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Abstract

Background: Endometriosis is a chronic gynaecological disease of women of reproductive age linked to menstruation and the hormones that trigger it. The symptoms of endometriosis have a major impact on women's quality of life, either on a psychological level or on a societal one. Today, as many other female-specific topics, endometriosis is under-researched and under-diagnosed and many causes remain unknown. Although literature suggests that endometriosis patients are prone to use social network as a self-management tool and discuss various topics related to their disease, very few papers applied infodemiological (epidemiology based on internet health-related content) methods to endometriosis.

Objective: The main objective of this study is to understand whether infodemiology could be useful for public health decision makers in the management of patients with endometriosis and to prove it to be a reliable study methodology.

Methods: Firstly, social media post were collected between January 2020 and 2022 from France geolocalized sites using keyword for endometriosis. Automatic natural language processing methods were used to identify relevant patients with endometriosis posts expressing difficulties and unmet needs. Then, semi-structured interviews were conducted during July 2022 with 9 women with endometriosis and healthcare professionals. Discussions were recorded and transcribed verbatim were analysed through a thematic analysis allowing to generate general statistics on the most discussed topics.

Results: A total of 2,396 written by 1,742 patients with endometriosis were included. 2,317 (96.70%) were identified as containing at least one difficulty. The top 3 unmet needs and difficulties were difficulties present throughout the care pathway (71.1%; n = 1701), pathology-related (57.2%; n = 1,356) and treatments and medical procedures (20.6 %; n = 492). Semi-structured interviews show that the top 3 main difficulties for patients with endometriosis were difficulties related to treatments (30% of the detected medical concepts), impact of the disease on the patient's environment (29% of the concepts) and transversal difficulties (16% of the concepts).

Conclusions: The bi-patient-centric approach with limited manual work allows to identify difficulties encountered by patients with endometriosis in France. The mixed-methodology of this study appears ideal to demonstrate their complementarity and to justify the use of AI algorithms for public health decision-making. Furthermore, endometriosis is a disease affecting a wide range of women, each with their own specific difficulties. They now expect societal and medical recognition of their illness and care pathways adapted to their individual symptoms.

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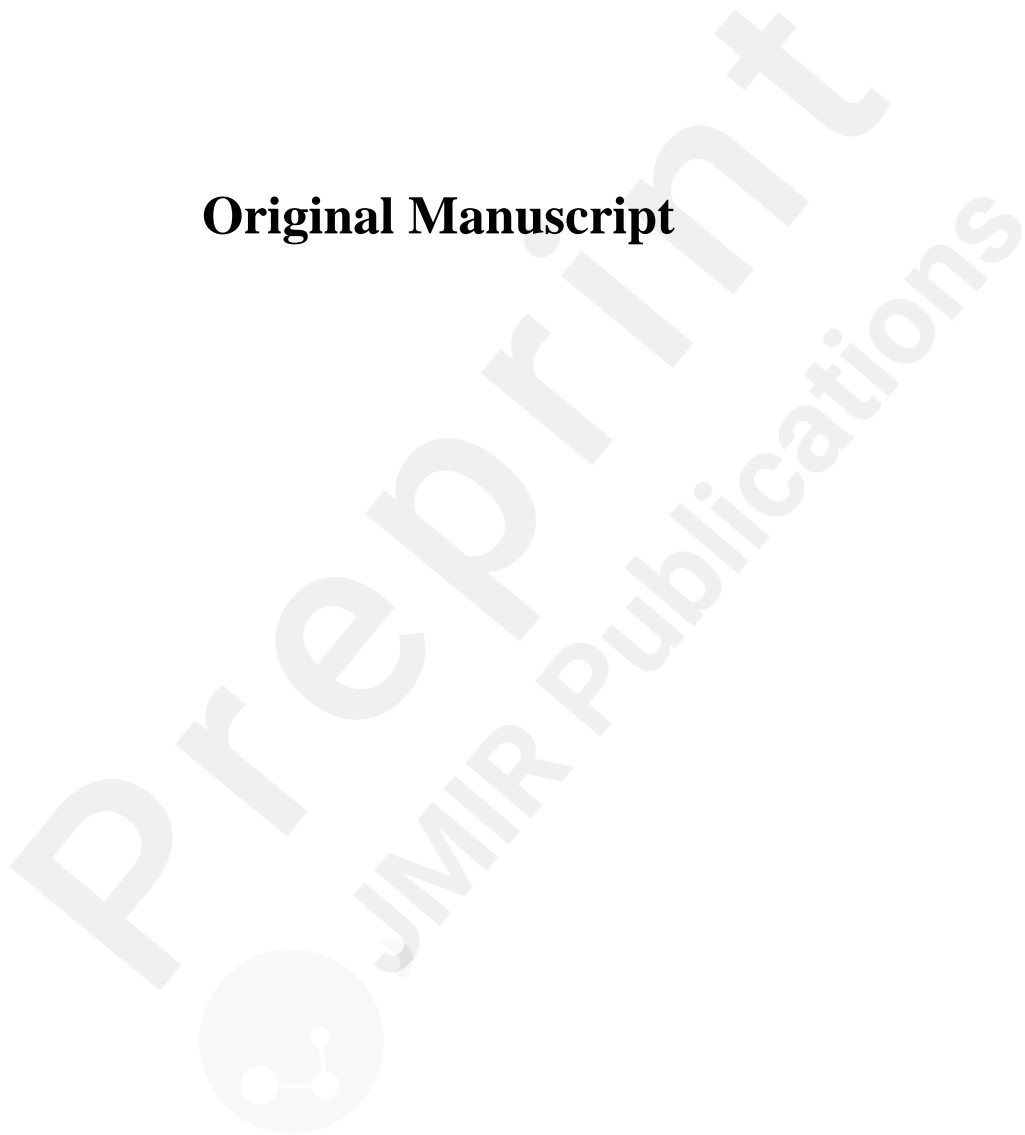
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Original paper

The use of infodemiology in the development of targeted public health actions on endometriosis in France: a mixed & patient-centric methodology

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Keywords: Real-world evidence; Social media; Endometriosis; Unmet needs and difficulties; Women health; Semi-structured interviews; Public policies; Infodemiology; Public health

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Introduction

Background

Women health & endometriosis

Endometriosis is a chronic gynaecological disease of women of reproductive age that is characterized by the development of uterine lining (i.e., endometrium) outside the uterus, colonizing other nearby organs¹. The prevalence of endometriosis in France cannot yet be accurately estimated due to diagnostic difficulties² but it is estimated that 1.5 to 2.5 million women are affected by the disease in 2022³.

This disease, linked to menstruation and the hormones that trigger it, occurs in women of childbearing age and diminishes or even disappears with the menopause³. Generally, the main symptoms associated with endometriosis are pain at multiple sites (chronic pelvic or digestive pain, dysmenorrhea, dyspareunia). These chronic pains are unique to each individual and can occur either during or outside the cycle⁴. In addition, the severity of endometriosis does not correlate with the severity of symptoms, a patient with a mild severe endometriosis could have severe painful symptoms⁴. Furthermore, the inflammation that causes the pain can lead to infertility in women and 30 to 40% of women with endometriosis, in France, are infertile⁵.

