Communication about reproductive intentions and planning with women of reproductive age affected by a chronic health condition: a systematic review

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Master of Family Medicine
Masterproef Huisartsgeneeskunde

Academic year: 2024 - 2025

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1. ABSTRACT

Background: Preconception counselling improves pregnancy outcomes, especially in high-risk pregnancies of women with non-communicable diseases (NCDs). Physicians historically advised against pregnancy in case of NCDs but advances in medical care currently allow managing the safety of pregnancies by careful planning and monitoring. This, however, requires timely and open communication between healthcare providers (HCPs) and patients. HCPs shared that they struggle with conversations on reproductive intentions and planning and the available model for discussing reproductive life planning has yet to be adapted for women with serious NCD. Patient-centred communication strategies require insight in the perspectives of these women.

Objectives: To examine the perspectives of women with NCDs and their partners on the positive and negative influencing factors, delivery characteristics and content of patient – physician communication about reproductive intentions and planning.

Methods: A systematic review was conducted according to PRISMA guidelines. The databases Medline, EMBASE and ProQuest PsycArticles were searched with terms related to chronic NCDs and family planning, pregnancy and parenthood. English, Dutch or French papers on qualitative studies, surveys and mixed-method studies examining the perspectives of women with chronic NCDs on conversations with HCP regarding reproductive intentions and planning were considered eligible. The methodological quality of the included studies was assessed with Critical Appraisal Skills Programme (CASP) checklists. Data on study population, methodology, scope and relevant findings was extracted. The meta-synthesis of the findings was on the one hand structured by conceptual models (e.g. the Intervention Taxonomy (ITAX) framework for describing delivery characteristics of communication) and on the other hand relied on an inductive approach to code the perspectives of women on the valued content of patient-physician communication.

Results: The search strategy yielded 9407 unique papers, of which 17 were selected that reported on a qualitative study (n=10/17), a survey (n=5/17) or a mixed-method study (n=2/17). One study focused on the perspectives of partners beside patients. The studies addressed six different NCDs, of which most commonly: cystic fibrosis (n=5/17) and rheumatic diseases (n=5/17). The identified negative and positive factors influencing patient-physician conversations about reproductive intentions and planning included patient factors (-: limited knowledge and skills for health management; +: pro-active attitude), clinician factors (-: limited communication skill training; +: having invested in strong patient-physician relationships) and setting factors (-: limited resources; + integrated care systems). Women expressed a strong desire for HCPs to initiate the conversations about reproductive intentions and planning, and to regularly revisit the topic during their reproductive life span. Women preferred face-to-face interactions, with HCPs paying attention to clear, empathic and supportive language. Regarding the content of the conversations, women wanted a wide range of topics to be covered (e.g. medication safety during pregnancy, impact of condition on long term family life). They also valued making their own informed choices on their reproductive life, whilst receiving decisional support (e.g. personalized information & a HCP acknowledging the emotional complexity of the decision).

Conclusion: This systematic review emphasizes the need for physicians in clinical practice to proactively and repeatedly initiate in-person conversations about reproductive intentions and planning and to collaborate with all relevant health care professionals, whilst investing in their doctor-patient relationship. This systematic review also calls for research focusing on diverse populations and for the development of a patient-centred communication model and communication skills training, for which the impact on care experiences, short- and long-term clinical outcomes (e.g. proportion of unplanned pregnancies) and psychosocial outcomes (e.g. decisional regret) should be evaluated.

2. ABSTRACT (DUTCH)

Achtergrond: Preconceptiezorg verbetert zwangerschapsuitkomsten, vooral bij hoog risico zwangerschappen zoals bij vrouwen met chronische niet-overdraagbare aandoeningen (NOA's). Vroeger raadden artsen zwangerschap af bij vrouwen met NOA's, maar door medische vooruitgang kan de veiligheid van zo'n zwangerschap tegenwoordig worden gewaarborgd door zorgvuldige planning en opvolging. Dit vereist tijdige en open communicatie tussen zorgverleners en patiënten. Zorgverleners gaven in het verleden aan gesprekken over zwangerschapsplanning als moeilijk te ervaren en bestaande modellen voor het bespreken van reproductive life planning zijn niet aangepast aan vrouwen met NOA's. Patiëntgerichte communicatiestrategieën vereisen inzicht in de perspectieven van deze vrouwen.

Onderzoeksvraag: Het doel van dit onderzoek is het onderzoeken van perspectieven van vrouwen met NOA's en hun partners met betrekking tot positieve en negatieve beïnvloedende factoren, de karakteristieken en de inhoud van de communicatie tussen patiënt en arts over reproductieve intenties en planning.

Methodes: Een systematische review werd volgens PRISMA-richtlijnen uitgevoerd in Medline, EMBASE en ProQuest PsycArticles, met zoektermen die betrekking hebben op chronische niet-overdraagbare aandoeningen, gezinsplanning, zwangerschap en ouderschap. Engelstalige, Nederlandstalige of Franse studies met een kwalitatief design, vragenlijsten en mixed-methods design kwamen in aanmerking. Ze dienden perspectieven van vrouwen met chronische NOA's te bestuderen met betrekking tot communicatie met zorgverleners over reproductieve intenties en planning. De methodologische kwaliteit van de geïncludeerde studies werd beoordeeld aan de hand van Critical Appraisal Skills Programme (CASP) checklists. Data over de onderzoekspopulatie, methodologie, scope en relevante bevindingen werd geëxtraheerd. De meta-synthesis van de bevindingen werd enerzijds gestructureerd aan de hand van conceptuele modellen (zoals het Intervention Taxonomy (ITAX) framework voor het beschrijven van communicatiekenmerken) en anderzijds via een inductieve benadering om perspectieven van vrouwen te coderen over de inhoud van communicatie tussen arts en patiënt.

Resultaten: De zoekstrategie leverde 9407 artikels op, waarvan 17 studies geselecteerd werden die rapporteerden over een kwalitatieve studie (n=10/17), een vragenlijst (n=5/17) of een mixed-methods studie (n=2/17). Eén studie rapporteerde over de perspectieven van partners van vrouwen met NOA's. Zes verschillende aandoeningen werden onderzocht in de studies, waarvan cystic fibrosis (n=5/17) en reumatische aandoeningen (n=5/17) het meest voorkwamen. De geïdentificeerde negatieve en positieve factoren die van invloed zijn op arts-patiënt conversaties over reproductieve intenties en planning, omvatten patiënt factoren (-: beperkte kennis en skills voor gezondheidsmanagament, +: proactieve houding), zorgverlener factoren (-: beperkte training betreffende communicatieve vaardigheden, +: geïnvesteerd hebben in sterke arts-patiënt relaties) en setting factoren (-: beperkte middelen, +: geïntegreerde zorgsystemen). Vrouwen verkozen dat zorgverleners het initiatief namen in het initiëren van conversaties over reproductieve intenties en planning, en dat dit onderwerp herhaaldelijk door zorgverleners werd aangekaart. Ze gaven voorkeur aan face-to-face gesprekken, met duidelijke, empathische en ondersteunend taalgebruik. Betreffende de inhoud van de conversaties, wensten vrouwen dat een breed aanbod aan onderwerpen besproken werd (bv. veiligheid van medicatie tijdens zwangerschap, impact van aandoening op gezinsleven op lange termijn). Bovendien hechtten ze ook waarde aan ondersteuning bij het maken van geïnformeerde keuzes (o.a. gepersonaliseerde informatie, zorgverlener die de emotionele complexiteit van de beslissing erkent).

Conclusie: Deze systematic review benadrukt de noodzaak voor zorgverleners om in de klinische praktijk proactief en herhaaldelijk in-person conversaties te initiëren over reproductieve intenties en planning, samen te werken met alle relevante zorgverleners, en gelijktijdig te investeren in de arts-patiënt relatie. Deze review roept ook op tot onderzoek dat focust op diverse populaties, de ontwikkeling van patiëntgerichte communicatiemodellen, en training van communicatieve vaardigheden, waarvan het effect op zorgervaringen, klinische uitkomsten op korte- en lange termijn (o.a. proportie van ongeplande zwangerschappen) en psychosociale uitkomsten (o.a. keuzespijt) geëvalueerd dient te worden.

3. INTRODUCTION

Improving maternal health and reducing child mortality remain key global priorities, as presented in the United Nations' Sustainable Development Goals for 2030. Despite large efforts made between 1990 and 2015, continued progress is essential to further reduce neonatal as well as maternal morbidity and mortality and improve maternal and neonatal health outcomes (1). Therefore, reproductive health and preconception care is crucial and its importance on improving fertility and pregnancy outcomes is well acknowledged (2), as both chronic and acute illnesses, alongside environmental exposures and ingestion of teratogenic agents, can exert adverse effects on fertility and fetal development (3). During the preconception period – the time before a woman becomes pregnant – a critical window presents itself for optimizing reproductive health and addressing these risk factors.

Preconception care, as defined by the World Health Organization as "the provision of biomedical, behavioural and social health interventions to women and couples before conception occurs, aimed at improving maternal and child health outcomes in both the short and long term" (4), encompasses a broad range of interventions, such as medication management, promoting healthy lifestyle and striving for stabilization of chronic diseases. Although medical optimization is important, preconception care critically depends on effective, timely and empathetic communication between healthcare professionals and patients as well (5).

Reproductive planning is particularly important for females affected by chronic non-communicable diseases (NCDs), who face higher risks of pregnancy-related complications and necessary treatment to control the chronic illness may negatively impact fetal health. Physicians historically advised against pregnancy in case of chronic NCDs but advances in medical care currently allow managing the safety of pregnancies by careful planning and monitoring. Due to these developments, timely and open communication between healthcare providers and patients has become increasingly important. Effective communication and education provided by healthcare providers should thus be a core component integrated into routine health management. Through effective reproductive counselling, informed decision-making becomes possible, enabling the implementation of necessary interventions to enhance maternal and neonatal health outcomes prior to conception.

For the general practitioner (GP), effective communication regarding reproductive intentions and planning, is particularly important, as primary care physicians play a pivotal role in identifying chronic conditions that may affect pregnancy outcomes. Furthermore, as a lot of pregnancies remain unplanned, their role is crucial in addressing preventive care issues in the preconception period. Moreover, GP's often serve as the first point of contact for patients seeking reproductive health advice and they are frequently involved in long-term patient care, which allows them to build a trusting relationship. This relationship can thus foster open communication about sensitive topics, such as medication use, lifestyle changes and mental health, which are essential components of reproductive health for women with chronic conditions (6).

