptäckt av en missbildning hos fostret och hamnar i ett psykologiskt trauma vid beskedet. Beslutet att fortsätta eller avbryta graviditeten upplevs av många som svårt och vilar på olika ställningstaganden. Personer som får beskedet att fostret har en missbildning söker information för att försöka förstå deras situation och inhämta kunskap för att kunna fatta ett informerat beslut gällande graviditetsavbrytande. Enligt forskning har dessa personer svårigheter att förstå informationen från vårdpersonal och upplever att personalen inte alltid bemöter deras informationsbehov. Forskning saknas som undersöker lämpliga tekniker för att erbjuda information efter en upptäckt av medfött hjärtfel hos fostret. Vidare antyder forskning att dessa personer använder Webben för att söka efter och läsa kompletterande information. Storleken och strukturen på Webben innebär en risk att det skulle vara svårt att hitta relevant information om medfödda hjärtfel och att det skulle vara låg kvalitet på den tillgängliga informationen. På senare tid har en ökad mängd forskning rapporterat bristande kvalitet för webbsidor om olika hälsorelaterade ämnen. De flesta av dessa studier har dock använt forskare eller vårdpersonal som granskare av webbsidor. Det är dock möjligt att de personer som informationen riktar sig till uppfattar webbsidorna på ett annat sätt. Ingen studie har tidigare undersökt kvaliteten på webbsidor om medfödda hjärtfel.

Syfte

Syftet var att utforska erfarenheter och behov av information efter en diagnos av medfödda hjärtfel hos fostret, och att utvärdera kvaliteten av offentligt tillgängliga webbsidor om medfödda hjärtfel.

Metod

Studierna var utforskande och beskrivande, med kvalitativa och kvantitativa metoder. Delarbete I var en kvalitativ intervjustudie som utforskade erfarenheter bland 11 föräldrar till barn som diagnosticerades med medfödda hjärtfel under graviditeten. Delarbete II var en kvalitativ intervjustudie som utforskade erfarenheter bland 26 personer som 5-15 veckor innan en telefonintervju var med om en diagnos av medfödda hjärtfel hos fostret. Delarbete III var en kvantitativ beskrivande studie av 67 Engelskspråkiga webbsidor om medfödda hjärtfel. Informationen utforskades gällande innehåll. Vidare utvärderades tillgängligheten, reliabiliteten, användbarheten och information om behandlingsalternativ med två systematiska verktyg, DISCERN och LIDA. I delarbete IV användes en mixad metod för att utforska 10 Svenskspråkiga webbsidor om medfödda hjärtfel. Nio personer med erfarenhet av en diagnos av medfödda hjärtfel hos fostret utvärderade webbsidorna med skattningar av utseendet, detaljer, relevans, lämplighet, information om behandlingsalternativ och övergripande kvalitet. Samma personer svarade skriftligt på öppna frågor och deltog i en gruppdiskussion om webbsidorna. Textbaserat material från intervjuer, diskussioner, skriftliga svar på öppna frågor, och information på webbsidor analyserades med innehållsanalys. Kvalitetsskattningar analyserades med statistiska beräkningar gällande överensstämmelse mellan granskare, skillnader mellan de som avbröt respektive fortsatte graviditeten, och skillnader mellan de inkluderade webbsidorna.

Resultat

Delarbete I resulterade i tre teman som representerar erfarenheterna relaterade till att söka och förstå informationen från såväl vårdpersonal som via Webben. Den emotionella chocken innebar svårigheter att ta in och komma ihåg information, vilket ansågs underlättas med upprepade och visuell information. Personlig och kontinuerlig kontakt med specialister ansågs det bästa sättet att få information. Deltagarna värderade ärlig information och var nöjda med informationen från vårdpersonalen. Vissa sökte information via Webben, andra gjorde det inte alls. De som gjorde det litade inte på informationen och beskrev svårigheter att hitta relevanta webbsidor. Vårdpersonalens rekommendationer av webbsidor efterfrågades.

Delarbete II resulterade i ett övergripande tema som representerar ansträngningarna och viljan att såväl söka som finna information i en situation av förvirring. Upptäckten innebar en emotionell chock, som medförde svårigheter att förstå och komma ihåg informationen. Situationen klargjordes vid mötet med specialisten, som ansågs vara av övergripande hög kvalitet men innehållande komplex och överväldigande information. Information tillgänglig i ett så tidigt skede som möjligt efterfrågades, med detaljerad och

ärlig information om deras situation såväl under som efter graviditeten. Deltagarna värderade upprepad, skriftlig och visuell information. Samtidigt som vissa undvek Webben, använde andra det för information. Sökningarna på Webben hade upplevts svåra, men de som fick rekommendationer beskrev att det hjälpt dem. Webbssidor ansågs vara av bristande kvalitet med komplex och otillräcklig information som ibland upplevdes partisk emot graviditetsavbrytande. Information om graviditetsavbrytande ansågs av vissa vara särskilt bristande, vilket resulterade i oro och obesvarade frågor. Andra var nöjda med den abortrelaterade informationen de fick från vårdpersonalen.

Delarbete III visade att få webbsidor innehöll information om ämnen relaterade till graviditet. Fyra webbsidor innehöll information om graviditetsavbrytande. Medelvärdet för DISCERN var 27.9 av 80, för LIDA 92.3 av 141. Samtliga frågor i DISCERN hade medelvärden under 3.0, vilket innebär allvarliga brister. För LIDA hade interaktivitet, aktualitet, och produktion av information medelvärden under 50 procent, vilket innebär låg kvalitet.

Delarbete IV visade att medianerna för utseende, detaljer, relevans, lämplighet, och övergripande kvalitet var 3.0, vilket innebär delvis uppnådda kvalitetskriterier. Medianen för behandlingsalternativ var 2.0, vilket innebär ouppnådd kvalitetskriterium. Överensstämmelsen mellan granskare varierade mellan 0.18 och 0.40, vilket innebär god nivå. Skillnader observerades mellan webbsidorna för samtliga undersökta kvalitetskriterier. I jämförelse med andra webbsidor hade en webbsida särskilt låga skattningar gällande utseende, detaljer, relevans, lämplighet och övergripande kvalitet. Ytterligare två hade låga skattningar för detaljer i jämförelse med två andra webbsidor. Den kvalitativa analysen resulterade i sex kategorier som representerar granskarnas perspektiv. Problem beskrevs gällande olämplig reklam, partisk information, illustrationer av låg kvalitet, komplext språk och låg trovärdighet. Informationen ansågs vara förminskande gällande allvarliga hjärtfels påverkan på livet, med en överdrivet optimistisk synvinkel. Vidare ansågs informationen vara obalanserad gällande alternativen att fortsätta eller avbryta graviditeten, med bristande information om graviditetsavbrytande.

Slutsats och kliniska implikationer

Personer som väntar barn och får en diagnos av medfödda hjärtfel hos fostret försöker förstå det oväntade, vilket innefattar svårigheter att ta in och tolka information. Webben används för kompletterande information, men det är svårt att hitta relevanta webbsidor och kvaliteten är låg. Vårdpersonal behöver använda metoder som syftar till att förbättra förståelse och hågkomst av information. Det finns behov av rekommendationer gällande sökstrategier och webbsidor. Resultatet visar ett behov av framtida studier som undersöker hjälpmedel för att på bästa sätt erbjuda tillräcklig och kompletterande information, och sätt att höja kvaliteten av webbsidor om medfödda hjärtfel.

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