Patients are currently treated with drugs or surgery. On the one hand, oral contraceptives (continuous or cyclic), often combined with non-steroidal anti-inflammatory drugs (NSAIDs), allow the regulation or even suppression of menstruation to reduce pain⁶. On the other hand, surgery aims to remove the endometriosis lesions in the various locations, thus helping with the pain. For women with no desire to procreate or at severe stages of the disease, a hysterectomy (surgical removal of the uterus) may be performed⁶. The symptoms of endometriosis have a major impact on women's quality of life, either on a psychological level (moral, sexual, personal) or on a societal one (economic or

professional)⁴.

Today, although research on endometriosis is making progress, many causes remain unknown. According to the French National Institute for Health and Medical Research (INSERM), in the last 5 years approximately 1,200 articles on endometriosis per year have been published worldwide⁷.

In the 2020's, there is much evidence that female-specific topics are often underrepresented in clinical research but also in the literature⁸. The French report proposing a National Endometriosis Strategy (2022-2025), published by Dr C. Zacharopoulou in March 2022⁹ describes the need for a "holistic and cross-sectoral approach to this societal disease", including medical (symptoms recognition and implantation of control programs) and societal (menstruation taboo) support. Hence, the lack of recognition of endometriosis has encouraged women to speak out on social networks in opposition to a medical paternalism.

Real life data & infodemiology

As a result of the deficient knowledge and care for their disease, endometriosis patients turn to social networks (SN) for emotional support and educational content. Patients use social network to share their experiences extensively and by doing so create real-world data, meaning data generated during routine care of a patient that reflect current practice¹⁰. According to the Health Data Institute (HDI), patients have an ease of expression on these platforms that is unique. Social networks represent opportunities for patients to consult testimonies about their illness and share about their health condition spontaneously with their peers¹¹. These practices have intensified during the COVID-19 pandemic. Since then, the use of social networks is still growing in the general population and especially on health topics¹².

Data generated on social networks is the object of a growing interest, fostered by its volume and quality. Analyzing health-related internet content such as social network data for public health purposes is considered as a

discipline in itself, defined in the early 2000's by Gunther Eysenbach as infodemiology¹³. Thanks to artificial intelligence algorithms and natural language processing models, large volumes of users' posts can be analyzed to gather insights that directly reflect patients' lives with their disease on a daily basis and their own health perception. Social network listening can be a time-saving method that allows the creation of larger samples than traditional methods (questionnaires, semi-structured interviews (SSIs), focus groups)¹⁴. It also represents a valuable source for patient-centric approaches towards which "New Public management" (NPM) is leaning to redefine the management of public health policies¹⁵. It underpins the management of patients according to their needs, their wishes and includes them in the discussion around their illness¹⁶. By empowering patients, health outcomes (such as their satisfaction, their quality of life,...) are maximized¹⁷. In addition to the purely medical aspects of one's life, one's behaviors (care pathway, compliance, lifestyle) are also taken into account¹⁵, as these elements are regularly spontaneously expressed on social networks by patients¹⁸. Currently, health data from social networks are scarcely stated by the French health authorities. However, steps towards such recognition are already underway in other countries, which could encourage French political stakeholders to consider social networks data more often. The guidelines provided by the US Food and Drug Administration (FDA) state that social network data is now to be considered of interest for public health, opening the door to the recognition of such data¹⁹. Although literature suggests that endometriosis patients are prone to use social networks as a self-management tool²⁰ and discuss various topics related to their disease²¹, very few papers are interested in applying infodemiological methods to endometriosis. Existing work focuses on characterizing content in discussions related to the disease^{22,23}.

Prior work

A literature review was carried out on the PubMed database. The theme of endometriosis or its pathophysiology is cited in numerous clinical studies, for example, the keyword "endometriosis" yields 12,000 articles in the last 10 years. In comparison, the query "breast cancer" (chronic disease with the same incidence: 1 woman in 12²⁴) identifies 220,378 articles, demonstrating the lack of knowledge and scientific research relating to endometriosis.

In other fields, notably sociology, this pathology appears much more rarely. In terms of infodemiology (or social media listening - SML), in the last 10 years, the results were:

- 48 papers on Pubmed with the query: "social network*" OR "social media" AND "endometriosis"
- 14 papers on Cairn with the query: endometriosis AND "social network*" OR "social networks"¹

These numbers seem low for a chronic disease that is widespread in the general population. In comparison, 379 SML studies on breast cancer are identified on Pubmed. The topics explored by SML articles are narrower than this study, including one social network only or small database, being more market-centered. The interviews focus on social network users²⁵, or sometimes on caregivers²⁶, but not on patients.

Objectives

The main objective of this study is to understand whether infodemiology could be useful for public health decision makers in the management of patients with endometriosis and to prove it to be a reliable study methodology. This study also contributes to the knowledge of endometriosis, and its societal and real-life impact.

Three research answers led the study methodology:

- (1) To what extent does endometriosis require awareness-raising measures to improve patients' support throughout their care

¹ Translated from the French query as Cairn is a French database

pathway and to implement better-targeted action(s)?

(2) Are the difficulties encountered by endometriosis patients mentioned on social networks comparable to those reported during SSIs? A comparison of the innovative algorithmic approach and the traditional discursive approach.

(3) Does the analysis of health data via artificial intelligence on social networks represent an innovative strategy allowing a patient-centric approach to public health?

Methods

Infodemiology: methodology **mixed**

Data

Data extraction

This observational, retrospective, social network infodemiological study encompasses data retrieved from social network posts of patients with endometriosis. Public posts written in French between January 2020 and January 2022, and geolocated in France were included.

Data extraction requires the construction of a query allowing to define the words (and hashtags) a post should or shouldn't contain to be included in the study. The BrandwatchTM extractor (a tool used by Kap Code allowing social network management and collecting data from multiple social networks) was used as part of the Detec't© solution²⁷ to retrieve posts (and their associated metadata such as time and date of the post) about endometriosis patients. In addition, the construction of the query required prior research on the mediatic and political contexts of the topic in order to exclude sources that could provide noisy data, i.e. data not related to personal experience of endometriosis.

Pre-processing

Extracted posts were prepared for analysis by

Table 1: Grid representing difficulties and unmet needs used in the deep learning model

eliminating duplicated and noisy posts (concerning animals, inappropriate sources, etc.). Only patients' posts were included in the study. They were selected using a previously published pipeline²⁸ combining two XGboost classifiers²⁹ trained on 12,330 social network posts to categorize posts as being posted by a patient, a caregiver or neither. Predictions were validated by manual annotation.