Evidence-based guidelines for preconception care, as established by the Centers for Disease Control and Prevention and the Preconception Health and Health Care Initiative, emphasize screening via comprehensive medical history and risk assessment, alongside health promotion and targeted interventions. Nonetheless, there exists a scarcity of evidence-based guidelines and research on communication methodologies and tools to facilitate discussions on preconception health for health care providers (7).

Gaps remain in how communication around reproductive counselling should be initiated and delivered, resulting in many women, especially women with chronic illnesses, not receiving tailored information regarding how their condition, treatment regimen or medication use may influence their fertility and pregnancy outcomes. Therefor reproductive health discussions remain sporadic in clinical practice and may be overlooked in primary care and specialist contexts where chronic illnesses are frequently managed, unless the patient explicitly initiates the conversation (8).

This communication gap reflects deeper barriers. The sensitive nature of the topic and lack of training in how to appropriately address reproductive intentions may prevent healthcare providers from starting the conversation, with many healthcare providers across different disciplines frequently reporting uncertainty in initiating and structuring conversations on reproductive intentions and planning. Lack of knowledge on this topic, time constraints and not knowing a female's reproductive intentions can further hinder consistent communication (8, 9). These challenges often translate into unmet informational and emotional needs from the patients' perspective. In a systematic review by Hammerberg, women with chronic conditions expressed a desire for condition-specific guidance related to reproductive planning but noted that their providers frequently failed to offer such information, leading to women seeking out reproductive health advice on their own (10).

Few studies have systematically examined how women with chronic conditions experience professional-patient communication regarding reproductive planning and what specific communication strategies or tools are perceived as helpful. This represents a critical gap in both research and clinical practice, as to provide patient-centred reproductive counselling, gaining insight in patients' perspectives on these topics is crucial to ensure that conversations about reproductive intentions and planning are aligned with patients' needs, preferences and values.

Given these existing limitations, a pressing need emerges to better understand the communicative aspects of reproductive counselling for women with chronic NCDs. Little is known about what women themselves identify as positive and negative factors in a conversation about reproductive intentions and planning, including how they evaluate the quality of communication they receive, what characteristics of communication they value and which materials they prefer to support their reproductive decision-making processes.

This study primarily focuses on the communicative aspects of reproductive care. Unlike Hammerberg et al. (10), who primarily explores information and service needs of women with NCDs, our review seeks to fill a gap in understanding how communication around sensitive topics like reproductive intentions and planning, can be optimized to enhance patients' informed decision-making. Furthermore, our review intends to provide recommendations on improving conversations on reproductive intentions and planning, making it more patient-centred and tailored to the unique needs of women with chronic conditions. We thus aimed to examine the perspectives of women with NCDs and their partners on the positive and negative influencing factors, delivery characteristics and content of patient – physician communication about reproductive intentions and planning.

4. METHODS

4.1 Search strategy and study selection

This systematic review adhered to the guidelines outlined by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) (11).

The literature was screened by the first author and spanned the entire range of publication dates from November 1958 to April 2024. A thorough search strategy was executed to retrieve all relevant articles from the following three electronic databases: Medline (via Pubmed), EMBASE and Proquest PsycArticles. An initial search for articles in Medline led to identifying key words and index terms, used in a second search conducted across all three databases. The final search string was tailored to the unique specifications of each database and the final search was conducted between March 15th, 2023 and April 11th, 2024.

The search strategies used terms aiming to cover the topic areas of 1) female AND 2) chronic or non-communicable diseases AND 3) family planning services, preconception or reproductive health care AND 4) parenting or pregnancy. The snowball strategy was subsequently used to examine the reference lists of the relevant articles. The details of the finalized search strategy are tabulated in table 1. In order not to miss any relevant articles, we did not use any methodological filter. Both the search strategy and inclusion criteria were predetermined and documented in a protocol, as presented in the supplementary file (appendix I). All research studies found through the search strategy were systematically evaluated for inclusion based on their eligibility.

The initial screening of articles, based on titles and abstracts, was conducted by the first author. Studies failing to meet the inclusion criteria at this stage were excluded. Full-text articles were subsequently assessed by the first author against the predefined inclusion and exclusion criteria.

Eligible studies for this systematic review encompassed all empirical investigations, comprising qualitative, quantitative and mixed-method studies, while excluding reviews. Peer-reviewed papers (not abstracts of conferences) available in English, Dutch or French were considered. There were no restrictions regarding publication dates. Additionally, studies were required to address communication concerning the desire for parenthood and/or reproductive life planning between, on the one hand, healthcare providers, particularly medical doctors, and, on the other hand, women (potentially including their partners) with prevalent non-communicable diseases.

This review specifically focused on non-communicable chronic diseases, prevalent among women of reproductive age, who require medication that could impact pregnancy. Encompassed conditions included all auto-immune and rheumatic diseases (such as rheumatoid arthritis, lupus, spondylitis, scleroderma, psoriasis), as well as the following other specific non-communicable chronic conditions: chronic renal insufficiency, congenital heart defects, heart failure, hypertension, hypotension, mental health disorders (including anxiety, depression, schizophrenia), diabetes mellitus, thyroid diseases (including hypo- and hyperthyroidism), Hashimoto disease, asthma, cystic fibrosis, epilepsy, migraine, multiple sclerosis, myasthenia gravis, celiac disease, inflammatory bowel disease, endometriosis and polycystic ovary syndrome.

The selection of included non-communicable diseases was based on the included list of the similar previous review by Hammerberg et al. (10) and the most common non-communicable conditions of reproductive age as listed by Kerstens et al. (12).

The included conditions were selected based on their impact on fertility or pregnancy, such as pregnancy being contra-indicated for women with conditions like congenital heart failure, as well as their prevalence among the studied population. Chronic diseases with a relative frequency of 0.3% or more were considered for inclusion. Studies focusing on cancer, menopause, and sexually transmitted diseases were excluded. Additionally, studies solely addressing information provision without interpersonal communication were also excluded.

Table 1: Search strategies

Database	Search Strategy
Medline (via PubMed)	(Female[Mesh]) AND ((chronic disease[MeSH Terms]) OR (diabetes[MeSH Terms]) OR (rheumatic disease[MeSH Terms]) OR (psoriasis[MeSH Terms]) OR (asthma[MeSH Terms]) OR (cystic fibrosis[MeSH Terms]) OR (hypothyroidism[MeSH Terms]) OR (hyperthyroidism[MeSH Terms]) OR (renal insufficiency, chronic[MeSH Terms]) OR (hypertension[MeSH Terms]) OR (hypotension[MeSH Terms]) OR (heart failure[MeSH Terms]) OR (heart defects, congenital[MeSH Terms]) OR (epilepsy[MeSH Terms]) OR (multiple sclerosis[MeSH Terms]) OR (migraine disorders[MeSH Terms]) OR (inflammatory bowel diseases[MeSH Terms]) OR (celiac disease[MeSH Terms]) OR (endometriosis[MeSH Terms]) OR (polycystic ovary syndrome[MeSH Terms]) OR (psychotic disorders[MeSH Terms]) OR (anxiety[MeSH Terms]) OR (depression [MeSH Terms])) AND ((family planning services[MeSH Terms]) OR (preconception care[MeSH Terms]) OR (reproductive health[MeSH Terms]) OR (reproductive health services[MeSH Terms]) OR (sexual health[MeSH Terms]) OR (womens health services[MeSH Terms])) AND ((parenting[MeSH Terms]) OR (pregnancy[MeSH Terms]))
EMBASE	(Female AND (chronic disease OR diabetes OR rheumatic disease OR psoriasis OR asthma OR cystic fibrosis OR hypothyroidism OR hyperthyroidism OR chronic renal insufficiency OR hypertension OR hypotension OR heart failure OR congenital heart defects OR epilepsy OR multiple sclerosis OR migraine disorders OR inflammatory bowel diseases OR celiac disease OR endometriosis OR polycystic ovary syndrome OR psychotic disorders OR anxiety OR depression) AND (family planning services OR preconception care OR reproductive health OR reproductive health services OR sexual health OR womens health services) AND (parenting OR pregnancy))

ProQuest PsycArticles	(“Female” AND (“chronic disease” OR “diabetes” OR “rheumatic disease” OR “psoriasis” OR “asthma” OR “cystic fibrosis” OR “hypothyroidism” OR “hyperthyroidism” OR “chronic renal insufficiency” OR “hypertension” OR “hypotension” OR “heart failure” OR “congenital heart defects” OR “epilepsy” OR “multiple sclerosis” OR “migraine disorders” OR “inflammatory bowel diseases” OR “celiac disease” OR “endometriosis” OR “polycystic ovary syndrome” OR “psychotic disorders” OR “anxiety” OR “depression”) AND (“family planning services” OR “preconception care” OR “reproductive health” OR “reproductive health services” OR “sexual health” OR “womens health services”) AND (“parenting” OR “pregnancy”))

4.1 Quality assessment of the studies

Critical Appraisal Skills Programme (CASP) checklists were used to assess the risk of bias and methodological quality of the included studies. For the different study designs included in our systematic review, two separate checklists were used: one for qualitative studies (13) and one for descriptive studies, including surveys and mixed-method designs (14).

4.2 Study characteristics

Relevant data were extracted on study populations, methodology, and the scope of each study, to facilitate critical appraisal and assess homogeneity. The results were organized in a tabular format (table 4).

Study population

The extracted data from each article included: gender of participants, sample size, country in which the study was conducted, recruitment setting and chronic health condition.

Methodology of the studies

Data were collected on primary aim of the study and evaluated outcome. Information on data collection methods included the type of questioning employed, the interaction partners involved and the setting or mode through which data collection was conducted.

Scope of the studies

To evaluate the scope of the different studies, we collected data on which of the following aspects of the perspective of patients on conversations about reproductive intentions and planning were addressed: (i) positive and negative patient, clinician and setting factors influencing these conversations (15), (ii) the delivery characteristics of these conversations and (iii) the content of these conversations.

4.4 Meta-synthesis of the findings

A meta-synthesis was performed to integrate the findings regarding communication about reproductive intentions and planning of the included articles.

Positive and negative patient-, clinician- and setting factors of patient-physician communication

Data on both positive and negative factors affecting patient-physician communication about reproductive intentions and planning was collected and categorized. The factors were classified based on the framework proposed by Becher et al. (15), which groups negative and positive factors in the following categories: patient-related factors, clinician-related factors and setting-related factors. The factors that did not fit in this framework were grouped under 'other'.

