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Towards mining the history of the active patient. A mixed-methods discourse analysis of the journal *Allergia,* 1957–1990

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In the 20th century, patient organizations have become key players in the medical landscape. They assume responsibilities in the healthcare system, support and engage in research efforts, and often enter symbiotic relationships with clinicians as well as pharmaceutical industry. Thus, they have been important in shaping today's active and informed patient. Yet patient organizations have hardly been studied from a historical viewpoint. Part of the reason is the large, but at the same time fragmented and inconsistent source material. One potential solution is the use of digital text analysis, but at the same time there are significant legal and technical obstacles. This paper presents first steps towards making digital tools work for sources deriving from patient organizations. We will present the challenges encountered already at the digitization and pre-processing stage and share initial findings of a pilot study of the journal of the Swedish Asthma and Allergy Association, *Allergia*. The purpose is to gather experiences and establish work modes that can be applied to future research on the history of patient organizations, and other historical research working with similar corpora.

Scope

Patient organizations are powerful actors in many health care systems, yet little is known about their history. Learning more about their emergence and development is not only crucial for a better understanding of 20th century medicine, but can also provide important insights about current challenges in medicine regarding informed consent, the patient-physician relationship, and patient participation in clinical and research settings.

One reason for the lack of historical research on patient organizations is the characteristics of the source material. Patient organizations typically produced large volumes of printed documents, primarily journals and newsletters, which make up a corpus too large for traditional analysis alone. So far, it has not been possible to use computational tools to aid the analysis since patient organization journals, other than professional medical journals, are not available in digital form. Hence, decades after Roy Porter's famous call for "a medical history from below", the traditional imbalance between physician-centered and patient-centered medical history risks being perpetuated in the age of digital humanities (Porter 1985).

This paper is an effort to explore possible ways of preparing and analyzing sources from patient organizations with digital methods. As the structure of these sources is highly heterogenous, fragmented, and inconsistent, the

insights gained through our work process should also be of interests for historians in other fields.

Background: Patient organizations and allergy in the 20th century

No clear definition exists of what should be regarded as a patient organization. Small self-help groups as well as large charities use the label. There are patient organizations for specific illnesses, for various illnesses of a certain organ, for patients within a particular healthcare system or clinic, or users of a certain technology or therapy. Patient organizations may be run by and for patients, or by healthcare professionals or family members on behalf of the sick. However, this paper concerns the history of a particular type of patient organization: the illness-specific, patient-run association which directs its efforts primarily towards the medical realm.

This type of organization appears to have first emerged in the United States in the 1870s. The earliest known example, the U.S. Hay Fever Association, organized people who suffered from the then still contested ailment today known as pollen allergy (Mitman 2003). Clubs for deaf people that provided a social space for Sign Language and Deaf culture, and mutual aid societies that supported members in the case of sickness look back on longer histories. Although from a current viewpoint, the latter examples may appear to fit into the category "patient organization", their scopes and origins are historically separate from the new type of organization that the Hay Fever Society represented.

In the following, when we use the term "patient organization", we refer to a specific kind of organization. What characterizes the type of organization we study is that their target membership are people who suffer from a particular disease or disease category, such as allergies, heart disease, or diabetes. Further, the organizations envision themselves as self-representations by patients for their own collective interests, and they self-categorize as actors in the medical realm. Thus, while for instance medical professionals or family members can often join, they do not primarily serve these groups. It is not uncommon for patient organizations to collect money or provide relief, but this is secondary to their scope as interest groups. Finally, while patient organizations often do address matters outside of medicine, they fundamentally believe that the condition they are formed around belongs in the medical sphere. They organize people in their capacity as patients. This distinguishes them from many disability organizations, since the latter often address primarily sociopolitical, educational, or labor issues (Stoll 2017; Söderfeldt 2013; Zames Fleischer and Zames 2012; Cohen 2001).

Thus defined, patient organizations have today become a widespread and influential phenomenon. They often function as hubs in medical networks,

and assume central functions as intermediaries between different medical actors (Akrich et al. 2008). Individual patients receive information, training, and support beyond that which their own physicians can offer. Medical scientists use them as a communication channel to reach the relevant patient group with news from the research front, and for pharmaceutical companies they are a perfectly tailored marketing space (Trojan, Kofahl, and Nickel 2017; Herxheimer 2003; Rose et al. 2017).

Several developments in 20th century medicine have contributed to creating the niche in which patient organizations work. The antibiotic era is dominated by chronic illness and an associated change in the role of the clinic: the sick are no longer usually found in hospital wards, but out in society (Szabo 2009; Grob 2005). Patient organizations assure that the self-managing patient is well-informed and trained to fulfill medical tasks according to approved medical recommendations. Furthermore, the move towards a healthcare system that provides more transparency and puts more emphasis on informed consent and patient rights needs a system of patient representation. Decision-makers in healthcare have increasingly become obligated to listen to patients demands, opinions, and needs and patient organizations provide that input in an easily accessible way (Haarmann 2017).

Historically, the origins of patient organizations are connected with the emergence in the 19th century of a new illness – hay fever. The first descriptions of a sickness caused by blossoming plants date to the beginning of the 19th century. In the following decades, an increasing number of people in Europe and the United States began searching for relief from seasonal sneezing, headaches, running eyes and noses. Most sufferers belonged to the wealthier, more educated classes and their ailment appeared closely related to the other nervousness epidemics that accompanied modern, urban life. Still, the diagnosis that went by names such as hay fever, rose cold, or summer (or autumn) catarrh remained controversial. Most physicians believed the symptoms to be psychosomatic (Schadewaldt 1980 pp. 42-82). Even among believers in a somatic model, the cause was up for debate: was it a sensitivity to smells, a reaction to the weather, or was there a microscopic agent behind it? New developments in immunology in the first decades of the 20th century led to a certain stabilization and scientific acceptance. Hay fever became accepted as a pathological immune reaction – an allergy (Keirns 2008).