Ethical consideration

The public nature of information posted on social networks was taken into account. Data used in this study was extracted from publicly available sources and not from private groups. Users consent to exploitation by a third party when subscribing to a social network. Results are presented at the aggregate level and no personal information is shared in this work.

Detection of difficulties in patients' posts

Preliminary work: difficulties classification grid

Difficulties expressed in patients' experiences were identified using a deep learning model trained on similar data previously categorized according to a grid based on existing literature. Patients can encounter difficulties and express unmet needs, at every stage of their care pathway and in every aspect of their environment. This grid (table 1) aims to cover all of them. It was also used to categorize difficulties expressed during the SSIs, to enable comparison with infodemiological results.

Unmet needs	Period of care pathway impacted by the type of unmet need
Diagnosis	Before the care pathway
	During the care pathway
Intervention	During the care pathway
Duration of care and	During the care pathway
Environment	During the care pathway
Care pathway	All along the care pathway

Model training and validation

We applied on endometriosis social network data a previously trained deep learning algorithm able to identify categories of difficulties from the classification grid. This algorithm is based on the transformer-based model CamenBERT³⁰, and was designed as a two-steps pipeline.

First, a set of 250,000 posts were sampled from the Detec't© database²⁷ covering several therapeutic areas, among which gynaecology. Randomization of posts' size and source was done to ensure an unbiased training dataset. These posts were used to fine-tune the classification model. Secondly, a set of 3,900 posts was sampled with the same conditions and annotated manually by medical experts. 2,649 expressed difficulties were identified and divided into the 6 categories corresponding to the main stages of the care pathway. This was used to train a multi-label classifier using K-fold cross-validators, i.e. using several different splits between training and validation.

Post-processing and qualitative analysis

Posts containing at least one difficulty

identified by the algorithm were grouped by step of care pathway. They were then reviewed manually to validate the presence of the detected difficulty. Proportions for each type of difficulties were computed. A handwritten analysis of the posts was carried out in order to determine the

specificities found in each category of the care pathway and to explain patients' difficulties.

The analysis of the verbatims was based on declarative data, and no personal interpretation of the posts was made.

Semi-directive face-to-face interviews

Research design

The infodemiological study was completed by a qualitative analysis of semi-directive interviews from patients and healthcare professionals between June and July 2022.

Participants included French-speaking healthcare professionals and patients, including an expert patient who was in charge of developing therapeutic education programs for patients with endometriosis from Endomind association (association created in 2014 and approved by the Ministry of Health and recognized as being of public utility, whose objective is to raise public awareness of the disease and to improve patients' care management). They were all recruited on a voluntary basis. Participants' recruitment took place both online (on Facebook groups dedicated to endometriosis patients) and offline (relayed by doctors specialized in endometriosis and during a conference on endometriosis).

Data collection

Interviews have been conducted by a public health university graduate trained in qualitative research methodologies at the EHESP School of public health and with face-to-face interview skills. Interviews were conducted in French and lasted between 1 hour and 1.5 hours. Two interview guides were produced: one for patients and the second one for healthcare professionals. The

patient guide follows the structure of the classification grid (table 1) with an added category "other" corresponding to opinions on public policies and social networks. To ensure patients didn't feel stigmatized, the words "disease" or "pathology" were deliberately not used. The healthcare professional guide was meant to assess their management of patients with endometriosis and to gather objective insights about their patients' expressed difficulties. Prior to interviews, consent for recording was asked. Recording was used to ensure standardization of collected data and secondary analysis. Quotes from the interviews have been translated to English only after the data analysis to limit translation bias. All participants provided oral informed consent to participate in the study prior to interviewing and no identifiers were collected as part of study procedures.

Data analysis

All recordings were listened to and transcribed during June and July 2022 by the university graduate student (appendix).

The interviews were analyzed in two steps. Firstly, a standardized analysis grid was created to classify the verbatims from each interview and ensure their comparability. Secondly, this grid was analyzed and translated into a thematic table which was constructed using a bottom-up approach: first, the patients' testimonies had to be conceptualized, then the number of appearances of each concept in all interviews was computed. These concepts were then grouped into general themes (corresponding to the categories from table 1 plus the "other" category described above) and sub-themes. Statistics were then compiled on the frequency of appearance of each concept in all the verbatims. A concept may be mentioned several times by a patient.

Results

Infodemiology study

Population and posts

Between January 2020 and January 2022, a

total of 11,827 posts in French were retrieved. After preprocessing the data, 2,396 posts written by 1,742 patients with endometriosis were included.

The data came from 30 different forums, including Twitter and Doctissimo (1,987 posts out of a total of 2,396, i.e. 83% of the posts). Other forums such as Babycenter.fr or fiv.fr² appear among the most cited, showing women's interest in pregnancy-related issues. 88.6% of the patients did not express their age and 17.2% didn't express their gender. The other 82.7% were women, which is expected given the pathophysiology of endometriosis. One patient was gendered as male, the qualitative analysis of the post shows that the patient defines himself as a "transgender male".

Difficulties encountered

2,396 posts were studied, 2,317 (96.70%) were identified as containing at least one difficulty. All six categories from our classification grid were found (table 2).

Transverse difficulties

The category represented in 71.7% of the posts ($n = 1,701$) concerns transverse difficulties, i.e. difficulties present throughout the care pathway of endometriosis patients.

Difficulties related to pregnancy

First, difficulties related to the desire for pregnancy were identified. Patients express a need to share experiences and support related to the impact of the disease on procreation. Resorting to assisted reproductive technology is common.

² Fiv = In vitro fertilization in French

Table 2: Presentation of the infodemiological study results

Period of care pathway	Type of difficulties and unmet needs	Proportion of posts, n (%)	Proportion of patients, n (%)
All along the care Pathway	Transverse in the care pathway	1,701 (71.7)	1,353 (77.7)
During the care pathway	Pathology	1,356 (57.2)	1,141 (65.5)
	Treatment/Medical intervention	492 (20.6)	442 (25.4)
	Management, organization of care and follow-up	398 (16.8)	355 (20.4)
	Impact on the environment	356 (15.0)	292 (16.8)
Before the care pathway	Screening and diagnosis	241 (10.2)	224 (12.9)

"I have endometriosis and was only diagnosed when I was desperate to get pregnant after 18 months of trying without success. The average time between the first symptoms and the diagnosis is about 10 years. [...] only a medical opinion specialized in this field can answer your question."

A strong psychological impact of the disease on patients

A large majority of women express fear or stress following the announcement of the disease. As treatments to limit pain are mainly hormonal, women express concerns about the side and adverse effects (SEs/AEs), particularly concerning mood disorders (depression).

"Hello good evening, all my life I've had endometriosis pain, then it was adenomyosis. (...) I've never been able to stand the hormonal drugs [...] [...] I have migraines, I cry all the time, I have mood swings and I don't know what to do any more!"