Delivery characteristics of preferred patient-physician communication

Results on delivery characteristics of preferred communication between patients and physicians were collected and divided into the following categories: preferred initiator of the communication (e.g. patient or HCP), type of HCP deemed appropriate to initiate the conversation, desired education or training of the HCP, tone and language, mode of communication, preferred materials used, scheduling and scripting. The latter four were based on the Intervention taxonomy framework (ITAX; 16), and the former factors were derived from inductive coding of described delivery characteristics.

Content of patient-physician communication

Data concerning the content of professional-physician communication about reproductive intentions and planning were summarized through an inductive approach, facilitating the identification of themes from the findings of the included studies, rather than being pre-defined by a model.

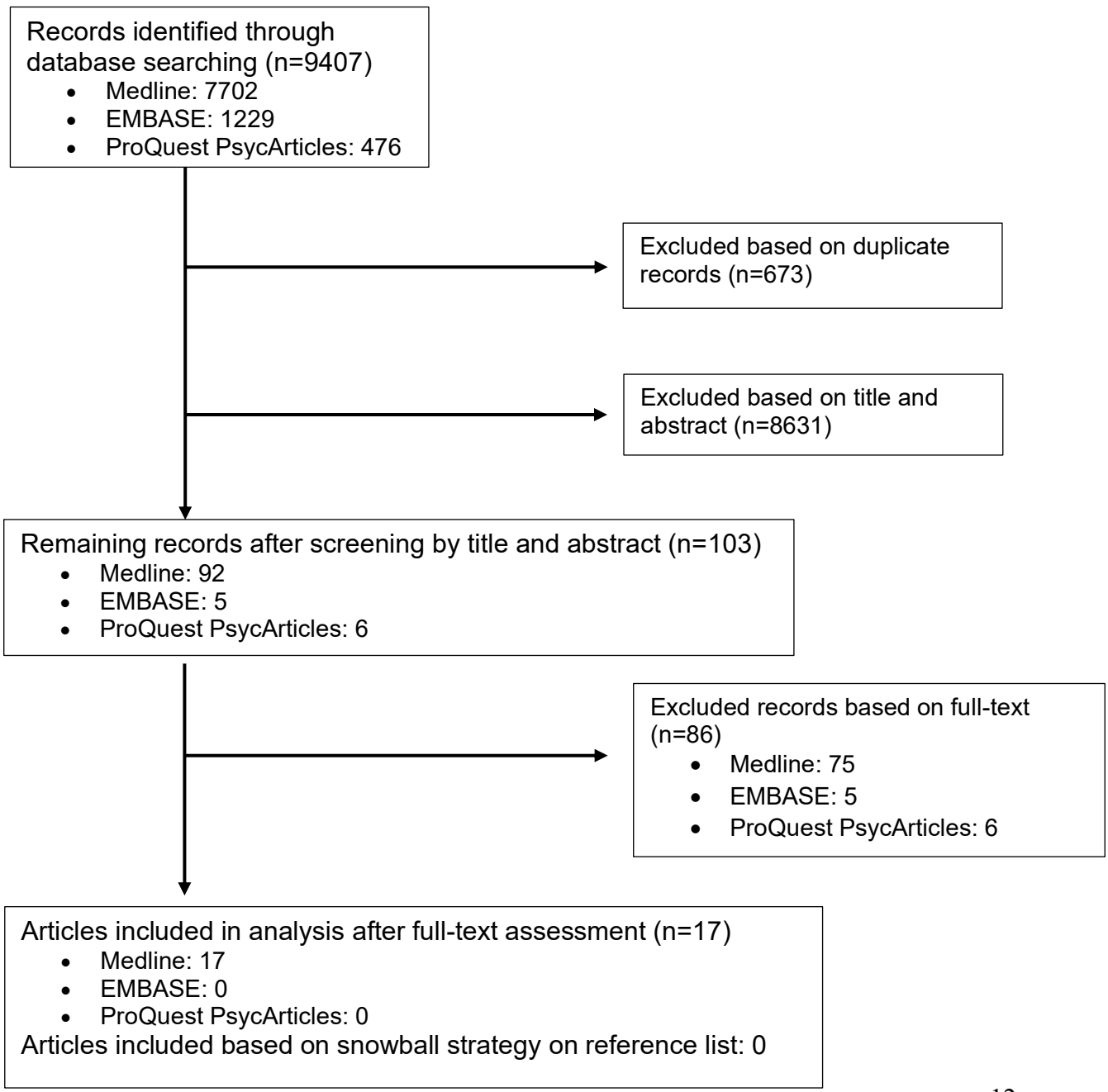
5. RESULTS

5.1 Results of search strategy and study selection

The study selection process was described in the flow diagram depicted in figure 1. After explorative searches a final search string was developed for each database (table 1). The database searches with the final search strings retrieved 9407 papers. A total of 7702 articles were identified through the PubMed search. From the EMBASE search, 1229 were retrieved, and the ProQuest PsycArticles search yielded 476 articles. A total of 8734 results remained after removal of duplicates.

After selection based on title and abstract, 103 studies seemed eligible. Another 86 articles were excluded after full-text screening, because they did not meet inclusion criteria. This means that finally 17 articles met the inclusion criteria and were included in the review. The snowball strategy on the reference list of the included studies did not identify additional studies.

Figure 1: flow chart of literature search.



5.2 Quality assessment of the studies

Table 2 describes the quality of the qualitative studies based on the CASP checklist for qualitative studies, a structured checklist consisting of ten questions, used to evaluate the quality and credibility of the methodology of each qualitative study. More details on the rationales behind the assessments can be found in appendix II.

The CASP Qualitative checklist indicated that four in ten qualitative studies had highly valuable findings, whereas the findings of the other six were valuable. All studies failed to describe the relationship between the researcher and participants. Whether the recruitment strategy was appropriate for the aims of the research was only clear for four studies and two studies could not convince us on the rigour of their data-collection.

The quality of the surveys and mixed-methods studies based on the CASP checklist for descriptive research was described in table 3. This checklist consists of eleven questions to evaluate the methodologic quality and credibility of each included survey and mixed-methods study. In appendix III, more details can be found on the rationales behind the assessments.

All surveys and all mixed-methods studies had valuable findings based on the CASP checklist for descriptive studies. Both mixed-methods studies and two out of five surveys did not provide detailed information regarding their recruitment strategy. None of the included studies adequatly measured measures to reduce bias. Furthermore, none of the included studies adequatly adressed whether enough participants were included to minimize the role of chance. Both mixed-method studies failed to convince us on the rigour of their data-collection, wheraes this was clear for all five surveys.

Table 2. Quality assessment of qualitative studies with the CASP Qualitative Checklist

Reference (author, year of publication)	Are the results valid?						What are the results?			Will the results help locally? (i.e. how valuable is the research?)
	Clear statement of the aims of the research?	Is a qualitative methodology appropriate?	Research design appropriate to address the aims of the research?	Recruitment strategy appropriate to the aims of the research?	Data collected in a way that addressed the research issue?	Relationship between researcher and participant adequately considered?	Ethical issues been taken into consideration?	Data analysis sufficiently rigorous?*	Clear statement of findings?	
Britton et al., 2023 (19).	+	+	+	?	+	?	+	+	+	valuable
Fragkoudi et al., 2023 (22).	+	+	+	?	+	?	+	-	+	valuable
Hailey et al., 2019 (23).	+	+	+	+	+	?	+	+	+	highly valuable
Holton et al., 2019 (24).	+	+	+	-	+	?	+	-	+	valuable
Kazmerski et al., 2017 (25).	+	+	+	+	+	?	+	+	+	highly valuable
Leech et al., 2021 (26).	+	+	+	?	+	?	+	+	+	valuable
Marshall et al., 2023 (28).	+	+	+	?	+	?	+	+	+	valuable
McCorry et al., 2012 (29).	+	+	+	+	+	?	+	+	+	highly valuable
Oliverio et al., 2023 (31).	+	+	+	+	+	?	+	+	+	highly valuable
Wolgemuth et al., 2020 (34).	+	+	+	?	+	?	+	+	+	valuable
Total	10/10	10/10	10/10	4/10	10/10	0/10	10/10	8/10	10/10	

*Did at least two researchers independently analyze data before comparison?

Table 3. Quality assessment of surveys and mixed—methods studies with the CASP Checklist for Descriptive studies

Reference (author, year of publication)	Are the results valid?										
	Did study address a clearly focused issue?	Did authors use appropriate method to answer their question?	Were subjects recruited in an acceptable way?	Were measures accurately measured to reduce bias?	Were data collected in a way that addressed the research issue?	Did study have enough participants to minimise play of chance?	Detailed presentation of resulsts?*	Was data analysis sufficiently rigorous?	Clear statement of findings?	Can results be applied to local population?	How valuable is the research?
Surveys											
Admiraal et al., 2022 (18).	+	+	?	-	+	?	+	+	+	+	valuable
Ehrenberg et al., 2023 (21).	+	+	+	-	+	?	+	+	+	+	valuable
Lynch et al., 2020 (27).	+	+	+	?	+	?	+	+	+	+	valuable
Rao et al., 2023 (32).	+	+	+	?	+	?	+	-	+	+	valuable
Toomey et al., 2013 (33).	+	+	?	-	+	?	+	-	+	+	valuable
Mixed-methods studies											
Ackerman et al., 2015 (17).	+	+	?	-	+	?	+	-	+	+	valuable
Chakravarty et al., 2014 (20).	+	+	?	-	+	?	+	-	+	+	valuable
Total	7/7	7/7	3/7	0/7	7/7	0/7	7/7	3/7	7/7	7/7	

*Adaptation of the question “How are results presented and what is the main result?” to fit a +/-/? format.

5.3 Results of study characteristics

Table 4 describes the characteristics of the included studies.

Study population

Participants

The majority of the included studies (n = 13/17) solely explored the perspectives of women with chronic NCDs. Three studies also explored the perspectives men with NCDs (22, 23, 32) but these were not extracted. One study focused solely on partners of women with chronic NCDs (21). Most studies included a mix of women who were planning pregnancy, were currently pregnant or had previously been pregnant and/or had children. One study explicitly excluded women who were currently pregnant (29) and one study only included women if they were currently pregnant (28).

Chronic non-communicable diseases

The included studies focused on six different chronic non-communicable diseases, including mostly cystic fibrosis (n = 5) and rheumatic diseases (n = 5). Two of the five studies on rheumatic diseases, also reported on inflammatory bowel diseases. Two other studies solely investigated participants with inflammatory bowel disease. Three articles addressed diabetes type 1 and/or 2. Multiple sclerosis and chronic kidney disease were reported in one study only.