From the 1920s onward, allergies became established clinical diagnoses and the first medical treatments – immunization shots – became available. However, the profile of the illness also began to change. Hay fever lost its glamour and exclusiveness, while other allergies – to food, cosmetics, chemicals – gained increasing attention (Jackson 2007, pp.69-76, 138-147). In the post-war era, focus turned away from social elites to disadvantaged children in polluted environments (Mitman 2008, pp. 130-166). From having been

somewhat of a quirk of certain members of the elite, allergies became a major health scourge.

The original social composition of the patient group, the treatment of choice – travel to certain health resorts, which meant that sufferers had the opportunity to meet each other – and the lack of acknowledgement of the diagnosis from most members of the medical establishment however likely contributed to the early formation of clubs and associations for allergics. In Europe, the first patient organization was also a hay fever society – the Hay Fever Federation of Heligoland, formed in 1897. After some successful decades, their failure to adapt to the new face of the illness meant that this organization deteriorated and nearly disbanded in the 1970s. Instead, the Swedish Asthma- and Allergy Association became one of the most prominent organizations for allergic patients in the post-war era.

Method

In 1957, the Swedish Asthma and Allergy Association launched its journal *Allergia*, which has since been issued three to six times per year. This periodical is the source for our study. All volumes from 1957 until and including 1990, altogether just over 4.000 pages, were OCR digitized by Uppsala University Library and delivered as high-resolution PDF-files. Although permission was obtained from the Asthma and Allergy Association, it could not be guaranteed that the periodical contains no copyrighted material owned by other authors. Hence, we were prevented from making the digitized corpus available to researchers outside of our project and to the public.

When trying to extract plain text from the PDF-files the operation at first produced jumbled and juxtaposed sentences, making any further computational analysis impossible. To overcome this obstacle a custom solution was developed by the team, where basic scripting and freely available open source software packages (ImageMagick; Tesseract OCR) were used to extract the image data and subsequently redo both the OCR and the page segmentation. Using the default settings for Tesseract OCR we immediately got a better result and could proceed with the analysis.

Our purpose for this study was twofold. We aimed to adopt and implement methods for digitization and mixed-methods analysis on a particular type of historic raw material. Doing so requires going through all steps of the process from scanning to analysis, in an attempt to answer research questions of genuine historical interest. Findings from previous research allowed us to form hypotheses to test with a mix of computational and traditional text analysis. The assumption was that transformation processes in the field of allergy would be reflected in vocabulary shifts in *Allergia*. Further, we wanted to explore ways to characterize the publication as a whole with the aid of statistical methods.

Hence, the research questions were:

- Does the frequency of keywords related to particular subjects change over time in a way that represent discursive transformation?
- Which terms in the corpus are overrepresented in different decades, and how does it reflect changes in *Allergia*'s content, and in society more in general?
- What methods are suited to find vocabulary shifts in the material that are of empirical value to a historical study?

We address these questions through natural language processing data curation and statistical analyses of word frequencies. The methodical approaches are described in more detail below, adjacent to each experiment.

Findings

Riksförbundet mot astma och andra allergiska sjukdomar (National Association against Asthma and other Allergic Diseases), formed in 1956 as an umbrella organization of local asthmatics' clubs, the most prominent of which had formed in Uppsala five years earlier (Åhlander 1957). The organization has changed its name several times. In this article we will refer to it as Swedish Asthma and Allergy Association or RmA (abbreviation for *Riksförbundet mot allergi,* National Association against Allergy, the most long-lived designation in the studied time period).

A central issue for the organization at the moment of its formation was to support research, as the founders believed that asthma and allergy research was being neglected and suffered from a lack of funds. A central organization, it was expected, would be able to engage in lobbying, raise money for research, and through an affiliated advisory board provide state-of-the-art resources for information campaigns ("Det nya riksförbundet. Tillkomst, ändamål, uppgifter." 1957).

Other goals included supporting the work in the local clubs and promoting healthcare and other support systems for allergics. From the reporting in the journal, it is clear that the different local chapters across Sweden were quite active. They offered various kinds of social and educational events, which served to raise money, offer information, and bring members together. A sample of notices about local events reported in *Allergia* 1, 1970, contains among many things a yard sale in Stockholm, a breathing exercise class in Avesta, a lecture about dermatology in Teg, and several holiday parties (*Allergia* 1 1970 pp. 13-18). Clearly, the RmA possessed a strong basis on the local level.

Apart from reporting from these events, *Allergia* also contained a wide variety of articles about the pursuits of the central organization and about allergic diseases in their different facets: medical, political, environmental, and social. From the start, the paper also contained advertising for products

related and unrelated to allergies. Medicine, supplements, and allergy-friendly detergents, but also craft supplies, cars, and coffee were advertised.

For extracting patterns in the text, our initial approach was to use word frequency analysis of pre-defined keywords as a way to investigate to what extent certain topics were discussed in *Allergia.* We decided on a number of keywords related to contact allergy, and through measuring their relative occurrence in each annual volume of *Allergia,* we hoped to find trends that we would subsequently be able to study further. The keywords were *tvättmedel* (laundry soap), *diskmedel* (dishwashing soap), *nickel*, *tvål* (soap), and *schampo* (shampoo). We opted to divide the scanned texts into sections consisting of one annual volume each in order to get a large enough volume of text per smallest studied time unit (year), while still being able to follow fluctuations over time. Should the use of certain words appear to increase or decrease at specific moments, we would select the corresponding journal volumes for close reading as a way of testing the hypothesis that significant changes in vocabulary indicate discursive transformation.