Difficulties related to their sexuality

Many patients report pain during sexual intercourse (dyspareunia). Sexuality-related topics can sometimes be difficult to discuss with healthcare professionals. Social networks are a more favorable way for them to share their fears and anxieties and to find testimonies. These difficulties related to sexual

life can lead to difficulties in relationships, in couples and even deteriorate their self-image. *"My gynaecologist said that it was normal for me to be in pain during sexual acts... So, talk to your gynaecologist about it, it's important because having sex while in pain is not at all pleasant."*

Difficulties related to the pathology

Endometriosis is strongly correlated with painful symptoms in various places; unsurprisingly, 57.2% (n = 1356 posts) of the posts express difficulties related to the disease. In social networks, patients express pain that can be located in multiple places depending on the organs affected by the disease (regular pelvic pain, digestive pain, pain during defecation or urination, etc.). They describe pain that occurs in attacks but can also last several days and can trigger vomiting or even require going to the emergency room. Paradoxically, pain is described as "unbearable" but patients mention it as an everyday occurrence with no real emotion attached, these events are trivialized.

"I have endometriosis and [...] I was prescribed [medication]. [...] I take a bit too much because the pain is so bad. and the result is: the pain is getting better but I'm completely high."

Difficulties with treatments or medical intervention

For 20.6% of patients (n = 492 posts), treatments or medical procedures are a source of difficulty and concern.

The main difficulty present in the posts is the lack of specific and targeted treatment for endometriosis. Patients say that they are subjected to diagnostic delays for a long time before finding adequate medication to relieve symptoms. Most often, patients seem to be on the pill or on hormonal treatment to reduce or even stop their period.

Secondly, they describe SEs/AEs linked to these hormonal treatments. They are numerous and affect patients as much physically as psychologically, representing a real burden. Among these SEs/AEs are: weight gain, acne, mood alteration, and loss of libido.

In addition, patients ask questions regarding a variety of subjects such as the hygienic-dietary measures to follow in order to limit pain or the risks linked to taking NSAIDs during the COVID-19 pandemic. Some patients express interest in the benefits of alternative medicines: naturopathy, the use of green clay as a poultice or by ingestion to reduce pain during bleeding... On the other hand, others expressed disagreement with doctors who, faced with ineffective treatments, suggested food supplements or homoeopathy. They express their dissatisfaction with the lack of trust given to them by the healthcare professionals during their diagnostic delays.

"We don't talk about it enough. They took 5 years to diagnose my endometriosis, I had more than 6 different treatments in less than a month, I had to repeat the year because I missed all my classes because of the pain."

Other difficulties

Management, organization of care and follow-up were mentioned in 16.8% of the posts.

Problems relating to communication and the patient-doctor relationship were mentioned, such as the lack of empathy and training on the part of physicians concerning the specificities of endometriosis. The "impact on the environment" appeared in 15.0% of the posts, as the patients mentioned the numerous impacts of the disease on their personal (family life) and professional lives. The disease is disabling on a daily basis, with mentions of difficulties in walking, the need to stop sport or the burden of administrative procedures linked to the disease.

"I am 20 years old and have endometriosis. [...] If I run for 5 seconds, I am exhausted, I can no longer go eat at friends' or family's house, I can't go out like people of my age, not to mention that my relationship is totally platonic because the pain is such that all sexual activity is reduced to nothing."

"My gynaecologist told me that I had always had endometriosis... In 2001, I had already had a laparoscopy to see what was wrong with me [...] In short, I was discovered to have stage IV endometriosis and I came close to having a hysterectomy... with apologies from the medical profession!"

Table 4: Summary table of concepts mentioned by patients during the SSIs

Primary themes (%)	Secondary themes	Specific concept	No. mentions in
--------------------	------------------	------------------	-----------------

	(%)		interviews (N = 85)
Screening and diagnosis (14)	Screening (7)	Medical error / delay in treatment	2
		Diagnosis announcement because of screened infertility	3
		In accordance with its diagnosis	1
	Shock of the announcement (7)	Yes	2
		No (normalization of pain)	4
Symptoms (14)	Pain (14)	Painful symptoms	6
		Objectification of pain	6
Treatments/Medical interventions (30)	Types of treatments (11)	Natural methods	2
		Hormonal treatments (long term pill)	6
		Alternative medicine	1
	Surgery (4)	Hysterectomy	1
		Repairing consequences of endometriosis	2
	Outcomes of treatment ingestions (9)	Mental burden of ongoing treatment	2
		Delivery of treatments	6
	Adverse events (6)	NSAIDs (inefficacy)	2
Hormonal treatments		3	
Impact on the environment (29)	Daily life unmet needs (29)	Disability	3
		At school	3
		At work	3
		Deterioration of family relationships	4
		Daily activity	5
Transverse in the care pathway (16%)	Infertility (5)	Infertility	4
	Psychological (11)	Psychological and social impact	9
Management, organization of care and follow-up (6%)	Medical care (6)	Favorable	3
		Unfavorable	2

Face-to-face interview results

Socio-demographic characteristics of the study sample

Overall, 9 individuals were interviewed during the study: 7 patients (including an expert patient member of the association Endomind) and 2 healthcare professionals (midwife and an obstetrician-gynaecologist specialized in infertility and endometriosis). Patients were recruited from different geographical areas in

France. Women were between 15 and 55 years old and were classified in two categories depending on their diagnosis delay: either “more than 10 years” or “less than 10 years” (table 3). Out of all the interviews, a total of 85 medical concepts were mentioned (excluding the themes “others” as it was not mentioned in the infodemiological study) and were used to calculate statistics in table 4. These concepts have been grouped according to the steps of the care pathway (themes) and sub-themes.

General knowledge about political topics

Throughout testimonies and answers, patients do not express a clear opinion on current public policies regarding endometriosis and none of them express their views on social networks (table 3). They explain that normalization of the debate around endometriosis in the society is already a major step in the recognition of their disease. The healthcare professionals are more informed about current political decision-making strategies, because of their engagement on the topic.

Table 3: Socio-demographic characteristics of the qualitative study sample (n = 9)

Characteristics	Value
All participants' characteristics	
No. of participants, N	9
Patients, n (%)	6 (66)
Healthcare professionals, n (%)	3 (33)
Patients' characteristics	
No. of participants, N	6
> 10 years diagnosis delay, n (%)	3 (50)
< 10 years diagnosis delay, n (%)	3 (50)
Interests	
No. of participants, N	9
Self-expression on social media, n (%)	0 (0)
Use of social media, n (%)	7 (77)
Political knowledge, n (%)	7 (77)

Analysis of patients' interviews

Concepts expressed by patients, counts and proportions, are displayed in table 4.

Difficulties around diagnosis and perception of the disease

Data shows that, independently from age, there is a delay in the diagnosis: 14% of

patients express difficulties related to screening and diagnosis. Screening was delayed for two patients. Three patients had a diagnosis as a consequence of complications of the disease, which deteriorate fertility. Only one patient expressed a self-diagnosis. She is aware of the speed of her diagnosis, and what she finds problematic is the "luck" she had in being diagnosed so quickly; she denounces the lack of information and the trivialization of menstrual symptoms.