Study setting

One study was conducted in both the US and multiple European countries (Italy, Germany, France, UK and Spain - 20). The other studies were conducted in a single country, including: the United States (n=10; 19, 21, 23, 26, 27, 28, 31, 32, 34), Australia (n=3; 17, 22, 24), Ireland (n=1; 33) and Northern-Ireland (n=1; 29) and the Netherlands (n=1; 18), and. Nine out of the seventeen included studies were mono-centric investigations. Five were multi-centric. Three studies solely recruited online.

Methodology of the studies

Different methodologies were used to examine the perspective of patients on professional-patient communication, as outlined in table 4.

Ten studies relied on a qualitative study design, of which eight used semi-structured one-on-one interviews only and one additionally performed focus group discussions (26). One study solely analyzed data from an online discussion group on a social media platform (24). All qualitative studies (irrespective of data-collection strategy) described their coding process but only six studies specified which software package was used (19, 22, 25, 26, 28, 31) and eight studies shared that data analysis was performed by multiple researchers (19, 22, 23, 25, 28, 29, 31, 34).

Five studies used a descriptive survey with mainly multiple-choice response options. The majority of surveys were web-based (18, 21, 27, 33). Four studies based their surveys on already existing questionnaires (18, 21, 27, 32), of which one also added de novo developed questions to match the research aim (27). One study did not give any information on the questionnaire used (33).

Two studies used a mixed-methods study design. Ackermann et al. collected qualitative data through a semi-structured one-on-one interview and focus group sessions, and quantitative data through a web-based questionnaire (17), while Chakravarty et al. used a one-on-one interview, a web-based questionnaire and analyzed patient's online activity through social media monitoring using keywords of interest (20). Ackermann et al. provided information on their coding process and shared that data analysis was performed by one sole researcher, while Chakravarty did not provide information on these topics. Neither specified which software package was used.

Scope of the studies

Two studies (18, 20) mainly focused on both positive and negative factors related to the patient-, clinician-, and setting factors that influence patient-physician communication. The other fifteen studies' main goal was to explore patients' perspectives on the characteristics and/or content of communication about reproductive intentions and planning.

Table 4. Studied population, methodological details and methods of data-collection

Reference (author, year of publication)	Studied population*	Chronic condition	Methodological details				Methods of data-collection in patients		
			Primary aim	Scope			Type of questioning	Partners in interaction	Setting/mode
				Positive/ negative factors	Delivery character-istics	Content			
Qualitative studies									
Britton et al., 2023 (19).	32 women/ US/ multi-centric	Type 2 diabetes	To characterize perspectives and experiences regarding preconception care (PCC) patient education among women with type 2 diabetes.		√	√	Semi-structured interviews	1-on-1 interview	Telephone
Fragkoudi et al., 2023 (22).	19 women and 3 men / Australia/mono-centric	Multiple Sclerosis	To explore the experiences of Australian female and male patients living with MS in relation to family planning and identify information and health service needs to better support them.		√	√	Semi-structured interviews	1-on-1 interview	Face-to-face / telephone / videoconference
Hailey et al., 2019 (23).	10 women and 10 men/ US/mono-centric	Cystic fibrosis	To describe the parenting and reproductive health concerns of individuals with CF and to identify the psychosocial and educational needs related to parenthood with CF.		√	√	Semi-structured interviews	1-on-1 interview	Face-to-face / telephone
Holton et al., 2019 (24).	11 women/ Australia/online discussion group	Cystic Fibrosis	To identify the child-bearing concerns and related information needs and preferences of women with CF.		√	√	Private facebook group discussion	Peers on forum	Facebook forum
Kazmerski et al., 2017 (25).	22 women/ US/mono-centric	Cystic Fibrosis	To explore attitudes and decision-making regarding pregnancy among young women with CF.		√	√	Semi-structured interviews	1-on-1 interview	Face-to-face at hospital
Leech et al., 2021 (26).	20 women (interviews) – 18 women (focus group discussions)/ US/ mono-centric	Cystic fibrosis	To explore the experiences and perspectives of women with CF related to their reproductive decision making through individual interviews.		√	√	Semi-structured interviews Semi-structured focus group discussions	1-on-1 interview Group discussion	Telephone
Marshall et al., 2023 (28).	22 women / US/ mono-centric	Pre-existing diabetes	To explore and describe experiences of preconception counselling among patients with preexisting diabetes.		√	√	Semi-structured interviews	1-on-1 interview	Telephone/ video conference

Reference (author, year of publication)	Studied population*	Chronic condition	Methodological details Primary aim	Scope Positive/ negative factors	Delivery character-istics	Content	Methods of data-collection in patients Type of questioning	Partners in interaction	Setting/mode
McCorry et al., 2012 (29).	14 women/Northern Ireland/mono-centric	Type 1 diabetes	To explore the attitudes about pregnancy and preconception care seeking in a group of non-pregnant women with type1 diabetes mellitus.		√	√	Semi-structured interviews	1-on-1 interview	Face-to face at patient's home/ at university
Oliverio et al., 2023 (31).	30 women/US/mono-centric	Chronic kidney disease	To gain a deeper understanding of reproductive health counselling experiences and unmet needs for counselling and decision-making and to develop a conceptual framework to move the field forward.		√	√	Semi-structured interviews	1-on-1 interview	Face-to-face at hospital/ Telephone
Wolgemuth et al., 2020 (34).	30 women /US/multi-centric	Rheumatic disease	To explore the sexual and reproductive health care and counselling needs for young women with RD in the context of their rheumatology care.		√	√	Semi-structured interviews	1-on-1 interview	Telephone
Surveys									
Admiraal et al., 2022 (18).	89 women / /Netherlands/ multi-centric	Inflammatory bowel disease and rheumatic diseases	To identify facilitators and barriers on patient and professional level regarding the provision of PCC in women with IBD and RD.	√	√	√	Questionnaire	Not specified	Web-based survey
Ehrenberg et al., 2023 (21).	94 partners/US/ multi-centric	Cystic fibrosis	To investigate partners' perceptions of, and preferences for women's SRH care in CF.		√	√	Questionnaire	Not specified	Web-based survey
Lynch et al., 2020 (27).	209 women/US/online recruitment	Rheumatic diseases	To assess the information needs of women with chronic autoimmune conditions across the pregnancy continuum.		√	√	Questionnaire	Not specified	Web-based survey
Rao et al., 2023 (32).	54 women and 46 men/US/mono-centric	Inflammatory bowel disease	To assess counselling and knowledge about IBD and reproductive health in a tertiary care IBD patient population.		√	√	Questionnaire	Not specified	At hospital

Reference (author, year of publication)	Studied population*	Chronic condition	Methodological details Primary aim	Scope Positive/ negative factors	Delivery character-istics	Content	Methods of data-collection in patients Type of questioning	Partners in interaction	Setting/mode
Toomey et al., 2013 (33).	31 women/ Ireland/mono-centric	Inflammatory bowel disease	To assess the knowledge of issues surrounding planning and carrying a pregnancy with IBD, current practices and the impact that the condition has on these patients and their family planning.		√		Questionnaire	Not specified	Web-based survey
Mixed-methods studies									
Ackerman et al., 2015 (17).	27 women /Australia/multi-centric	Rheumatoid arthritis	To determine the need for (and preferred modes of delivery of) information regarding pregnancy, postnatal care and e arly parenting among women with RA.		√	√	Semi-structured interviews Focus group discussion Questionnaire	1-on-1 interview Group session	Telephone Face-to-face / Videoconference
Chakravarty et al., 2014 (20).	969 women/ US – UK – Germany – Italy – Spain – France/online recruitment 350 professionals/US – Germany – France – Italy/online recruitment	Inflammatory bowel disease and rheumatic diseases	To identify family planning and pregnancy issues for female patients of childbearing age living with a chronic inflammatory disease and to assess whether current clinical practice routinely provides adequate support to alleviate these concerns.	√	√	√	Interview Questionnaire Social media monitoring	1-on-1 interview Peers on forum	Telephone Web-based survey

*N/Country/Setting of recruitment of responders

5.4 Meta-synthesis of the findings

Positive and negative patient-, clinician- and setting factors of patient-physician communication

Analysis of the included studies identified a range of patient-, clinician-, setting- and other factors, influencing patient-physician communication regarding reproductive intentions and planning of women with chronic non-communicable diseases. Both negative and positive factors were identified for each domain. All identified factors are outlined in table 5.

Negative factors

Negative patient factors commonly included limited knowledge on and skills for health management (e.g. lack of awareness on the importance of reproductive intentions and planning), hesitance to initiate such discussion, forgetfullness, and emotional, social or psychological factors.

At the clinician level, negative factors commonly included insufficient communication and skill training among healthcare providers and competing clinical priorities. Cultural barriers, variability in practice, and absence of an established patient-provider relationship due to unfamiliarity with the HCP, were other negative clinician factors.

At the setting level, the majority of articles mentioned resource gaps or fragmented care coordination as the main barrier, as well as systemic and structural constraints such as time constraints, and insufficient availability of HCPs.

Other negative setting factors identified, were absence of a standardised care model, geographical limitations and research infrastructure gaps.

Positive factors

Several factors positively impacting patient-physician communication, were identified. Positive patient factors included proactive attitudes and behaviour, such as active information seeking, as well as initiating conversations about reproductive planning and demonstrating signs of comfort and readiness in engaging with reproductive conversations. Enhanced knowledge, the course of a prior pregnancy and referral from a HCP were also mentioned as positive patient factors.

Positive factors at the clinician level included adequate training and knowledge of healthcare providers, coordination and continuity of care, the provision of structured counselling and clear communication, as well as building a trusting patient-physician relationship.

Setting-related facilitators involved the availability of integrated care systems and accessible educational resources.

Other factors positively influencing patient-physician reproductive communication were emotional and community support as well as social structures (e.g. peer-support and support networks) and collaborative practices, such as shared-decision making between patient and physician, as well as the inclusion of chronically ill women's partners in the reproductive conversation.