This approach was methodically rudimentary. First, we did some basic cleaning of the data. Most importantly, we joined all words wrongly separated in the OCR-process due to hyphenation. Secondly, we tokenized the cleaned data with efselab/Swepipe to enable solid word frequency counting (Östling 2018). That means that we segmented each word in the corpus and transformed it into a long list of tokens. To get rid of OCR noise and uninteresting information, we also stripped the corpus of all non-word tokens (only punctuation or numbers) and all single-character tokens. Thereafter, we calculated token hits per search term in relation to all tokens per year to track how relative frequencies changed over time.

Since we were interested in all variants of the keywords, we decided to use mostly open searches at this stage. This meant that when looking for, for instance, *diskmedel* (dishwashing soap) we would also get hits on related terms (compound words) such as for instance *maskindiskmedel* (machine dishwasher soap) and *diskmedelsmärke* (brand of dishwashing soap). For terms where homographs and homonyms could distort the output, or where there were no relevant substrings in the material, we searched on closed keywords. In the graphs below, the asterisks (*) are placeholders, matching any beginning or ending of a compound word.

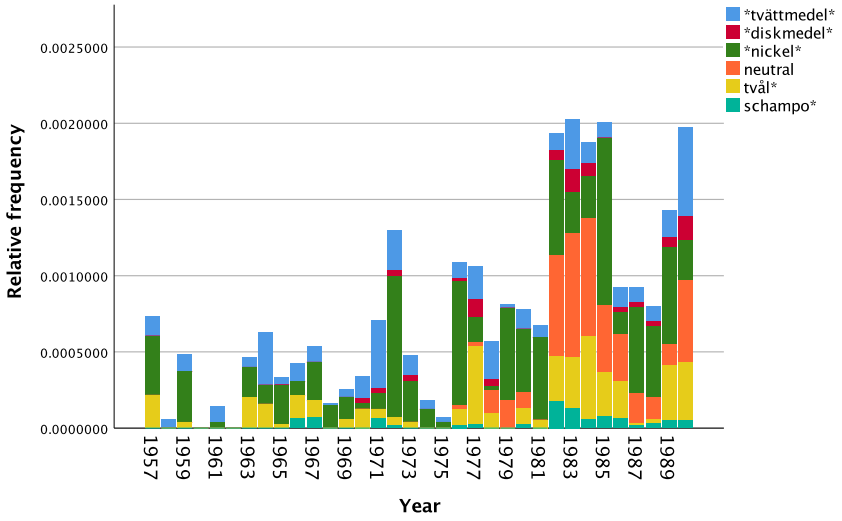

Fig. 1. Relative frequencies of pre-defined contact allergy keywords, per year.

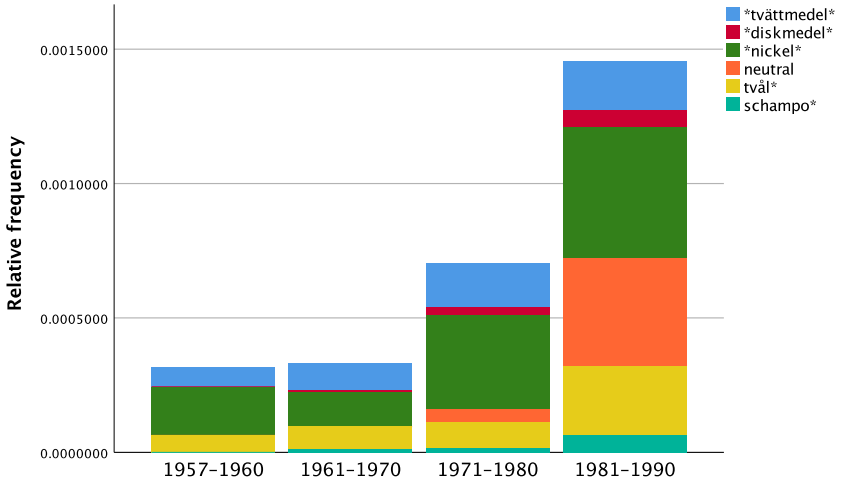

Fig. 2. Relative frequencies of pre-defined contact allergy keywords, per decade.

Using this method, we could identify individual years with higher or lower frequencies of the chosen keywords, and observe an increasing trend of contact allergy related terms throughout the 1970s and 1980s (see Fig. 2). In an attempt to control this result, we did a close reading of one volume from the 1960s and one from the 1980s. It then quickly became apparent that the word frequency analysis had not been able to capture more than a fraction of the

discourse on contact allergies. The limited set of keywords, which we had assembled based on preconceptions about central topics related to contact allergy, proved to be much too blunt. In fact, contact allergies were discussed in the paper in a highly diversified way that included mentions of a large number of different materials and substances which we had not been aware of. Rather than discussing in general terms product categories such as soaps and detergents, *Allergia* listed specific substances. Since we had not included these search terms in the word frequency analysis, a great part of the discourse on contact allergies went undetected.

Through close reading, we could identify the following terms related to contact allergy (translated from Swedish):

- Formaldehyde, glue, synthetic resin (Krogh 1964)
- Rubber, plastic ("Jag låg som i en myrstack" 1964)
- Chrome, lipstick, eyeliner ("Professorsföreläsning i Umeå" 1964)
- Formalin, textile ("Allergikern har svårt att finna formalinfria klädesplagg" 1964)
- Laurilsulfate ("'Allt som ger upphov till allergier kan inte bringas ur världen'" 1964)
- Turpentine, solvent ("Kraftig varning mot terpentineksem" 1964)
- Primula, rose geranium, essential oils, formalin, silk, nylon, azo dye, para-amino dye, sulfonamide, procaine, para-aminobenzoic acid, balsams, gasoline, paint thinner, emulsifiers, sodium lauryl sulfate, garter clips, bra clips, eyeglass frames, ear clips, aftershave, perfume, powder, hand lotion, insecticide, pyrethrum, cement, matches, "detergentia [rare synonym for detergent]" ("Inga allergengömslen får förbises" 1964)
- Permanent wave solution ("Allergisk på omskolning" 1964)
- Chemicals, metals ("Läkare vidareutbildas i allergologi" 1964)

In the face of this finding, we considered extending the keyword list, to try to capture the discussion on contact allergies more accurately and see if we could indeed confirm any trends. Complicating this was the extreme diversity in the vocabulary, which means that identifying all or most relevant keywords would require a close reading of the journal in its entirety. After harvesting keywords in this way, it would be possible to statistically measure the frequency of the vocabulary we had determined to be related to contact allergy. Merely quantifying findings from a comprehensive close reading would however add very limited value to the analysis.