The announcement of the diagnosis was a shock for two patients, with difficulties of acceptance in the initial moments. For others, the normalization of pain during menstruation, or prior knowledge of the disease, simplified the announcement of the diagnosis.

"It's not that the diagnosis took a long time, it's that I took a long time to accept it too, due to a lack of information (...) between the moment I said to myself that there was a problem and the moment I was diagnosed it took 6 months."

"When you're already used to having uncomfortable periods, (...) you put up with it without asking too many questions. (...) We get used to dealing with these very feminine problems. Women do what they can, (...) I used to lie down in my car between midday and 2."

Difficulties related to the pathology

Pain being subjective, patients were asked to express it explicitly so that they could be compared and analyzed. Words such as "fainting", "vomiting", "walking folded in half", or "a pain similar to cramps in the calf" came up in all the interviews, representing 14% of the concepts. The chronicization of pain is illustrated in patients' testimonies by their ability to describe this pain:

"I have pain from 10am to 2pm and after lunch it goes down a bit in the afternoon and in the evening, it comes back and sometimes it wakes me up at night."

Difficulties with treatments or medical intervention

30% of concepts are related to treatment strategies, respectively 15% and 15% describing drugs or surgical interventions, AEs and consequences. As far as treatments are concerned, they are often mentioned by the patients, and a distinction is made between painkillers and hormonal treatments. Natural methods and alternative medicines are also mentioned in patients' verbatims.

Firstly, painkillers are generally taken by the patients before their diagnosis of endometriosis, and were described as ineffective (n = 2) on their menstrual pain. Some patients even developed intolerance to NSAIDs (n = 1). Then, once the diagnosis was made, all patients were prescribed hormonal treatments. Two concepts were treatment-related: a mental burden and concerns about off license prescription (continuous pill taking). Half of the patients explain the numerous SEs/AEs caused by the hormonal treatments: "consecutive bleeding", "a hellish weight gain". For women who had children and no longer wish to procreate, stopping the treatment is immediately sought after.

"On the management of pain, I found it great to have solutions other than chemical ones to deal with the pain (I was told about acupuncture)."

"Taking the pill continuously is not harmless (...) nature is to have these periods (...) so I am necessarily going against nature, there are inevitably repercussions (...) in my body."

"A lifetime of gynaecological follow-up was heavy at one point, it stays in your mind all the time, you live with it. And then it's an intrusive follow-up in some ways and when we've already had quite a few problems at that level... I didn't want to do it anymore."

Social impact and quality of life

Daily repercussions of the disease throughout their treatment are expressed (29%). There are

impacts on academic activities (absence from school), professional activities (absence from work), family, social activities (cancellation of events) and sports (inability to do physical exercise during or outside of menstruation).

"I've already missed weddings because of this, I've missed parties because I was so sick."

"I do my things but I'm in pain: I say wait two seconds, I lie down on the floor and I'm writhing in pain but I have to be active in my life."

"My mum didn't necessarily want to help me (...) I was on my own, (...) by typing in "gynaecologist + endometriosis [on the internet]". We don't talk about anything physical, and I had a problem with my periods (...) I needed my family, I was very young, I was just out of the final year of high school, so it was a source of sadness and I was a bit angry with them."

Transversal difficulties and healthcare pathway

6% of the concepts identified refer to the organization of care. Patients express mixed feelings: even if the medical care by healthcare professionals was mostly well received by the patients (n = 3), some concerns are evoked about their potential distance with the patients. 15% of the concepts highlight unmet needs throughout the care pathway. Infertility is mentioned in more than half of the testimonies, as well as topics such as mental health suffering or AEs. All these difficulties (11% of concept in the transversal difficulties category) have a moral impact on patients' daily lives. On top of that, 11% of testimonies in this category, illustrate patients blaming poor social recognition of endometriosis.

"Doctors have less time to give emotionally to their patients, it's true that gynaecologists are a slightly colder and more distant profession."

"I am part of the 10% who have

endometriosis and then when you have been operated, only 5% recur, and I am still part of that. And 40% of women manage to get pregnant (...) I feel like I'm always part of the small percentage of shit that recurs and doesn't go."

Healthcare professionals' results

Difficulties related to the pathology

Both professionals agree that a correlation between symptoms and disease severity is impossible. However, *"understanding global pelvic pain"* is a necessary prerequisite for tomorrow's medicine, and should be a major focus for patient management according to the French medical Practice Guidelines. Indeed, this lack of healthcare knowledge around pelvic pain leads to a delay in diagnosis which in turn has serious consequences for women's health. A generational change is underway: it's only since 2020 that endometriosis has been included in the medical exams and a certification about endometriosis management has been created. The reasons for this lack of knowledge about the pathology are expressed by the need for continuous training of healthcare workers and the lack of physicians in general. Midwives could help with filling the lack of medical human resources and alternative medicine could be a solution, promoting well-being and holistic approaches. In specific cases, alternative medicines used in parallel with evidence-based treatment, could provide relief from chronic pain.

"When [the pain] starts to come out of the cycle, you get away from the causes of the endometriosis a little bit and it's more like the consequences of the endometriosis that hasn't been taken care of."

"Imagine being punched in the stomach for 7 days every month and then it gradually becomes chronic because the body remembers the pain, the nerves become hyper sensitive."

Infertility

In vitro fertilization is cumbersome, time-consuming, psychologically difficult and costly (depending on the financial means of the families). In the public sector, the process is free but complicated and the delays are long. In contrast, the delays are much shorter in the private sector, although fee overruns are common. In vitro fertilization processes are difficult and impact not only mental and physical health but also family balance and the patient's professional life.

"There is a very negative feeling among doctors and patients towards the national health system. It reimburses slowly, even though it is a patient's right."

Management of care

The "multidisciplinary nature of the symptoms" leads to difficult care paths and the number of specialists involved requires organization. According to the healthcare professionals interviewed, the people around the patients are a precious help in order not to feel alone in the face of the disease or its management. The mental burden felt by the patients is significant.

"How do you find your place in society when you are 24 years old and disabled by a condition that people don't understand?"

Discussion

The aim of this discussion is to postulate whether the infodemiological method is a useful tool for the implementation of targeted public health actions. The SSIs, a reliable traditional method, are the basis of comparison for this innovative method.

Comparison of difficulties

In the table below (figure 1), proportions of difficulties obtained on social network data (through manually validated algorithmic predictions) and identified in the verbatims of the SSIs, have been put together for comparison.

The three most encountered difficulties in

each methodology, we find differences:

- In the infodemiological study: difficulties present throughout the care pathway, pathology-related and treatment-related difficulties are the most represented.

- In the SSIs: difficulties related to treatments, to the impact of the disease on the patient's environment and transversal difficulties are the most represented.