Table 5. Positive and negative patient-, clinician- and setting factors for professional-patient communication about parenthood and reproductive planning

Reference (author, year of publication)	Negative factors of patient-physician communication				Positive factors of patient-physician communication			
	Patient factors	Clinician factors	Setting factors	Others	Patient factors	Clinician factors	Setting factors	Others
Ackerman et al., 2015 (17).	Health management uncertainty and concerns Knowledge gaps	Insufficient HCP expertise Cultural competence gaps	Resource gaps Geographical limitations Systemic and structural constraints	/	Proactive attitudes and behaviour	Training and knowledge Care coordination and quality Communication and relationship building	Integrated Care Systems Accessible Educational Resources	Community and emotional (peer-) and social structures
Admiraal et al., 2022 (18).	Lack of Awareness Knowledge gaps	Insufficient HCP expertise Practice variability	Systemic and structural constraints	/	Proactive attitude and behaviour Comfort and readiness Course of a previous pregnancy HCP referring for PCC	Training and knowledge Care coordination and quality Communication and relationship building	Integrated Care systems Accessible educational resources	Community and emotional (peer-) and social structures
Britton et al., 2023 (19).	Initiation hesitancy Lack of awareness Knowledge gaps Health management uncertainty and concerns	/	Systemic and structural constraints	/	Proactive attitude and behaviour	Communication and relationship building	Accessible Educational Resources	Community and emotional (peer-) and social structures
Chakravarty et al., 2014 (20).	Forgetfulness Health management uncertainty and concerns	Lack of familiarity Practice variability	Systemic and structural constraints	/	Proactive attitudes and behaviour	Communication and relationship building	Integrated Care systems Accessible educational Resources	/

Reference (author, year of publication)	Negative factors of patient-physician communication				Positive factors of patient-physician communication			
	Patient factors	Clinician factors	Setting factors	Others	Patient factors	Clinician factors	Setting factors	Others
Ehrenberg et al., 2023 (21).	Emotional, social and psychological barriers Knowledge gaps	Lack of familiarity	/	/	Proactive attitiudes and behaviour	/	Integrated care systems	Collaborative practices
Fragkoudi et al., 2023 (22).	Health management uncertainty and concerns Unmet information needs	Lack of proactive engagement	Resource gaps Systemic and structural constraints	/	Proactive attitude and behaviour	Training and knowledge Communication and relationship building	Integrated Care systems	Community and emotional (peer-) and social structures
Hailey et al., 2019 (23).	Health management uncertainty and concerns Emotional, social and psychological barriers	/	Systemic and structural constraints	/	/	Communication and relationship building	Integrated care systems	Community and emotional (peer-) and social structures
Holton et al., 2019 (24).	Health management uncertainty and concerns Unmet information needs Emotional, social and psychological barriers	/	Resource gaps Systemic and structural constraints	/	Proactive attitudes and behaviour	Communication and relationship building	Integrated Care systems	Community and emotional (peer-) and social structures
Kazmerski et al., 2017 (25).	Health management uncertainty and concerns Unmet information needs Emotional, social and psychological gaps	Practice variability Cultural competence gaps	Systemic and structural constraints Geographical limitation	Family integration	Proactive attitudes and behaviour	Training and knowledge Care coordination and quality	Integrated Care systems	Community and emotional (peer-) and social structures

Reference (author, year of publication)	Negative factors of patient-physician communication				Positive factors of patient-physician communication			
	Patient factors	Clinician factors	Setting factors	Others	Patient factors	Clinician factors	Setting factors	Others
Leech et al., 2021 (26).	Uncertainty in decision-making	Insufficient HCP Training	Fragmented care coordination Systemic and structural constraints	/	Proactive attitudes and behaviour	Care coordination and quality	Integrated Care systems	/
Lynch et al., 2020 (27).	Unmet information needs	/	Resource gaps	/	Proactive attitudes and behaviour	Training and knowledge Care coordination	Integrated Care systems	Community and emotional (peer-) and social structures
Marshall et al., 2023 (28).	/	Lack of proactive engagement	Lack of Standard models	/	Proactive attitudes and behaviour	Communication and relationship building	/	/
McCorry et al., 2012 (29).	Emotional, social and psychological barriers Knowledge gaps	Lack of Familiarity	/	/	Proactive attitudes and behaviour	Communication and relationship building	/	Community and emotional (peer-) and social structures
Oliverio et al., 2023 (31).	Unclear reproductive Intentions	/	Resource gaps Research infrastructure gaps Systemic and structural constraints		/	Communication and relationship building	Integrated care systems	Collaborative practices
Rao et al., 2023 (32).	Lack of awareness	Lack of proactive engagement	/	/	/	/	Accessible educational resources	/
Toomey et al., 2013 (33).	Knowledge gaps	Insufficient HCP expertise	/	/	/	/	/	/
Wolgemuth et al., 2020 (34).	Initiation hesitancy	Insufficient HCP training	Fragmented Care Coordination	/	Proactive attitudes and behaviour	Communication and relationship building	Integrated Care systems	Collaborative practices

Delivery characteristics of preferred patient-physician communication

Table 6 summarizes women's perspectives on the delivery characteristics of patient-physician conversations about reproductive intentions and planning.

In the majority of the included studies, patients expressed a preference for healthcare providers to initiate discussions regarding preconception counselling. A study by Chakravarty et al. however reported that two-thirds of participants preferred HCPs to initiate the conversation, whereas one-third preferred to initiate the discussion themselves or wanted HCPs to solely introduce the topic when appropriate to their individual circumstances (20). In a study by Ehrenberg et al., that explored the perspectives of partners of women with chronic NCDs, participants indicated a preference for their partner or the healthcare provider to initiate the conversation on reproductive planning (21). Only two studies did not explicitly specify preferences about which party should initiate the discussion (29, 32).

A limited number of studies (n=4) explicitly addressed who women deemed most appropriate to initiate the conversation about reproductive intentions and planning (18, 20, 21, 26). One study showed a clear preference for consultation shared by both the disease-specific specialist and the obstetrician together (18). Both Ehrenberg et al. and Leech et al. reported a strong preference for the disease-specific specialist to organize such discussion, whereas Chakravarty et al. identified the gynaecologist as the most appropriate healthcare provider.

All studies that addressed the mode of communication (n=9) reported a clear preference for face-to-face counselling (17, 18, 22, 23, 26, 28, 31, 32, 34).

Only a limited number of studies (n=7; 17, 18, 19, 20, 23, 26, 32) reported on patients' preferences regarding information materials. Written resources, including handouts and PCC posters displayed in public spaces, were slightly more preferred (n=5/7; 17, 18, 19, 23, 32) compared to digital materials, such as dedicated websites or online decision aids.

The preferred schedule for reproductive counselling is outlined by most studies, specifying when and how often these consultations should take place. Across the majority of studies, participants prefer for HCPs to initiate counselling early, often during the first visit or at the time of diagnosis, with a strong emphasis on revisiting the conversation regularly. Several studies suggest that these discussions should be revisited during transitions in disease management or at significant life stages, or whenever decisions are made that may influence family planning or fertility. Other studies recommend revisiting the conversation multiple times a year or even during each consultation. The need to integrate reproductive counselling into routine disease management, regardless of patients' pregnancy intentions, was highlighted by three studies (19, 22, 28). Reproductive counselling should be a continuous process rather than a onetime discussion. Furthermore, three studies (23, 24, 25) highlighted the importance of starting the sexual and reproductive health conversation early, with one study specifically recommending its initiation during the mid- to late teenage years (23).

Only a limited number of studies addressed tone and language (17, 19, 25, 26, 29, 34). Among these, the majority emphasized the importance of using a supportive tone and tactful empathic language during preconception counselling (17, 19, 25, 29). Three studies specified the need for clear language, free of technical terms and medical jargon (17, 26, 34).

The majority of the included studies (19, 20, 21, 22, 23, 24, 25, 26, 27, 28, 29, 31, 34) addressed the preferred scripting of a patient-physician communication on reproductive life planning, referring to the wording, communication style and framing of these conversations or how to communicate about this topic. The majority of studies emphasized that the communication should be be comprehensive, consistent, up-to-date, accurate, evidence-based and transparent, with communication methods being proactive and accessible. Another recurring theme was the strong preference for personalized information, adapted to the patients' individual circumstances and reproductive intentions. Furthermore, one study emphasized the importance of balanced communication, where medical risks should be accompanied by an acknowledgement of patients' personal goals and potential positive outcomes (31). Additionally, one study highlighted the importance of validatings patients' reproductive health decisions and the acknowledgment of their life circumstances and personal values in family planning (23). Two studies stressed the need for direct communication between disease-specific specialists and gynaecologists, to prevent patients from acting as intermediairies in these conversations (26, 34).

Content of patient-physician communication

Patients' perspectives regarding the content of reproductive intentions and planning are presented in table 6 and were further categorized in two themes: patients' specific information needs related to reproductive counselling, and their needs regarding communication and shared decision-making.

A wide range of specific information needs related to reproductive planning were identified across the included studies. Patients required information on medication safety during conception, pregnancy and breastfeeding, including drug toxicity, adverse effects, wash-out requirements and medication switching behaviour. Most articles reported a strong desire for information on fertility, pregnancy risk and disease management during pregnancy and after delivery. Patients also sought practical advice to manage daily challenges of living with a chronic condition and planning for pregnancy or parenthood. Across multiple studies, patients described a strong desire for community networks and peer support, including access to online forums and sharing pragmatic advice and experiences from other women. Patients highlighted the need for information on parent-child communication, heritability of the condition, as well as long-term impact of the disease on reproductive intentions and planning but also on family life. Two studies identified the need for information regarding the patients' family, friends and workplace (17, 25).

Regarding communication and shared decision-making, a wide range of needs related to reproductive planning were identified across the included studies. Eight studies focused attention on communication and counselling inconsistencies in current reproductive counselling conversations such as conflicting advice and inconsistent, insufficient or infrequent counselling on reproductive intentions and planning (19, 21, 22, 27, 31, 32, 33, 34). Eight studies highlighted the need for individualized, patient-centred communication (17, 18, 19, 23, 24, 29, 31, 34). Two studies specifically established the value of healthcare providers acknowledging patients' personal values, life circumstances and background in the family planning discussion (17, 23). In several studies, patients expressed the need for more decision-making support, including more direct guidance from their disease-specific specialist. The desire for patient's autonomy in this discussion was noted in two of the included studies (19, 25), with one study explicitly underlining that the choice to have children was the decision of the patients alone (25). The need for providers to address the emotional complexity of reproductive decision-making in the context of chronic illness was also considered an important theme, with studies highlighting the desire for a sense of normalcy.