Having identified this limitation in the initially intended methodology, we chose a different approach. Instead of departing from what we thought might be interesting, we decided to take statistical overrepresentation of words in subsets of our corpus as a new starting point. Such a method, however,

requires some further preprocessing of the text data to provide meaningful output.

Thus, on the cleaned data set we used efselab/Swepipe to lemmatize and part-of-speech (POS) tag the material (Östling 2018). This means that the program automatically provided us with the lemma for each word in the corpus, and the POS tag for each lemma. For instance, an occurrence of "kontaktallergier" transforms into "kontaktallergi" (lemma) and "NN" (POS-tag for noun), an occurrence of "kontaktade" to "kontakta" (lemma) and "VB" (POS tag for verb), et cetera. A text normalization process of this kind makes statistical analyses more reliable.

Then, we used the information in the POS tags to single out only the lemmas with the highest semantical meaning, which we in this context operationalized as only nouns, verbs and adjectives. Thus, a corpus of all lemmas of nouns, verbs and adjectives in *Allergia* 1957–1990 is the text data foundation of all statistical analyses below.

To track overrepresentations of words and change over time, we divided this corpus into four subsets, one per decade, that is: 1957–1960; 1961–1970; 1971–1980; and 1981–1990. (The 1950s contain only four volumes, whereas the other decades ten volumes.)

We then used the software Antconc to compare each subset with the corpus as a whole (Anthony 2019). The output visualized in the word clouds below are thus all lemmas that are statistically significantly overrepresented per decade in relation to the whole corpus. As statistical measurement, we used log-likelihood (4 term), with a p-value of <0.05 (plus Bonferroni correction) as threshold, which is a well-established threshold level in corpus linguistics.[1]

The size of the words in the clouds below correlates to their "keyness" value, that is: how likely they are to occur in the specified subset in relation to the corpus as a whole. Thus, the larger the word, the more overrepresented it is in the volumes of *Allergia* for that decade.

[1] The Bonferroni correction is a statistical method used to compensate for unreliability concerning rare terms in a corpus. A threshold of p-value <0.05 (plus Bonferroni correction) is also the default choice for keyword comparisons between corpora in Antconc.

Fig. 3. Word cloud of overrepresented words in 1957–1960

Fig. 4. Word cloud of overrepresented words in 1961–1970

Fig. 5. Word cloud of overrepresented words in 1971–1980

Fig. 6. Word cloud of overrepresented words in 1981–1990

Among the automatically identified keywords, many clearly represent cultural change on a more general level: the language in *Allergia* grows less formal, with the titles “Herr [Mr.]”, “Fru [Mrs.]”, and “Fröken [Miss]” being overrepresented in the earlier volumes. Other changes give clues as to concrete allergy-related issues on the agenda, such as wall-to-wall carpets in the 1970s and smoking in the 1980s.

One particular change, however, caught our attention as it seems to be related to the conceptualization of allergies and the illness experience. In the 1950s and 1960s, the words *sjuk* and *sjukdom* (sick, illness), and the combinations *allergisjuk*/*astmasjuk* (sick with allergy/asthma) were overrepresented. After that, in the 1970s, it was instead the term *handikappad* (handicapped), as well as a couple of compound words containing it, that was overrepresented. This seems to suggest a change from thinking of allergies and asthma in terms of disease, and a self-identification as being people with an illness, to thinking in broader terms.

It also connects the RmA to a greater international movement that began around this time in the United States and Europe. Drawing inspiration from other 1960s social movements and counterculture, and reacting against institutionalization and infantilizing charity, disabled people started to appear in the public sphere with a radical agenda of inclusion. In the United States, the disability rights movement achieved milestone legislation such as the Section 504 and eventually the Americans with Disabilities Act, and did so through often spectacular acts of civil obedience and tireless lobbying (Zames Fleischer and Zames 2012). The American example inspired groups in Europe, notably in West Germany where a young generation of disabled persons challenged institutions and attitudes still colored by the eugenics and extermination practices of the Nazi era (Stoll 2017). In Sweden, a new type of discourse became noticeable from the mid-1960s onward. Both legislators and disability rights groups turned their attention to disabling structures in society rather than supposed inherent limitations in the body of the disabled individual (Larsson 2001). In short, there was a reframing of disability from the medical to the social model, where the latter emphasizes accessibility and civil rights rather than the affliction of the individual body (Shakespeare 2006). Presenting allergies and asthma as disabilities, rather than diseases, would then open up new possibilities of political action. A social model approach would enable allergics and asthmatics to place demands on shared spaces and the conduct of fellow citizens – such as to refrain from putting carpets in schools and offices, or restrict smoking and perfume use.