The main difference concerns transversal difficulties (psychological and social impacts of the disease; complications surrounding the desire for pregnancy). These themes are mentioned by patients in both approaches, with a higher count in the infodemiological study (71.7%) than in the SSIs (16.0%).

In the infodemiological study, difficulties linked to the disease, in particular painful symptoms, are found in second place (57.2%), whereas it is the medical treatments that are most frequently mentioned in SSIs (30.0%). Despite the notable statistical difference, the qualitative analysis of the results shows a similar feeling of pain among the patients in both approaches. In the interviews, the patients expressed it once and described it in detail. Pain never constitutes the major part of the conversations. Instead, its impact on daily life is emphasized; difficulties related to the impact of the disease on the environment represent 29.0% of the concepts. In the

infodemiological study, the pain is described spontaneously with more significant words, but it is still trivialized, whereas the bias of recall that is needed for the SSIs encourages patients to talk about the impact on their daily lives.

Both methods similarly highlight the difficulties of infertility caused by endometriosis and medical treatments. In the SSIs, patients mention it as a stress factor and in the infodemiological study, many patients express concerns about their ability to give birth. These results are approved by the healthcare professionals. The SEs of treatment detailed in both methods were similar (acne, weight gain and mood alteration) with much more varied responses in the social network data.

Medical care and follow-up are mentioned in both methods and complete each other. While the perception of medical care is very positive in the interviews, the social network data highlights the lack of empathy and training of healthcare professionals. This is described by many patients as an obstacle in their care pathway. In contrast, in the interviews, patients are well monitored and well cared for, and describe these difficulties in the past tense.

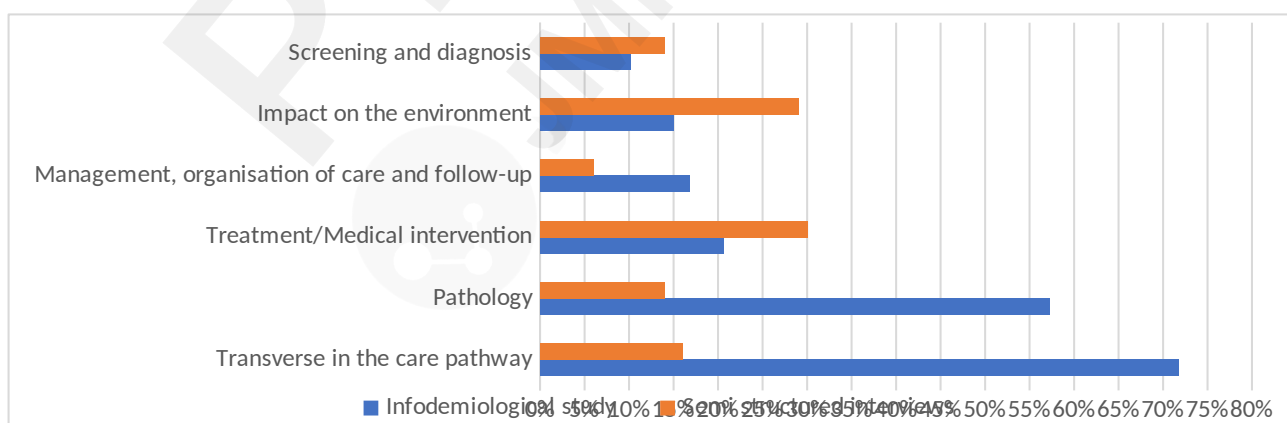


Figure 1: A comparison between the difficulties retrieved from the infodemiological study and SSIs

Comparison of the methodologies

First, social network data provides a fixed image of a difficulty expressed by a patient via

a limited number of words at a given time in his/her life. The instantaneity defines this mode of communication. The words used online are generally more negative than those used by the patients interviewed face-to-face,

who temper their remarks and critics. The analysis proves that SNs represent a space for free expression, and above all of community, in a context where patients can feel poorly taken care of (by the health authorities or socially). The anonymity encourages them to ask questions, maintain virtual relationships with other patients and mention taboo subjects such as sexuality. Thus, assuming that the posts are authentic (see Limitations), they are useful for patients who have suffered from poor treatment, discrimination regarding their disease or a strong impact of the disease on their entourage. Sometimes SNs are considered to represent only the negative side of the disease, a perception confirmed by the interviews. However, while they are not representative of the global care of a disease, they allow patients to find new experiences and alternative methods of care and it becomes a tool for patient empowerment and thus, for the development or the improvement of effective and relevant public policies.

In contrast, SSIs allow an understanding of the context of the patients' disease in their daily lives, but especially of the introspection of their thoughts and emotions about the disease. Non-verbal communication, such as pauses in the discussion or sad emotions, are important to analyze. The interviews made it possible to moderate the comments and understand certain implicit mental schemes. Even though the interview is designed to build up a progressive relationship of trust with the patient, it is sometimes still difficult to discuss some topics (sexuality). Moreover, the interviews reveal aspects of the disease that patients have been able to normalize over time, they also emphasize that patients have already learned to live with their disease and thus tend to express their feelings more easily. This global understanding of the repercussions of the disease provides keys to reading the social network data. One could argue, however, that by analyzing a large number of social network posts and thus multiplying short testimonies, an exhaustive understanding of the disease is also possible.

Ultimately, infodemiological analysis is less time-consuming than SSI analysis. Compared

to the multiple steps of creation of interview guides, transcription, conceptualization of verbatims that the interviews require, algorithms used in infodemiology pre-identifies posts mentioning the topic of interest and allows to draw conclusions more quickly.

The need for targeted public action in the case of endometriosis

The understanding of endometriosis related difficulties has evolved through time. Despite common belief, diagnostic delays were seen initially as the major issue. The problem is now wider and encompasses the whole care pathway and its organization. This study allows to identify three main pain-points in the management of endometriosis:

- the need to inform population on the disease and to fight against normalization of menstrual pain;
- the strong psychological impact, which is reflected in the search for testimonies on SNs (infertility) and the mental health consequences of potentially misdiagnoses;
- the generalization of case management and the need to improve the patient-physician relationship by fortifying healthcare professional engagement.

According to patients, communication about this disease is not yet optimal. In both methods the symptoms of endometriosis appear to be trivialized, particularly because of the lack of recognition of this disease. This inevitably has an impact on pain management strategies, even though in France, pain management is a legal obligation according to the public health code³¹. That is why population information is the main intervention to implement. Chronic pain can be extremely harmful to patients as there is an exponential development of pain over the years.³² Educating the population on menstrual pain to fight its normalization will decrease impact on patients' quality of life.