Table 6. Delivery characteristics and content of preferred professional-patient communication about parenthood and reproductive life planning

Reference (author, year of publication)	Delivery characteristics of preferred professional – patient communication about parenthood and reproductive live planning								Content of professional – patient communication about parenthood and reproductive life planning	
	Preferred initiator of communica-tion	Appropriate HCP to have conversation with	Desired HCP education	ITAX* aspect mode of communica-tion	ITAX aspect materials	ITAX aspect schedule**	Tone and language	ITAX aspect scripting***	Patients' specific information needs	Patients' needs regarding communication and shared decision-making
Ackerman et al., 2015 (17).	HCPs	Not specified	Not specified	Face to face	Written information In rural settings: -Online information -Information packs from HCP or arthritis consumer organizations.	HCPs should start PCC counselling at the time of diagnosis HCPs should revisit PCC counselling regularly, especially during transitions in disease management or life stages	Supportive and empathetic tone Clear language	Not specified	Drug toxicity / medication safety Access to physical and emotional support services Practical tips and strategies to assist with daily challenges Information for family, friends and the workplace Specific information on pregnancy and RA	HCPs should offer individualized information HCPs need to acknowledge life circumstances and personal values/background are crucial for family planning Patients need more decision-making support, primarily more direct guidance from rheumatologists Patients need pragmatic information from peers
Admiraal et al., 2022 (18).	HCP's	Disease specific specialist together with obstetrician	Not specified	Face to face	Written information (PCC posters everywhere)	Not specified	Not specified	Not specified	Medication safety Disease activity during pregnancy and following delivery	HCPs should offer individualized information
Britton et al., 2023 (19).	HCP's	Not specified	Not specified	Not specified	Written information (at locations where adolescents would see it, incl public transport stops, in school-based sexual health curriculums)	HCPs should provide PCC counselling regularly and routinely PCC counselling should be integrated in routine disease care, regardless of pregnancy intention	Tactful	HCP should initiate discussion Need for proactive and accessible communication methods	Clarity on timing of PCC	HCPs should offer individualized information Need for autonomy Emotional sensitivity in PCC communication

Reference (author, year of publication)	Delivery characteristics of preferred professional – patient communication about parenthood and reproductive live planning								Content of professional – patient communication about parenthood and reproductive life planning	
	Preferred initiator of communica-tion	Appropriate HCP to have conversation with	Desired HCP education	ITAX* aspect mode of communica-tion	ITAX aspect materials	ITAX aspect schedule**	Tone and language	ITAX aspect scripting***	Patients' specific information needs	Patients' needs regarding communication and shared decision-making
Chakravarty et al., 2014 (20).	2/3th HCP's 1/3th prefer to start conversation themselves or HCP to bring it up when appropriate to individual situation	Gynaecologist (instead of disease specific specialist)	Not specified	Not specified	Online information	HCPs should discuss PCC whenever a decision is made that could impact family planning or ability to become pregnant HCPs should revisit PCC counselling regularly	Not specified	HCPs should provide consistent and comprehensive information HCPs should provide up-to-date information	Disease state Adverse effects Treatment Medication switching behaviour Wash-out requirements	Not specified
Ehrenberg et al., 2023 (21).	Patient (partner) or HCP	Disease specific physician or advanced care provider	Not specified	Not specified	Not specified	Not specified	Not specified	HCP or partner should initiate SRH discussion	Pregnancy Fertility Sexual functioning Sexual activity Parenthood	Not specified
Fragkoudi et al., 2023 (22).	HCPs	Not specified	Not specified	Face to face	Not specified	HCPs should offer PCC routinely HCPs should integrate family planning in routine care	Not specified	HCPs should provide easily accessible, reliable and consistent information	Fertility Medication safety Support services for FP Reference to accessible information provided by HCP	Not specified
Hailey et al., 2019 (23).	HCPs	Not specified	Not specified	Face to face	Written or online information	HCPs should offer PCC early, preferably in the mid- to late teenage years	Not specified	HCPs should validate patients' reproductive health decisions and desire for children	Fertility Pregnancy risks Disease specific education on birth control and pregnancy Parent-childhood communication Information on support forums	HCPs should provide individualized information HCPs should recommend for potential parents to establish robust support systems prior to having children and offer online support forums HCPs should discuss how patients' illness influences their life priorities

Reference (author, year of publication)	Delivery characteristics of preferred professional – patient communication about parenthood and reproductive live planning								Content of professional – patient communication about parenthood and reproductive life planning	
	Preferred initiator of communica-tion	Appropriate HCP to have conversation with	Desired HCP education	ITAX* aspect mode of communica-tion	ITAX aspect materials	ITAX aspect schedule**	Tone and language	ITAX aspect scripting***	Patients' specific information needs	Patients' needs regarding communication and shared decision-making
Holton et al., 2019 (24).	HCPs	Not specified	Not specified	Not specified	Not specified	HCPs should provide information when patients considered pregnancy or from early age HCPs should revisit PCC regularly	Not specified	HCPs should provide relevant, accurate, up-to-date information about CF and childbearing	Medication safety Importance of treatment adherence during pregnancy Pregnancy risks Fertility Delivery information and its health impact	HCPs should offer individualized information
Kazmerski et al., 2017 (25).	HCPs	Not specified	Not specified	Not specified	Not specified	HCPs should start SRH education early HCPs should have open, repeated SRH conversations with patients	Empathetic and non-judgmental language	HCPs need to initiate the dialogue HCPs need to be open to patients starting the dialogue HCPs should provide clear information	Fertility Pregnancy risks	Need for autonomy Patient felt that decision to have children was theirs alone Need for integration of family into reproductive health discussion Desire for a sense of 'normalcy' with reproductive decision making Desire for input from HCPs team
Leech et al., 2021 (26).	HCPs	Disease specific specialist	Not specified	Face to face	Online information (decision aid)	Not specified	Clear language	HCPs should evidence-based and transparent information HCPs should improve interprofessional communication, so that patients don't have to be an intermediary in the provision of their reproductive health care	A clear treatment plan or guidance in reproductive decisions	Need for defragmented, coordinated reproductive health care Desire for improved communication and collaboration between HCPs

Reference (author, year of publication)	Delivery characteristics of preferred professional – patient communication about parenthood and reproductive live planning								Content of professional – patient communication about parenthood and reproductive life planning	
	Preferred initiator of communica-tion	Appropriate HCP to have conversation with	Desired HCP education	ITAX* aspect mode of communica-tion	ITAX aspect materials	ITAX aspect schedule**	Tone and language	ITAX aspect scripting***	Patients' specific information needs	Patients' needs regarding communication and shared decision-making
Lynch et al., 2020 (27).	HCPs	Not specified	Not specified	Not specified	Not specified	HCPs should provide timely and ongoing PCC	Not specified	HCPs should explain options clearly HCPs should be well informed HCPs should give patients the information and resources needed to make decisions	Fertility Medication safety Influence of disease on pregnancy and vice versa Educational resources Experiences of other women Support networks	Not specified
Marshall et al., 2023 (28).	HCPs	Not specified	Not specified	Face to face	Not specified	HCPs should offer PCC routinely, before patients wish to become pregnant	Not specified	HCPs should not only focus on risk but adopt a proactive stance	Not specified	Not specified
McCorry et al., 2012 (29).	Not specified	Not specified	Not specified	Not specified	Not specified	Not specified	Supportive tone	HCPs should provide more in-depth, detailed information	Pregnancy risks	HCPs should provide individualized information HCPs should invest in positive professional-patient relationships Preference for a holistic approach tailored to individual needs or patients' goals
Oliverio et al., 2023 (31).	HCPs	Not specified	Not specified	Face to face	Not specified	Not specified	Not specified	HCPs should provide balanced risk communication with acknowledgement of patients goals and potential positive outcomes	Pregnancy risks Medication safety Disease management during pregnancy Resources for peer and emotional support	HCPs should provide individualized information

Reference (author, year of publication)	Delivery characteristics of preferred professional – patient communication about parenthood and reproductive live planning								Content of professional – patient communication about parenthood and reproductive life planning	
	Preferred initiator of communica-tion	Appropriate HCP to have conversation with	Desired HCP education	ITAX* aspect mode of communica-tion	ITAX aspect materials	ITAX aspect schedule**	Tone and language	ITAX aspect scripting***	Patients' specific information needs	Patients' needs regarding communication and shared decision-making
Rao et al., 2023 (32).	Not specified	Not specified	Not specified	Face to face	Written information (Handout)	Not specified	Not specified	Not specified	Information on disease in relation to reproductive health Fertility Medication use Heritability	Not specified
Toomey et al., 2013 (33).	HCPs	Not specified	Not specified	Not specified	Not specified	HCP should raise PCC in future consultations	Not specified	Not specified	Not specified	Not specified
Wolgemuth et al., 2020 (34).	HCPs	Not specified	Not specified	Face to face	Not specified	HCPs should initiate SRH discussion at first visit and revisit topic over time, at least several times a year	Clear language	HCPs should initiatie first PCC conversation HCPs should provide clear, accurate, complete and transparant information HCPs should improve interprofessional communication to streamline reproductive health care, reducing the need for patients to act as intermediaries.	Pregnancy risks Medication safety Fetal risks Fertility	HCPs should provide individualized information HCPs should acknowledge life circumstances and personal values are crucial for family planning

*ITAX = intervention taxonomy (14)
** Duration and intensity of (desired) PCC counselling
***Level of detail guiding PCC communication between professional and patiënt

6. DISCUSSION

6.1 Novelty & Summary

This systematic review provides an overview of the literature about the perspectives of women with NCDs and their partners on patient-physician communication about reproductive intentions and planning. It identified negative and positive patient, clinician and systemic factors affecting this communication and presents the preferred delivery characteristics and content of these conversations. The inclusion of a wide range of chronic health conditions, such as rheumatoid artritis, cystic fibrosis, multiple sclerosis, inflammatory bowel diseases, diabetes and chronic kidney disease, emphasizes the widespread relevance of this topic across clinical contexts.

Whereas previous reviews (e.g. Hammerberg et al.) focused on preferred static information, this review focused on the more complex patient-physician communication on reproductive intentions and planning. Our findings highlight patients' desire for timely, personalized and proactive communication initiated by the health care providers, as well as their need for continuity of care and collaboration among professionals. By providing a synthesis of both positive and negative factors affecting the patient-physician reproductive health communication for women with NCDs, this review offers more nuance to the ongoing discussion on how to ameliorate patient-centred reproductive counselling in the context of chronic disease.

6.2 Critical reflection on own and included study methodology

The strength of this systematic review lies in its thorough methodology. The database search string, clearly defined selection criteria, and standardized data-extraction sheets are transparently reported and the processes can be replicated. Conceptual models (e.g. ITAX) structured the meta-synthesis of the data and where the findings were too novel, this approach was complemented by inductive coding. Moreover, including both qualitative and quantitative studies deepened the analysis and resulted in a more nuanced understanding of patients' experiences and needs.