Against this backdrop, it became noticeable that other overrepresented words in the 1970s and 1980s seemed to match the hypothesis of a move towards a social model/disability approach. Many of the words that appear in the clouds have to do with furnishings, shared spaces, and exposure to allergens. Conversely, in the 1950s and 1960s, we see an overrepresentation of words related to the individual treatment of illness, such as particular medicines and treatments. In the word clouds, we have marked words that relate to disease and medicine red, and words relating to environment and disability blue. Words not belonging to either category and ambiguous words were left gray. We were restrictive in the categorization, opting to categorize only those

words where we could have a high degree of certainty of what they refer to. For instance, “mg” seems like it would likely refer to medicine, but could also be part of a discussion of chemical exposure. “Cigarette” could refer either to medicinal cigarettes or to smoke exposure. “Invalid” could be used both within a medical discussion and one on disability. These words were left gray. Even with this restrictive categorization, we see a clear switch from disease/medicine to environment/disability among the overrepresented words. Computationally generated word clouds based on statistics paired with manually marked-up terms based on domain expertise thus seems as a plausible way for quantitative and qualitative perspectives to join hands in terms of visualization of results.

However, we were aware of the methodological limitations here. Overrepresentation of certain words could be due to very confined phenomena in the texts, such as for instance one or very few texts about a specific event. If the word “handikapp” never appeared in 1957–1970, and then repeated several times but on only one occasion during 1971–1980, we would see an overrepresentation in that period. In other words, one article on a particular subject can look like a trend. There are several events related to disability that could, if reported on in *Allergia*, have caused such phenomena. In 1965, an official government investigation on the situation for disabled people commenced and issued several reports during the following 10 years (Persson Bergvall and Sjöberg 2012). The United Nations World Year of Disabilities 1981 was announced in 1976 (Mittler 2005). The Swedish Disability Rights Movement grew more vocal during the 1970s, with several large demonstrations, manifestos, and cultural events (Derksen 2019). Just a few articles in *Allergia* about these or similar developments could explain the overrepresentation of the term “handicapped”. To scrutinize this closer, we did a search for the relative frequency of the terms *handikapp* (*handicap*) and *sjuk* (meaning sick, part of several medicine-related Swedish terms such as healthcare, hospital, disease).

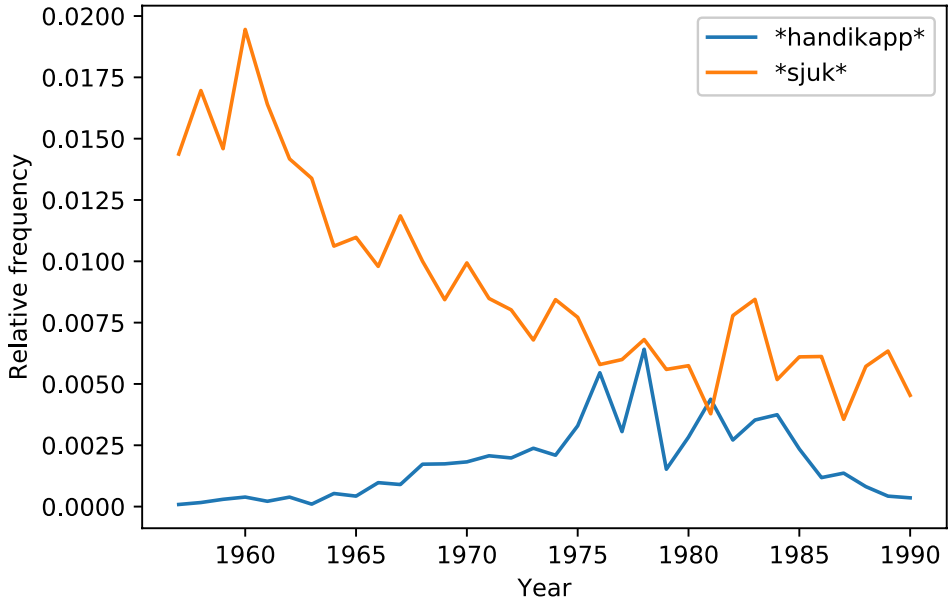

Fig. 7. Graph depicting the development of relative frequency of the terms *handikapp* and *sjuk* in *Allergia* 1957-1990.

The resulting graph shows a tendency over time where the relative frequency of *handikapp* increases and that of *sjuk* decreases, although with *sjuk* remaining more common throughout almost the entire period. In fact, the only year when *handikapp* was more common was the World Year of Disabilities 1981. Clearly, the overrepresentation of the disability-terminology was not only the result of just an isolated news story, but a trend. Interestingly, also, a trend towards less emphasis on disease and medicine appears to become visible here as well.

In order to further control these results, we performed a systematic close reading of the sources, reading all editorial articles between 1966 and 1976, which appeared to be the period when the opposite trends of *handikapp* and *sjuk* took off. A circumstantial finding was the first result: While reading the editorials, we also came across many advertisements. It immediately became apparent that many of the overrepresented words, both in the “medicine” and the “disability/environment” category, came from advertisements. Names and properties of pharmaceuticals appeared over and over in the same, repeated advertisements in the 1950s and 60s. In the 1970s we instead found more advertising for products such as air purifiers and vacuum cleaners, terms that also appear in the word clouds for those decades. A sample below of advertisements from each decade contains several words from the corresponding word clouds.