Despite the decrease of diagnosis delay, mental health consequences of over-diagnosing are questioned. Indeed, the representation of this disease in the media is

very pejorative and its psychological impact can be severe (shock at the moment of announcement, infertility worries). Benefit-risk balance of diagnosing must be found, preventing unnecessary harm in asymptomatic cases. The spectrum of endometriosis involves inter-personal specificities, justifying the need of raising awareness. Patients with 10 years of undiagnosed endometriosis won't cope with the same issues as the patient diagnosed at an early stage. This needs to be taken into consideration in public health decision making.

The main learning of this study is the necessary involvement of the healthcare professionals in the care of patients. The infodemiological study highlights that efforts need to be made by some healthcare professionals around lack of empathy and training. Even if this represents a minority of practitioners, this needs to be taken into consideration as long as it is expressed by patients. According to patients, general practitioners are the first line and must be properly trained and familiar with those care pathways. Understanding compliance problems is primordial, and no delay should be encountered in putting public policies into practice. However, caution should be taken in the implementation of new care networks, to ensure harmonization of patient management at the national level (reducing surgery by diagnosing earlier).

Social networks: highlighting weak signals in public health for the implementation of public policies

Public health has many definitions, however, its essence is a population-based approach to health management³³. The concept of "health in policies" highlights that health determinants occur throughout the life course of patients and are not confined to the world of health. This concept justifies the use of SNs as a tool for identifying public health weak signals and is used in the implementation of intersectoral health policies to reduce social inequalities in health³⁴.

In this context, infodemiology can be seen as an indispensable, innovative and complementary tool for tomorrow's healthcare system. It allows the collection of information that takes into account different populations, lets the voice of patients express itself without filter, and allows the identification of issues not identified by traditional methods (concerns related to NSAIDs, sexual relationships). It is therefore becoming essential for future health and public healthcare professionals to be familiar with real-life data, its methodology and its biases³⁵.

In the analysis of population-based chronic diseases, infodemiology appears useful and allows for improved patient care and management³⁶. Infodemiology can also be used to provide immediate feedback on public policies such as citizens' support or backlashes. SNs also allow for targeted prevention campaigns via relays of known accounts or those with strong digital influence. Moreover, in the current context of digitization of the health system, healthcare professionals should have a role to play on these platforms and should not underestimate their use³⁷. This would help to better manage the misinformation present on SNs.

Limitations

It is important to note the limitations of this work in order to reach an informed conclusion. This study contains biases at three levels:

Infodemiological methods

- First of all, this study does not claim to be exhaustive of everything that is said about endometriosis on SNs: only public data was analyzed.
- SNs are not representative of the population, and the generalization of the difficulties identified remains to be proven. Sociology of SNs has proven that people who express themselves are usually young (excluding the elderly, among others). It is also important to note the inequalities in access to the internet²³. Indeed, there is a selection bias around the level of interaction with SNs according to

socio-professional category, income and education level.

- Users can be also prone to a negativity bias (express negative experiences more often than positive ones on SNs) and to misinformation (no way of ensuring the veracity of contents analyzed). In general, the analysis of SNs is limited to declarative information (patients' feelings and perceived health), which may lead to an over-representation of negative observations.

- Finally, the influence of the media cannot be neglected, as it can guide the discussions³⁸.

Algorithm-specific biases can also be identified. A central bias of NLP is its limited ability to understand the expression of human emotions³⁹. For example, sarcasm or irony are difficult for algorithms to detect. Qualitative analysis and human validation are therefore essential. Furthermore, during the qualitative analysis of the endometriosis study, it was noticed that the category of the algorithm "transversal, difficulty throughout the care pathway" encompassed very heterogeneous sub-themes. This may have guided the statistics.

SSIs

The known biases of SSIs can also be found in this analysis⁴⁰. Although there was a desire to recruit patients randomly, the means used for recruitment were influenced by the social and professional background of the interviewer (selection bias). There is also a perception bias related to the social background of the patients interviewed: they were all from a rather well-to-do social background. This may have led to a bias in the description of the disease. It may also be noted that a greater number of healthcare professionals could have been interviewed, in order to enrich their views on the disease. Particularly healthcare professionals who had never treated endometriosis, or general practitioners. Methodological biases linked to the interviewer (way of asking the questions) can also be noted. The need for a human exchange during the interviews may lead to biases in perception, in the collection of information,

etc.

In general, the time limit must also be taken into account. Indeed, for the comparison to be optimal, a larger number of posts should have been included in the infodemiological study and in the recruitment of patients for the interviews. In addition, both methodologies include some qualitative analysis, so both are subject to personal interpretation bias. Limitations can also be noted on the comparability of the results. The small number of interviews conducted, although very enriching for this study, limits the interpretation of the statistics and their generalization to the population of patients with endometriosis. No significance test was performed on the statistical results, due to the low recruitment. Furthermore, the use of concepts as a statistical unit could be discussed.

Conclusion

We propose a bi-patient-centric approach with limited manual work to identify difficulties encountered by patients with endometriosis in France. In this work, we managed to identify 1,742 patients with endometriosis and to detect and analyze their difficulties and unmet needs during their care pathway thanks to manually validated NLP techniques. Face-to-face interviews allowed us to consolidate results found in the NLP study and to enrich posts found on social network with in-depth testimonies. The mixed-methodology of this study appears ideal to demonstrate their complementarity and to justify the use of AI algorithms for public health decision-making. Furthermore, endometriosis is a disease affecting a wide range of women, each with their own specific difficulties. The time for shortening diagnostic delays is over, patients now expect societal and medical recognition of their illness and adaptation of their care pathways to their individual symptoms. Difficulties encountered by patients in real life led to the conclusion that endometriosis should be the subject of more targeted public research and action. This study allows us to state that infodemiological and SSI results are

consistent and show the need for healthcare professionals to think about patient-centered care to improve their daily lives. Further research could be achieved to study the beneficial effects of optimal patient care on health costs, or to justify the use of social network as a reliable source of real-world data for chronic illnesses.

Acknowledgments

Conflicts of interest

No conflict of interest. Kap Code is a SML contractor that realizes social media studies, for and funded by pharmaceutical companies, on broad health-related subjects. This study was carried out independently.