The main limitation of this review process is that it was performed by a single reviewer rather than processes being replicated by two researchers reaching agreement after discussion. The different steps were, however, discussed and challenged by a senior researcher performing ad-random checks of for example the data-extraction from a certain paper.

This findings of this and any review are of course affected by the limitations of the studies which they include. The majority of the studies were conducted in high-income countries, which may make it difficult to generalize the findings to middle- and low-income countries, differing in preconception care settings and sociocultural factors. Additionally, all included studies focessed on women with NCDs who were already enrolled in healthcare systems, potentially excluding perspectives of less fortunate groups with more barriers to healthcare or reproductive counselling. Furthermore, the perspective of women suffering from chronic psychological diseases are not represented by this review and no relevant studies could be identified. These patients too have different perspectives on communication about reproductive intentions and planning. Finally, studies included in this review failed to report certain methodological details on for example interview procedures and software used for analysis.

6.3 Critical reflection on the findings

The findings of our review align with the current literature advocating for patient-centred, individualized and empathetic communication in reproductive healthcare (35, 36, 37) especially when communicating with women with chronic illnesses, as their disease may impact their fertility and pregnancy options.

A pertinent finding is the mismatch between patients' expectations and desires and the structural limitations healthcare professionals face, such as time constraints, knowledge gaps and fragmentation of care, highlighting systematic shortcomings that cannot be attributed solely to individual healthcare providers.

Furthermore, our review also emphasized an important, but often overlooked aspect of communication about reproductive intentions and planning: the need for ongoing, recurring and frequent reproductive discussions, as patients consistently expressed the desire for discussions to be repeated over time, growing with their changing life circumstances, health status and reproductive intentions.

Finally, our findings also illustrate variability in patients' preferences regarding which healthcare provider should initiate the PCC conversation, underscoring the need for a multidisciplinary approach and interprofessional communication among disease-specific specialists, general practitioners and gynaecologists, allowing for continuity of care where a patient does not have to act as an intermediate in the conversation.

6.4 Implications for general practitioner and other clinical practice

This review highlights the importance for general practitioners, as well as other clinicians, to proactively addressing reproductive intentions and to consider reproductive life planning as a part of routine chronic disease management. They should not adopt a wait – and – see attitude for patients to initiate the conversation. Integrating communication about reproductive intentions and planning into standard care and starting discussions early, ideally at diagnosis, and revisit it regularly, could reduce the identified negative factors.

This accentuates the need for healthcare professionals to develop not only the knowledge but also the communication skills needed to have empathetic, evidence-based conversations. This is particularly important for general practitioners, as they are often the first-line of communication and most accessible for patients. This review supports the need for ongoing high-quality education and training on reproductive counselling for all clinicians involved in chronic care.

The development of structured care pathways and promoting interprofessional collaboration, such as joint consultations between disease-specific specialists and gynaecologists, as well as simplifying the communication with first-line actors (GP's), would also address patients' desire for continuity of care.

These structured care pathways should also clearly define the role of the general practitioner in the conversation about reproductive intentions and planning. As the first point of contact and often a consistent presence in a patient's care journey, the GP plays and important role in advocating for the patients' life-goals such as their wish for pregnancy and parenthood, and thus their reproductive autonomy.

GP's should raise the topic of reproductive life planning early, taking into account and addressing the impact of age and chronic illness on fertility. Starting this conversation early and proactively is especially crucial in cases where medication adjustment or disease-specific fertility or pregnancy risks may delay conception.

Therefore, while current guidelines, such as the NHG guidelines (38), suggest a standard 12-month waiting period before starting the diagnostic work-up in the case of subfertility, earlier investigations should be considered for patients with chronic NCDs, as suggested by NICE guidelines (39) and the ACOG committee (40), and this should be reflected in future guidelines.

GP's could also play a key role in coordinating care, helping patients and their specialist by signalling the need for the disease-specific reproductive health conversations, for example through a referral letter. Furthermore, providing educational resources that are easily accessible (written or digital) and peer-supported would further improve these conversation and empower patients in their journey of reproductive decision-making. These considerations should be represented in future guidelines, structured care pathways and GP trainings to ensure timely reproductive counselling for women with NCDs and to help both clinicians and patients in navigating conversations on reproductive intentions and planning.

6.5 Implications for research

This systematic review highlights gaps in current literature, to be addressed by future research.

First, there is a clear need for more diverse research representing more variety in healthcare and allowing for an understanding of how cultural, resource and disease-specific differences influence conversations about reproductive life planning. Studies should be conducted in low- and middle income countries and among diverse study populations, such as women with chronic mental health conditions.

Secondly, future studies should strive for more consistent reporting regarding the methodology, such as detailed descriptions on patient recruitment, data collection and analysis, which would facilitate comparison across studies.

Thirdly, more than only one study should focus on the perspectives of partners of women with NCDs as reproductive decisions and parenthood are generally shared between two partners.

Fourthly, this systematic review calls for the development of a patient-centred communication model and communication skills training, taking account of the identified perspective of large groups of women with NCDs and co-designed by patient-representatives.

Finally, the impact of this model and training on care experiences, reproductive decisions, short- and long-term clinical outcomes (e.g. proportion of unplanned pregnancies) and psychosocial outcomes (e.g. decisional regret) should be evaluated.

7. CONCLUSION

This systematic review highlights the needed proactive role of the general practitioner and other healthcare professionals in conversations about reproductive intentions and planning for chronically ill patients. It highlights the need for physicians in clinical practice to proactively and repeatedly initiate in-person conversations about reproductive intentions and planning and to collaborate with all relevant health care professionals, whilst investing in their physician-patient relationship. This systematic review also calls for research focusing on diverse populations and for the development of a patient-centred communication model and communication skills training, for which the impact on care experiences, short- and long-term clinical outcomes (e.g. proportion of unplanned pregnancies) and psychosocial outcomes (e.g. decisional regret) should be evaluated.

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10. CONFLICT OF INTEREST

The authors have no conflicts of interest to declare.

11. FINANCIAL DISCLOSURE

None.

12. FUNDING

None.

13. APPENDIX I

PROTOCOL

1. Study Synopsis

Title of clinical trial	Communication about reproductive intention and planning with women of reproductive age affected by a chronic health condition: a systematic review
Principal investigator	Van Oers Céline
Subject under investigation	Communication needs and desires of professionals and/or patients affected by chronic illness when discussing reproductive health and family planning.
Purpose of	We aim to review the literature on (patient's and professional's perspective on and barriers and/or facilitators for) patient education materials and on professional – patient communication strategies for discussing patient's desire for parenthood and family planning in case of a chronic condition.
Primary objective	The primary objective is to identify patient education materials and professional – patient communication strategies for discussing patient's desire for parenthood and family planning in case of a chronic condition.
Secondary objective(s)	The secondary objective is to study patient's and professional's perspective on and barriers and/or facilitators for professional – patient communication on patient's desire for parenthood and family planning in case of a chronic condition.
Study Design	Systematic review
Summary of eligibility criteria	Eligible studies for this systematic review encompassed: * All empirical investigations, comprising qualitative, quantitative and mixed-method studies, while excluding reviews.

	* Peer-reviewed papers available in English, Dutch or French were considered. * Studies were required to address communication concerning the desire for parenthood and/or reproductive life planning between, on the one hand, healthcare providers, particularly medical doctors, and, on the other hand, women (potentially including their partners) with prevalent non-communicable diseases, excluding cancer. * Studies specifically focusing on non-communicable chronic diseases, prevalent among women of reproductive age, who require medication that could impact pregnancy, were included. * Studies focusing on cancer, menopause, and sexually transmitted diseases were excluded. *Studies solely addressing information provision without interpersonal communication were also excluded.
Version and date of final protocol	April 11th 2024

2. Background and rationale

Reproductive health is considered an important determinant for fertility and pregnancy outcomes (2), as chronic or acute illnesses, exposure to the environment and intake of teratogenic substances can have a negative impact on the fetal development (3). In preconception care, a combination of counselling and biomedical, behavioural, and social health interventions are important to discuss to improve the health of both women and their partners prior to conceiving, in an attempt to optimize maternal and neonatal outcomes (5).

Preconception care becomes even more crucial in females affected by chronic illnesses, as complications during pregnancy may arise or necessary treatment to control the chronical illness may affect the fetus' health. Therefor communication and education on the health risks by health providers, is essential for fertile females affected by chronic disease and their partners. Adequate reproductive counselling makes it possible for females to make an informed decision, and necessary interventions to ameliorate the maternal and neonatal health outcomes can be implemented prior to conceiving.

Evidence-based guidelines for preconception care have been published by the Centers for Disease Control and Prevention and the Preconception Health and Health Care Initiative, focusing on screening through anamnesis and risk assessment, health promotion and interventions. However, there is a limited availability of evidence-based guidelines and studies on communication techniques and tools to help health care providers start a conversation on preconception health (7).

Our aim is to search the literature, collect the available research and guidelines and review them, to get more insight in the perspective of patients on communicative processes used by health care providers to start a conversation on reproductive health and the desire to have children during consultations with women with a chronic illness. Furthermore, we will evaluate the studies, form recommendations on the best available communication techniques on preconception health for women affected by chronic disease and discuss aspects on which further research is necessary.

3. Study objectives and Design

Study objectives

This study will try to answer the need to evaluate the existing communication processes and techniques used to start a conversation on preconception health, focusing on fertile women affected by chronic illness. This in turn, might improve pregnancy outcomes in females with chronic illnesses.

Thus, the following objectives will be addressed more specifically:

- Primary objective: to identify patient education materials and professional – patient communication strategies for discussing patient's desire for parenthood and family planning in case of a chronic condition.
- Secondary objective: to study patient's and professional's perspective on and barriers and/or facilitators for professional – patient communication on patient's desire for parenthood and family planning in case of a chronic condition.

Study Design

This study will consist of a systematic review, focusing on communication strategies for preconception care between health professionals and fertile women (and their partners) affected by chronic illnesses. We will try to explore the communication strategies and needs, facilitators and barriers for communication on patient's desire for parenthood and family planning. A thorough search strategy will be executed to retrieve all relevant articles from the following three electronic databases: Medline, EMBASE and Proquest PsycArticles.

Eligible studies for this systematic review will encompass all empirical investigations (qualitative, quantitative and mixed-method studies), with exclusion of reviews. Papers need to be available in English, Dutch or French to be considered.