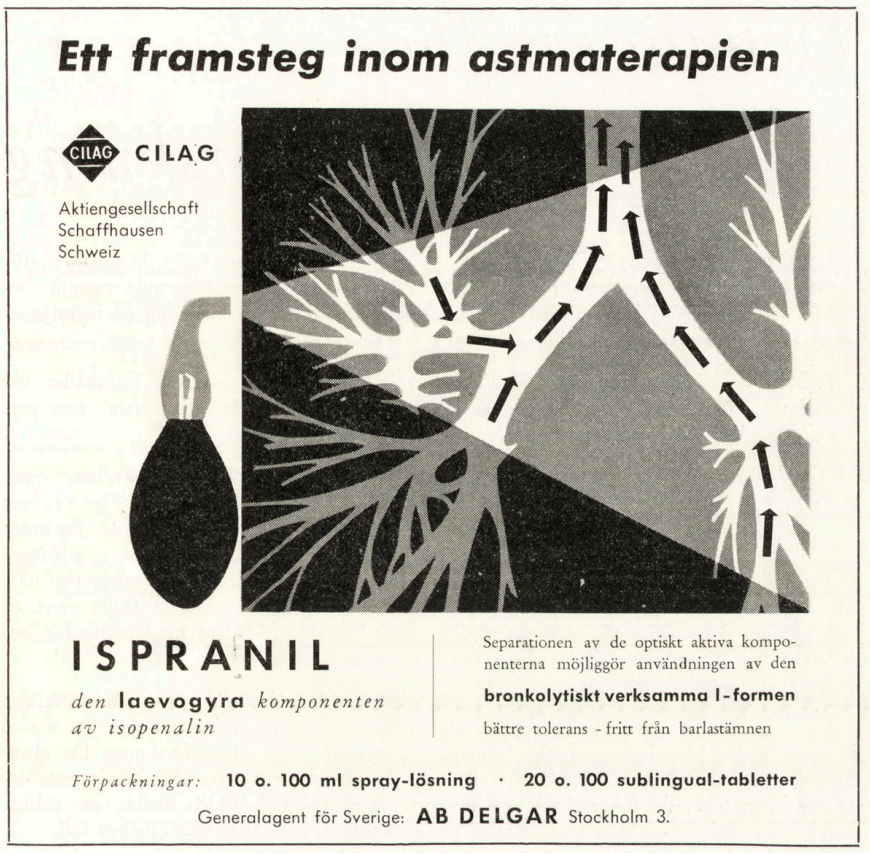

Fig. 8. Advertisement for asthma medication, *Allergia* 1 1958.

