



# Loss, Doubt, and Betrayal: Strands of Vaccination Skepticism on Three Facebook Pages Involved in the Controversy Over Human Papillomavirus (HPV) Vaccination

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This study conducted a discourse analysis of posts, comments, and contextual material on three Danish Facebook Pages, all established because of social groups' skepticism of human papillomavirus (HPV) vaccination. The researchers of this study accessed most administrator posts and visitors' comments, and pursued additional information through links provided on the Pages, supplementary media coverage, and available knowledge about the development of the controversy over HPV vaccination in Denmark. Using the discourse analysis framework, discourses of loss, doubt, and betrayal were identified. Associating important existential, propositional, and value assumptions affiliated with HPV vaccination, these three interconnected discourses embody important strands of vaccination skepticism. The loss discourse emerged from the personal stories about losing one's mobility or quality of life, which then mobilized expressions of sympathy and a genuine wish that things would improve. The doubt discourse was affiliated with posts and comments questioning the evidence behind HPV vaccination. Administrators and visitors doubted the information provided by the health authorities for many reasons. Some were skeptical of the epistemic value of studies showing HPV vaccination to be safe, and others simply did not trust the health authorities for sound medical advice. Finally, the betrayal discourse underlying the HPV vaccination skepticism was connected to statements that accused the health authorities of betraying all those who have experienced personal loss in relation to HPV vaccination. This discourse established a difference between "us" and "them." The "we" indicated all those afflicted by suspected adverse events, and all those taking a critical stance on HPV vaccination. The "they" were all those in favor of HPV vaccination, particularly the health authorities, pharmaceutical companies, and the Danish Cancer Society. Based on the study findings, it can be concluded that HPV vaccination skepticism is mediated through discourses that are personal, epistemological, social, or political, and value-laden in nature. Dealing with one of these dimensions alone, for example treating HPV vaccination skepticism as an information deficit or as a partisan issue, may risk missing the point entirely.

Keywords: HPV vaccination, Facebook pages, Denmark, vaccine skepticism, discourse analysis

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#### INTRODUCTION

Human papillomavirus (HPV) is a group of common viruses mainly transmitted through sexual contact, some of which are known to cause cancer. The first HPV vaccine, marketed by Merck & Co. under the trade name Gardasil®, became available in 2006, followed the year after by another HPV vaccine, Cervarix<sup>®</sup>, developed and manufactured by GlaxoSmithKline. With the availability of two vaccines, many countries implemented publicly funded HPV vaccination, typically as part of their existing national immunization programs, including vaccine safety monitoring schemes. However, some countries have also witnessed the rise of HPV vaccination skepticism related to the fear of increased promiscuity and/or suspected adverse effects following HPV vaccination. In Denmark, skepticism seemed to have revolved mainly around issues of vaccination safety and effectiveness. The HPV vaccination skepticism has attracted public attention in traditional news media and on social media, and is associated with low acceptance or uptake of HPV vaccination by parents who need to consent to the vaccination of adolescents (Suppli et al., 2018; Hansen et al., 2020).

This study aims to understand vaccination skepticism afforded by three Danish Facebook Pages (henceforth Pages) dedicated to providing a forum to voice skepticism about HPV vaccination (see introduction to the three Pages below). Facebook today is a major outlet for global conversations about health, allowing for public and private conversations about complex health issues such as vaccinations and debates surrounding those. Facebook is the most popular social media site among the Danes, with around 77% of all Internet users having a Facebook profile in 2019 (Slots- og Kulturstyrelsen, 2020). During the controversy over HPV vaccination that emerged in late 2012 and early 2013, major health organizations in Denmark and the Danish health authorities saw Facebook as the most important outlet for HPV vaccination skepticism.

We, too, see Pages as an important part of the communication environment that orients individuals as they make up their mind about HPV vaccination (Kahan, 2017). It is important to understand that Pages are distinct from other Facebook features, such as Profiles and Groups. Pages serve as the public profile of a single person, group, organization, business, and public authority, to mention a few. Anyone with a Facebook profile can create a Page, and thus become the first Page administrator (Admin). Admins can assign roles, such as Editor or Moderator, to other users, but only Admins and Editors can create posts. Moderators can respond to and delete comments and posts on the Page. Everyone on Facebook can like or follow Pages, and visitors to Pages can write comments or post reactions.

As the controversy over HPV vaccination grew stronger in force, many actors, institutions, and the media became involved, and they all interacted in complex ways. In Denmark, the three Pages dedicated to HPV vaccination skepticism could have served as mediators between the public debate in the traditional news media, the specific agendas of Admins, Editors, and Moderators (henceforth Admins for short), and the visitors' individual concerns. Posts on Pages that address issues in the public debate

often refer to media coverage from the point of view of the Admins, whereas comments and reactions allow visitors to state their subjective views, or tell their own story if the Admins approve. In a previous study, we conducted a content analysis of selected posts published by the Admins. We found that they focused on suspected adverse events and the alleged failure of the health care system to respond adequately to the afflicted girls and to acknowledge the risks associated with HPV vaccination. To construct their central message that the authorities were too eager in their endorsement of HPV vaccination, the Admins assembled media coverage with personal narratives, scientific information, political assertions, and more (Agergaard et al., 2020).

In this study, we aim to survey prevalent discourses in posts and visitors' comments. Discourses are relatively durable structures of meaning that emerge in social interactions, such as the ones that have taken place on the Pages dedicated to critical debate about vaccination that we study (Fairclough's, 2003). Discourse analysis, moreover, entails the establishment of connections between patterns of meaning-making in specific forums and the wider social context. Obviously, the three Pages that we study function within a much larger communication environment. They are, in Fairclough's (2003) terminology, "intertextual." We attended to different kinds of recurring assumptions about HPV vaccination found in posts, visitors' comments, and intertextual elements to answer our central research question:

• RQ: What are the overarching discourses on the three Pages dedicated to skepticism about HPV vaccination?