Studies will require to address communication needs and strategies concerning reproductive life planning and preconception care, between healthcare providers and fertile females with non-communicable chronic health conditions (and potentially their partners). Studies focusing on cancer, menopause or communicable chronic diseases will be excluded.

14. APPENDIX II

Table 2. Detailed version of the quality assessment of qualitative studies with the CASP Qualitative Checklist

Reference (author, year of publication)	Are the results valid?						What are the results?			Will the results help locally? (I.e. How valuable is the research?)
	Clear statement of the aims of the research?	Is a qualitative methodology appropriate?	Research design appropriate to address the aims of the research?	Recruitment strategy appropriate to the aims of the research?	Data collected in a way that addressed the research issue?	Relationship between researcher and participant adequately considered?	Ethical issues been taken into consideration?	Data analysis sufficiently rigorous?*	Clear statement of findings?	
Britton et al., 2023 (19).	yes	yes	yes	can't tell (no information on disease severity in studied population)	yes	can't tell (acknowledgement of influence of researcher, but limited detail on management of potential researcher bias)	yes	yes	yes	valuable
Fragkoudi et al., 2023 (22).	yes	yes	yes	can't tell (mention that all types of disease severity are accepted for inclusion, but no information on disease severity in studied population)	yes	can't tell (no involvement of research team in clinical care of patients, and no patients were known to research team prior to participating, but limited detail on management of power imbalances)	yes	no (unclear how many researchers were involved in data analysis)	yes	valuable
Hailey et al., 2019 (23).	yes	yes	yes	yes	yes	can't tell (description of role of researcher in data collection, limited detail on management of potential researcher bias, no detail on management of power imbalances)	yes	yes	yes	highly valuable

Reference (author, year of publication)	Are the results valid?						What are the results?			Will the results help locally? (I.e. How valuable is the research?)
	Clear statement of the aims of the research?	Is a qualitative methodology appropriate?	Research design appropriate to address the aims of the research?	Recruitment strategy appropriate to the aims of the research?	Data collected in a way that addressed the research issue?	Relationship between researcher and participant adequately considered?	Ethical issues been taken into consideration?	Data analysis sufficiently rigorous?*	Clear statement of findings?	
Holton et al., 2019 (24).	yes	yes	yes	no (no information on disease severity in studied population, little demographic information on patients who did an did not contribute to online posts)	yes	can't tell (description of role of researcher in data collection, but limited detail on management of potential researcher bias)	yes	no (only one author analysed data)	yes	valuable
Kazmerski et al., 2017 (25).	yes	yes	yes	yes	yes	can't tell (description of role of researcher in data collection, but limited detail on management of potential researcher bias)	yes	yes	yes	highly valuable
Leech et al., 2021 (26).	yes	yes	yes	can't tell (no information on disease severity of studied population)	yes	can't tell (description of role of researcher in data collection, but limited detail on management of potential researcher bias)	yes	yes	yes	valuable

Reference (author, year of publication)	Are the results valid?						What are the results?			Will the results help locally? (I.e. How valuable is the research?)
	Clear statement of the aims of the research?	Is a qualitative methodology appropriate?	Research design appropriate to address the aims of the research?	Recruitment strategy appropriate to the aims of the research?	Data collected in a way that addressed the research issue?	Relationship between researcher and participant adequately considered?	Ethical issues been taken into consideration?	Data analysis sufficiently rigorous?*	Clear statement of findings?	
Marshall et al., 2023 (28).	yes	yes	yes	can't tell (no information on disease severity of studied population)	yes	can't tell (no information was given about potential bias or influence of researcher on data collection)	yes	yes	yes	valuable
McCorry et al., 2012 (29).	yes	yes	yes	yes	yes	can't tell (description of role of researcher in data collection, but no information about management of potential researcher bias or power imbalance)	yes	yes	yes	highly valuable
Oliverio et al., 2023 (31).	yes	yes	yes	yes	yes	can't tell (No information was given about potential bias or influence of researcher on data collection regarding the participants, but they do mention no working relationships between interviewed clinicians and researchers)	yes	yes	yes	highly valuable

Reference (author, year of publication)	Are the results valid?						What are the results?			Will the results help locally? (I.e. How valuable is the research?)
	Clear statement of the aims of the research?	Is a qualitative methodology appropriate?	Research design appropriate to address the aims of the research?	Recruitment strategy appropriate to the aims of the research?	Data collected in a way that addressed the research issue?	Relationship between researcher and participant adequately considered?	Ethical issues been taken into consideration?	Data analysis sufficiently rigorous?*	Clear statement of findings?	
Wolgemuth et al., 2020 (34).	yes	yes	yes	can't tell (no information on disease severity of studied population)	yes	can't tell (description of role of researcher in data collection, but no information about management of potential researcher bias or power imbalance)	yes	yes	yes	valuable

*Did at least two researchers independently analyze data before comparison?

15. APPENDIX III

Table 3. Detailed version of the quality assessment of surveys and mixed-methods studies with the CASP Checklist for Descriptive studies

Reference (author, year of publication)	Are the results valid?										
	Did study address a clearly focused issue?	Did authors use appropriate method to answer their question?	Were subjects recruited in an acceptable way?	Were measures accurately measured to reduce bias?	Were data collected in a way that addressed the research issue?	Did study have enough participants to minimise play of chance?	How are results presented and what is the main result?	Was data analysis sufficiently rigorous?	Clear statement of findings?	Can results be applied to local population?	How valuable is the research?
Quantitative studies											
Admiraal et al., 2022 (18).	yes	yes	can't tell (no information on disease severity in studied population)	no (validated questions were used, but measurements were subjective and there was no information given on reducing measurement bias)	yes	can't tell (no power calculation was performed)	Results are presented in a descriptive way and in a table format with statistics Main results reported: main facilitators and barriers of PCC	yes	yes	yes	valuable
Ehrenberg et al., 2023 (21).	yes	yes	yes	no (validated questions were used, but measurements were subjective and there was no information given on reducing measurement bias)	yes	can't tell (no power calculation was performed)	Results are presented in a descriptive way and in a table format with statistics Main results reported: partner perspectives on women's sexual and reproductive health	yes	yes	yes	valuable

Reference (author, year of publication)	Are the results valid?										
	Did study address a clearly focused issue?	Did authors use appropriate method to answer their question?	Were subjects recruited in an acceptable way?	Were measures accurately measured to reduce bias?	Were data collected in a way that addressed the research issue?	Did study have enough participants to minimise play of chance?	How are results presented and what is the main result?	Was data analysis sufficiently rigorous?	Clear statement of findings?	Can results be applied to local population?	How valuable is the research?
Lynch et al., 2020 (27).	yes	yes	yes	partially (validated questions were used, but measurements were subjective, but there was information given on reducing measurement bias)	yes	van't tell (no power calculation was performed)	Results are presented in a descriptive way and in a table format with statistics Main results reported: information and communicatio n needs on family planning, satisfaction and quality of communicatio n with HCPs	yes	yes	yes	valuable
Mittal et al., 2014 (30).	yes	yes	can't tell (mention that no exclusion was made based on controlled vs uncontrolled disease, but no information on disease severity in studied population)	no (no information on validation of questions, measurements were subjective and there was no information given on reducing measurement bias)	yes	can't tell (no power calculation was performed)	Results are presented in a descriptive way and in a table format with statistics Main results reported: increase of understanding pregnancy risks after counselling,	yes	yes	yes	valuable

Reference (author, year of publication)	Are the results valid?										
	Did study address a clearly focused issue?	Did authors use appropriate method to answer their question?	Were subjects recruited in an acceptable way?	Were measures accurately measured to reduce bias?	Were data collected in a way that addressed the research issue?	Did study have enough participants to minimise play of chance?	How are results presented and what is the main result?	Was data analysis sufficiently rigorous?	Clear statement of findings?	Can results be applied to local population?	How valuable is the research?
							increase of knowledge about a reproductive plan, increase of support and information to make reproductive health choices after counselling				
Rao et al., 2023 (32).	yes	ues	yes	partially (validated questions, measurements were subjective and there was no information given on reducing measurement bias)	yes	can't tell (no power calculation was performed)	Results are presented in a descriptive way and in a table format with statistics Main results reported: prior reproductive health counselling by HCP, factors associated with patient-reported prior counselling, patient desire for health education	no (very limited information on data analysis)	yes	yes	valuable

Reference (author, year of publication)	Are the results valid?										
	Did study address a clearly focused issue?	Did authors use appropriate method to answer their question?	Were subjects recruited in an acceptable way?	Were measures accurately measured to reduce bias?	Were data collected in a way that addressed the research issue?	Did study have enough participants to minimise play of chance?	How are results presented and what is the main result?	Was data analysis sufficiently rigorous?	Clear statement of findings?	Can results be applied to local population?	How valuable is the research?
Toomey et al., 2013 (33).	yes	yes	can't tell (no information on disease severity in studied population)	no (no information on validation of questions, measurements were subjective and there was no information given on reducing measurement bias)	yes	can't tell (no power calculation was performed)	Results are presented in a descriptive way and in a table format Main results reported:	no (very limited information on data analysis)	yes	yes	valuable
Mixed-methods studies											
Ackerman et al., 2015 (17).	yes	yes	can't tell (no information on disease severity in studied population)	no (no information was given about potential researchers bias or management of power imbalances, validated questions, but measurements were subjective and there was no information given on reducing measurement bias	yes	can't tell (no power calculation was performed)	Results are presented in a descriptive way and in a table format with statistics Main results reported: information needs on medication safety, access to physical/emotional support services and practical strategies to cope with daily challenges,	no (only one author analysed qualitative data)	yes	yes	valuable

Reference (author, year of publication)	Are the results valid?										
	Did study address a clearly focused issue?	Did authors use appropriate method to answer their question?	Were subjects recruited in an acceptable way?	Were measures accurately measured to reduce bias?	Were data collected in a way that addressed the research issue?	Did study have enough participants to minimise play of chance?	How are results presented and what is the main result?	Was data analysis sufficiently rigorous?	Clear statement of findings?	Can results be applied to local population?	How valuable is the research?
							preferred format and channels of information, role of consumer-based arthritis organisations				
Chakravarty et al., 2014 (20).	yes	yes	can't tell (no information on disease severity in studied population)	no (no information was given about potential researchers bias, no validated questions, measurements were subjective and there was no information given on reducing measurement bias	yes	can't tell (no power calculation was performed)	Results are presented in a descriptive way and in a table format with statistics (percentages) Main results reported:	no (no information on data analysis, and how many researchers were involved in analysis of qualitative data)	yes	yes	valuable