Fig. 9. Advertisement for asthma inhaler, *Allergia* 1 1962

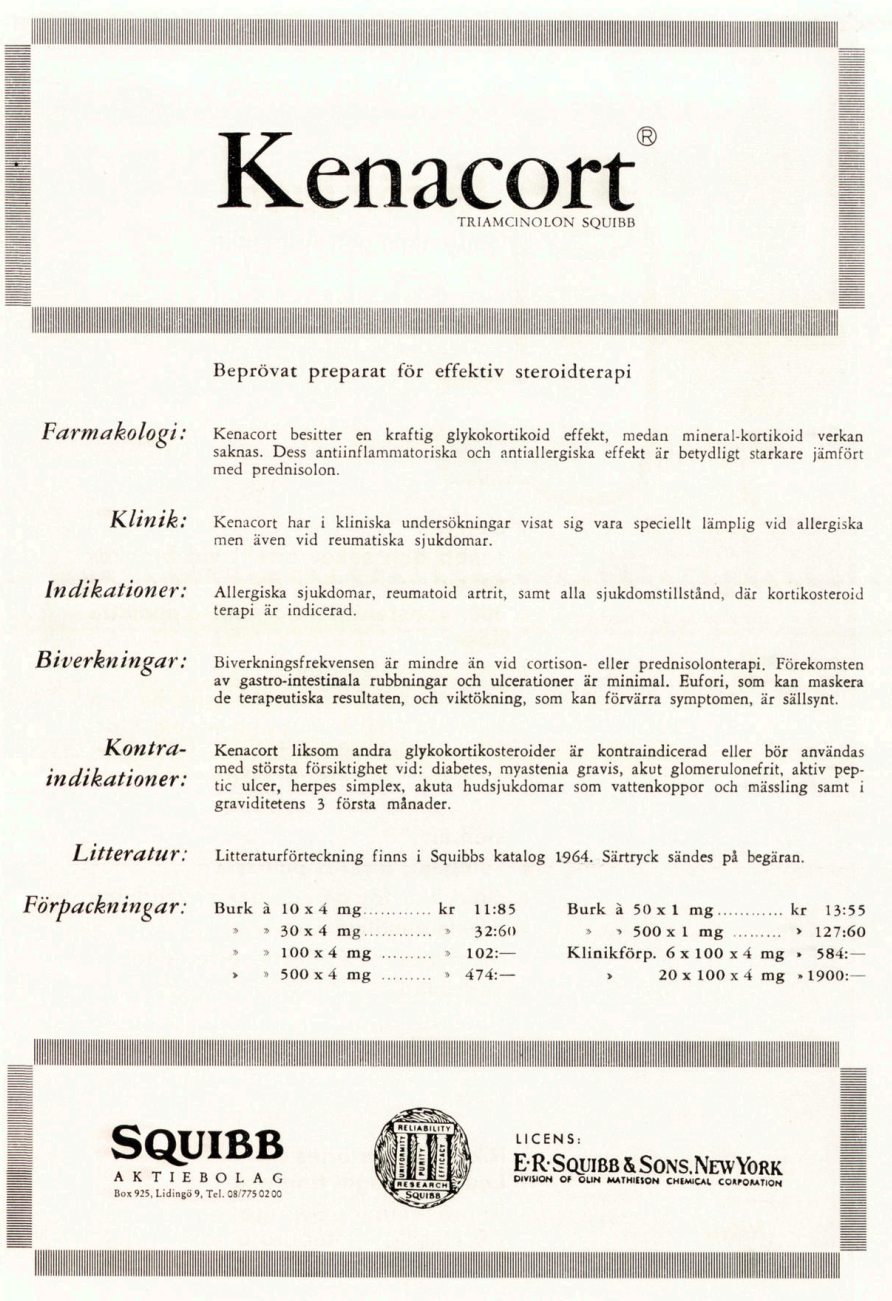

Fig. 10. Advertisement for steroid tablets, *Allergia* 1 1965

Fig. 11. Advertisement for air purifier, *Allergia* 2–3 1975

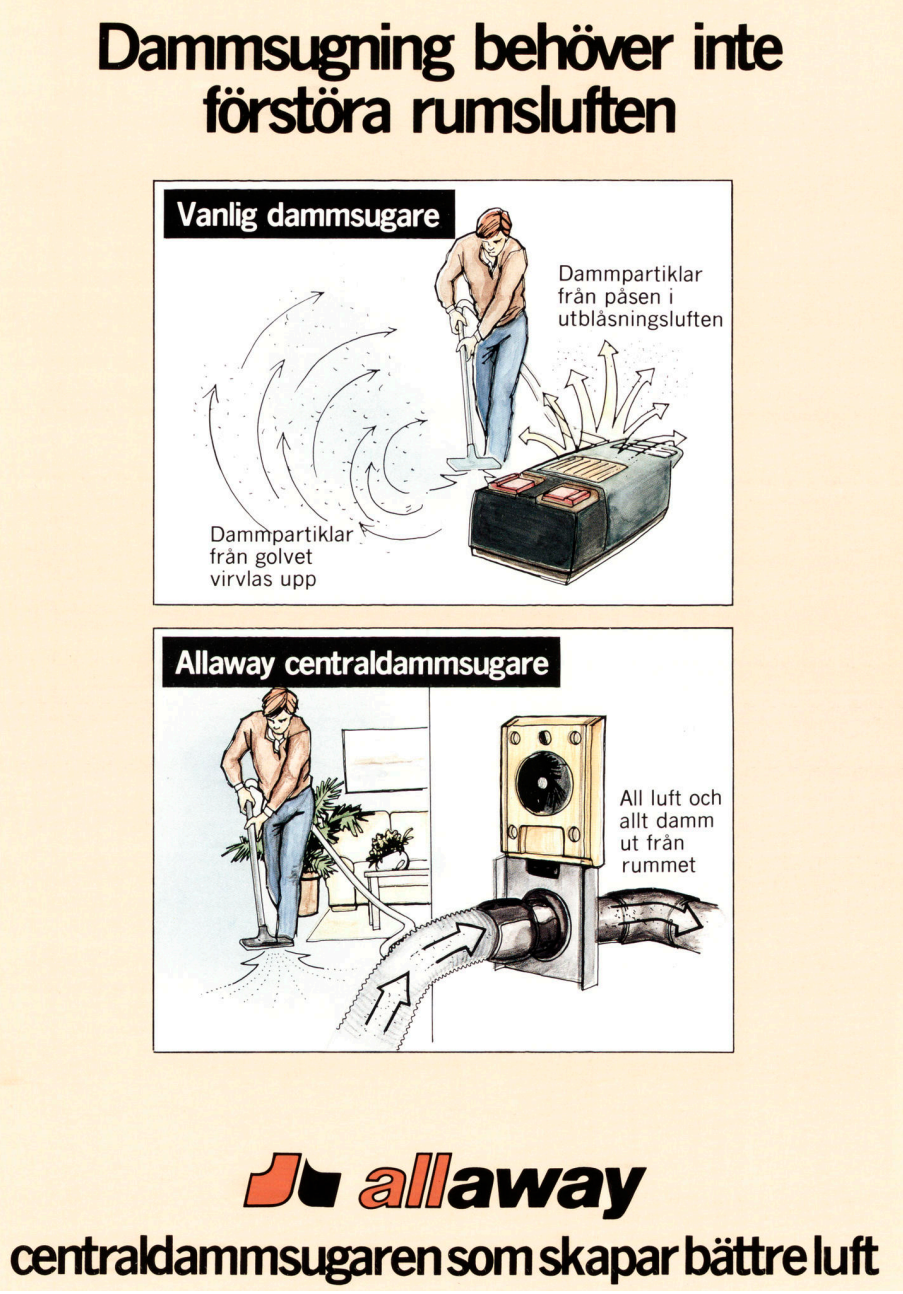

Fig. 12. Advertisement for central vacuum cleaner, *Allergia* 1 1985

A great part of the overrepresentation can therefore be explained with changes in the advertising market. In 1969, the professional federations LIF and RUFI, which represented Swedish pharmaceutical companies and foreign pharmaceutical companies catering to the Swedish market, agreed on a set of rules for "pharmaceutical information", including marketing to consumers.

Although advertising prescription-free drugs to consumers was not prohibited, the rules called for greater caution and required all information in the advertising to be based on evidence (Hentzel 1983; Lönngren 1999). The same year, marketing of pharmaceuticals in *Allergia* virtually ceased, as confirmed by reviewing all advertisements in the 1967 and 1969 volumes. In 1967, there were 9 ads for pharmaceuticals (and 2 for a medical-grade breathing device), and in 1969 there were none. More restrictive policies within the industry seems to be a likely explanation for this sudden shift.

Advertising should not be neglected in an analysis of discursive transformation. The text in advertisements also addresses the readers and affects them. A paper filled with pharmaceutical advertising gives a different image of the target group than one with air purifier ads. Further, the choice to advertise a product in a particular forum is the result of careful deliberation that takes the expected needs, desires, and interests of the readership into account. Even if a large part of the changing vocabulary was due to regulatory changes in advertising, this was nevertheless an important change in *Allergia*'s profile.

However, we also wanted to find evidence of whether or not the discursive shift towards a more disability and environment-focused stance was also reflected in the editorials. Interestingly, we found a very explicit discussion of the tension between the two perspectives in a 1966 editorial by Åke Rydell, Secretary of the RmA:

"Our ultimate goal is to reach a definitive cure for all allergies – asthma, all occupational allergies, hundreds of types of hypersensitivity, skin eczema, hay fever, migraine, etc. Therefore, we want to support allergy research. At the same time, we want to work for improved healthcare for those who are presently ill and incapable of productive work. Those who are handicapped by their allergy.