Abbreviations

AE: adverse event

NSAID: non-steroidal anti-inflammatory drugs

SE: side effect

SSI: semi-structured interview

SNs: social networks

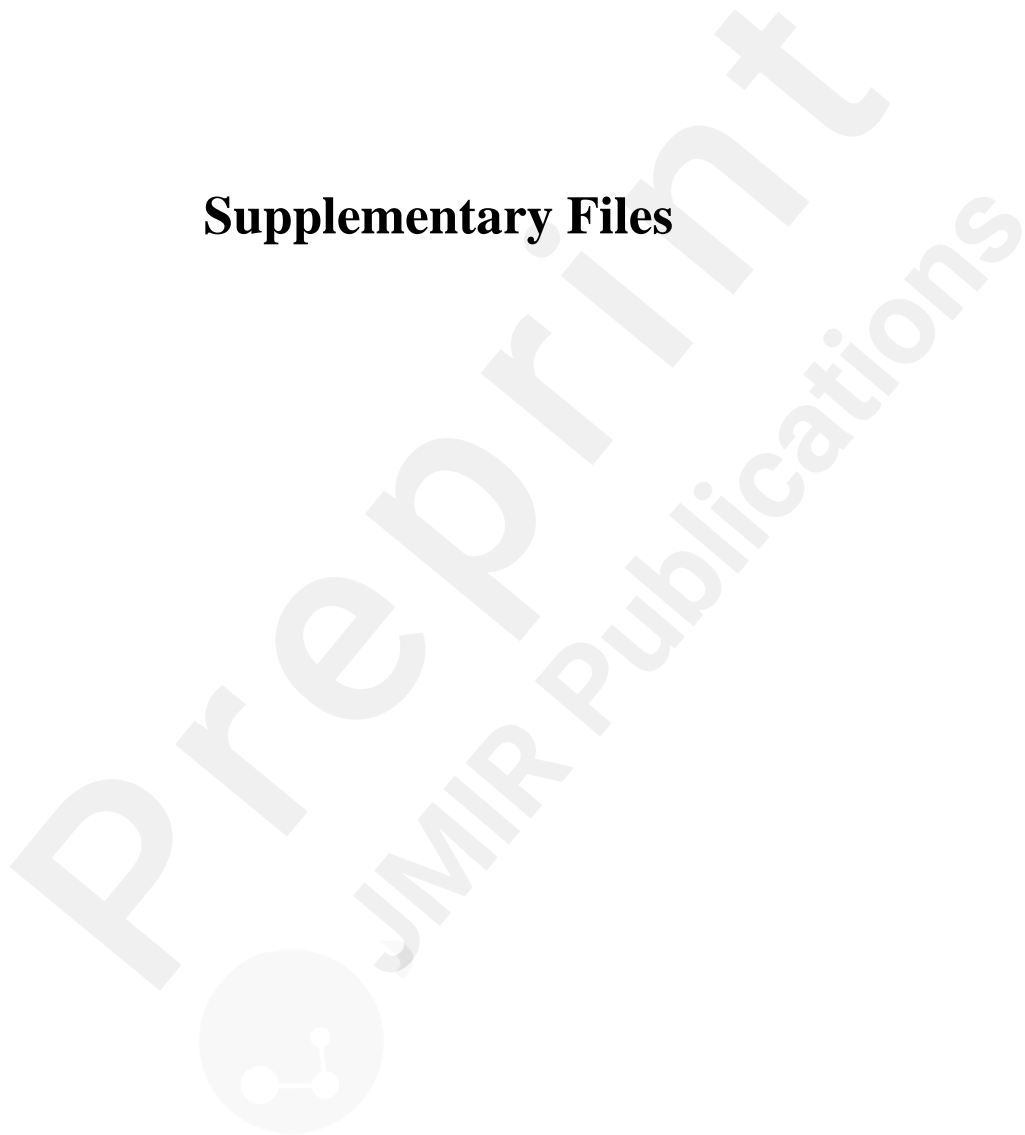
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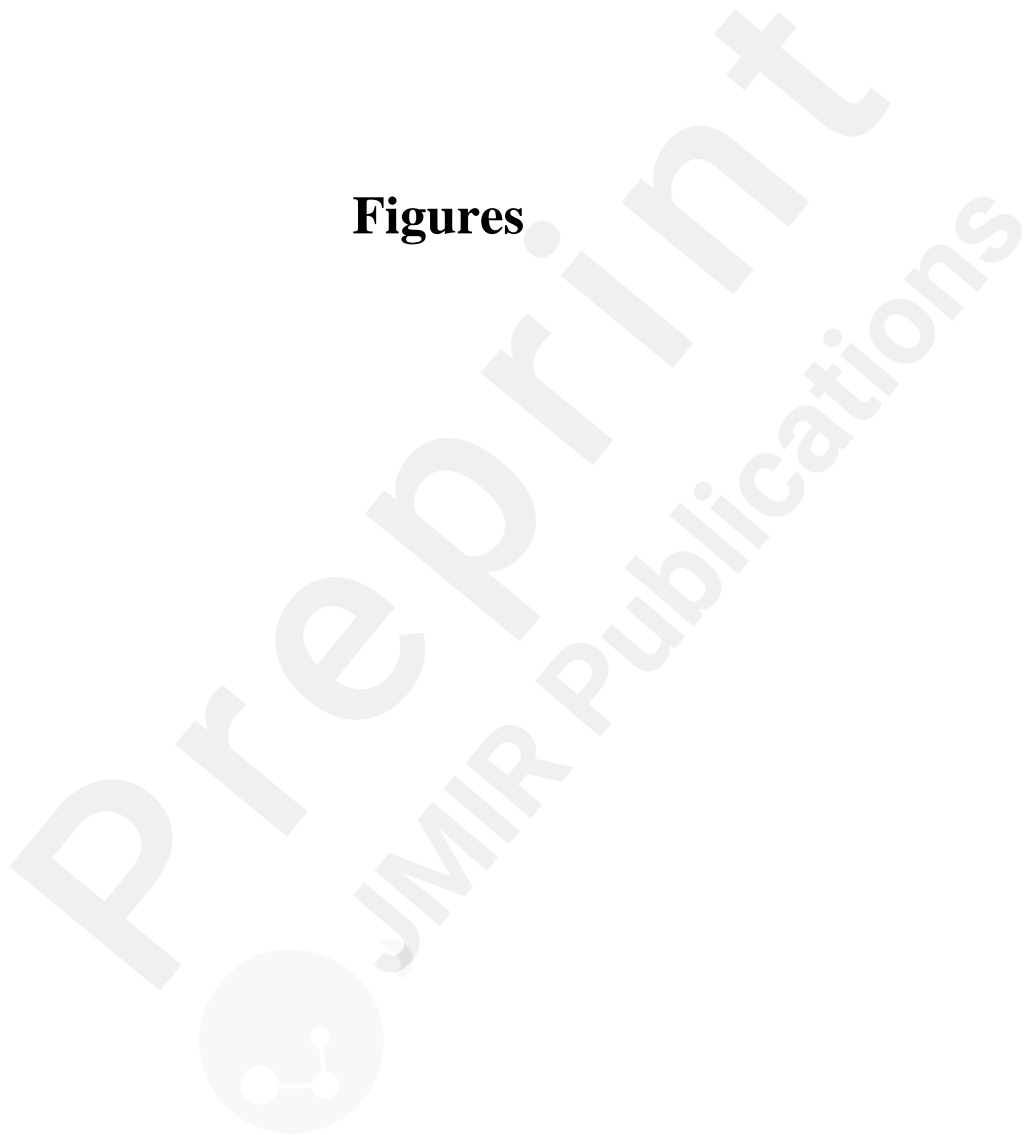
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Supplementary Files



Figures



A comparison between the difficulties retrieved from the infodemiological study and SSIs.