Handicapped has become a popular word, but it has an ambiguous meaning. Those who have been definitively broken down and incurably handicapped by their illness must receive every conceivable support. It is an undeniable social obligation to support these people, who by no fault of their own happen to be in a situation that excludes productive work. But what we should strive for – and here we need to abandon an all-too-common habitual thinking – is that handicaps must be eliminated! There should not be handicapped people. […A] person sick with allergy must not be labeled as handicapped because of his illness, he should instead be cured as far as possible and integrated in a more suitable working environment. Our aim should not be to support negative thinking in terms of handicap." (Rydell 1966)

In this editorial, Rydell strongly distances himself from the "handicap" label, which he appears to have interpreted as sign of resignation. He

emphasizes that a medical solution must be the ultimate goal, to turn allergics into non-allergics. While he does plead for accessibility and accommodations in the workplace, those are intermediate measures while working towards a cure. Rydell's position is clearly aligned with the medical model of disability, which views it as primarily a problem of the individual body which should be preferably eradicated through medical intervention.

Only three years later however, in another editorial, Rydell had made a significant leap in his attitude:

"In a socially advanced society, everyone must be entitled to develop and receive education, both general education and vocational education. This should be as obvious as the healthcare provided to each citizen in the case of acute disease. It should therefore be the responsibility of the state and the municipalities to provide every handicapped individual with all imaginable resources so that they can lead lives that are as normal as possible. In cases where further research is required to resolve yet unexplored areas of disease, we must provide the necessary funding for the research so that it can get to the root of the problem, and as far as possible remove the causes of handicaps. But when generally speaking about the handicapped, most people probably think of the mobility impaired, visually impaired, hearing impaired, and of different kinds of mentally abnormal individuals. Apart from them, there is a large number of people in our country who are handicapped for other reasons, not least those suffering from allergies various kinds, asthmatics, occupational allergy sufferers, and perhaps most concerningly many children of school age and younger, who are plagued by various allergies that significantly complicate their schooling and vocational education and therefore also impact their adult life.

It thus seems important that the state and the municipalities interpret "handicap" more widely than the official state investigation of handicap does. They must realize that there truly is a social and civic right for everyone to full care, education, and in general to a normal life as a full citizen in society." (Rydell 1969)

While Rydell still alluded to the hope for a cure, he now argued in emphatic terms for the inclusion of allergics and asthmatics in the handicap-category, and described their plight as a civil rights issue rather than a medical one. Within a very short period of time, a significant shift appears to have occurred in the discourse, affecting the meaning ascribed to the term "handicap" and the self-identification with that description. There are good reasons to assume that this change was heavily influenced by political changes that were underway in the same time period, as outlined above. RmA latched on to and quickly came to identify with a new understanding of disability as a

primarily social and civil rights issue, formulated by a growing number of disabled activists. This then appears to have significantly influenced *Allergia*'s contents over the following decades.

Conclusion

With this study, we have provided a hands-on experiment of what a digital history project can look like. Going through all steps, from digitization via pre-processing to analysis and visualization of results, was important for the purpose of establishing infrastructure and collaborative work modes. We were able to produce results that will be valuable to future research, foremost on an infrastructure and methodological level. While the initial hurdles with the provided plain text data was a definite setback, the problem could be easily solved given the relatively small amount of data. This would of course have been harder with a projected full-scale data set of hundreds of thousands of pages. The positive outcome, though, is that the team of researchers was able to leverage this experience to work together with the university library and the research network Digital Humanities Uppsala (Foka & Lindström n.d.) to establish new routines, avoiding similar future scenarios. More concretely, Uppsala University library will henceforth provide researchers also with plain text data when digitizing material, and not only high resolution pdf-files.

In the further methodological steps, it became clear that an early cross-checking between statistical output from computational analyses and close reading of the sources is vital. Asking very specific questions using pre-defined keywords without having a previous close encounter with the text proved to be a somewhat risky approach. On the other hand, the failure of this approach in itself allowed particular characteristics of the text appear clearly in a way that might not have happened with close reading alone. The diverse nature of the discourse on contact allergies is not in itself immediately striking. It was only when approaching the texts with a heightened awareness of the use of a limited set of keywords that it became obvious that those terms were much too narrow. This, we believe, is a good example of the way that a combination of human and automatic reading techniques can provide new ways of approaching texts, by defamiliarizing the textual and opening up for play (cf. Ramsay 2011).

Furthermore, a computational approach that departs from statistical overrepresentations rather than from predefined assumptions (i.e. sets of keywords) gives humanities scholars the possibility to study trends and conjunctures over time, also in very large digitized collections, and without any semantic input at all. Thus, it can function as a statistical corrective that avoids researcher biases. In this respect, our last methodical experiment works similarly to e.g. a *topic modeling* approach (Dahllöf and Berglund 2019), but with

the benefit of being a much more straightforward and comprehensible type of statistical measurement (cf. de Bolla et al. 2019).

The tentative results regarding allergy and asthma as sickness or as disability will need further scrutiny in order to be empirically valid. However, they do show that digital text analysis can produce meaningful results on a relatively small, structurally complex source material. Importantly, they can give clues to the qualitative analysis, so that the researcher can identify which sections and aspects of the source material to study more closely. In this particular case, digital methods enabled us to identify a different trend than the one we initially set out to study: instead of transformations in the spectrum of allergic diseases, we found evidence of a change in the very conceptualization of asthma and allergy. Coming to the same conclusion on the basis of close human reading would have been possible given the relatively small corpus, but with larger corpora this becomes unfeasible. Using a combination of digital and traditional methods would make it possible to perform similar analyses in such scenarios. Hence, our study provides support for digital methods as an important aid in identifying historical discursive transformations in large corpora.

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