# **BACKGROUND**

# Vaccination Skepticism and Social Media

Anti-vaccination attitudes or vaccination skepticism have caused concerns that the vocal few perpetuating misinformation online may cause collapsing the global vaccination rates (Vanderslott, 2019). Following Browne (2018), vaccination skepticism can be understood as an attitudinal continuum that captures different degrees of doubts regarding the safety, efficiency, necessity, and general advisability of vaccination. Overt opposition to vaccination in general belongs to the extreme end of the spectrum. Vaccination skepticism is not a new phenomenon, but the spread of the Internet has made all kinds of information and debates about vaccination much more accessible. Social media affords billions of users the opportunity to access health information and to interact socially around health issues. There seems to be an online competition between pro- and antivaccination views as well as a tendency for users to select information that confirms prior beliefs (Schmidt et al., 2018; Johnson et al., 2020). Recently, health researchers, medical professionals, and health care authorities have worried about the spread of all sorts of vaccination information online and the potential threat it represents to global health (Larson, 2018; Burki, 2019; Ghebreyesus, 2019).

Researchers from many different fields have taken an interest in online vaccination skepticism. Early studies tended to focus on

static content published on homepages and blogs (Wolfe et al., 2002; Bean, 2011; Kata, 2012; Moran et al., 2016). With the increased popularity of social media, research to an increasing degree seemed to have turned to social media sites such as Twitter (Tomeny et al., 2017), YouTube (Yiannakoulias et al., 2019), Instagram (Basch and MacLean, 2019), and Pinterest (Guidry et al., 2015). Content analysis is one of the most prevalent methods used, but researchers have also used issue mapping to connect anti-vaccination content to user interaction patterns on Facebook (Smith and Graham, 2019). People and topics tend to cluster around shared opinions and underlying assumptions about safety, effectiveness, and responsibility of vaccination (Hoffman et al., 2019). For example, Ma and Stahl (Ma and Stahl, 2017) performed a multimodal critical discourse analysis of antivaccination information on a public Facebook group to find that the group preferred sentimental content to scientific research and statistical evidence.

Studies such as these are important to advance our knowledge about content, sentiments, and patterns of interaction that define online vaccination skepticism. Many studies evoke the idea of an anti-vaccination movement, yet the sum of what we know seems to be that vaccination skepticism takes many different forms, and tends to be highly contextual. We find support in Ortiz et al. (2019) systematic review of social media content about HPV vaccination, which showed a wide variety of content and content producers. Cluster analysis may reveal overall patterns, but if we examine closely what occurs in specific social media or online groups, the whole notion of a coherent and collective "movement" around shared beliefs and attitudes appears problematic.

Contributions from ethnography, rhetoric, and medical humanities that approach vaccination skepticism from a situated point of view corroborate this point. Leach and Fairhead (2007) talked about "vaccine anxiety" to capture parents' (mostly mothers') fraught decisions to have their children vaccinated or not—decisions that required careful and individual weighing of personal, social, political, and scientific arguments. Similarly, Carrion (2018) explored "maternal epistemology" as the personal balance achieved between scientific expertise and maternal experience in making up one's mind about vaccination. The mothers in these two studies were not "anti-vax," anti-science, or ignorant about vaccination, but people with genuine concerns, which they felt were not being fully addressed by the health care system.

Hausman (2019) rhetorical analysis of the public debate over vaccination in the United States questions the whole idea of an anti-vaccination movement as a media construct, and a straw man for those who think that there is a direct link between scientific evidence and human behavior. Using a similar approach, Lawrence (2020) also demonstrates the complexity of vaccination skepticism, and argues for the need for more nuanced public discourse. We should stop treating anti-vaccination as a national or even global issue, but approach it at the local level to understand "the contextualized nature of vaccination decisions" (Lawrence et al., 2014, p. 111; see also Reich, 2016).

Moreover, Ward (2016) study of the controversy over swine flu vaccination in France showed that individuals and groups

rarely mobilize against vaccination as such, but tend to focus on specific problems associated with specific vaccines, specific vaccination campaigns, and/or broader cultural or political issues. What characterizes vaccination skepticism and ultimately vaccination controversies tend to differ between different geographical and temporal contexts and the vaccine(s) at issue. Ward et al. (2016, p. 1,926) recommends that analysts "pay closer attention to what distinguishes the different strands of vaccine criticism regarding both what they dislike about vaccines (or about a given vaccine), and how this issue is integrated in a more general political or cultural cause."

Social media is a set of platforms owned by large multinational corporations that often emphasize the use of their platforms for global conversations and global connectivity. However, significantly, social media is shaped by content providers and users at the local level who all have their own goals and all belong to specific cultural settings (Miller, 2016). Studying strands of vaccination skepticism on social media platforms, therefore, is a way to explore vaccination skepticism in national and local contexts, and thus to find out what is at stake regarding specific vaccines in specific circumstances (Ward et al., 2015; see for example, Okuhara et al., 2018; Orr and Baram-Tsabari, 2018). In the following paragraphs, we first provide a global outlook on HPV vaccination followed by a presentation of the Danish controversy over HPV vaccination. We emphasize the importance of taking a contextual approach to HPV vaccination skepticism.

# A Global Outlook on Attitudes and Behaviors Relating to HPV Vaccination

Attitudes and behaviors related to vaccination are complex and context-dependent. The WHO advisory group on vaccination emphasized that personal, social, and practical issues may affect vaccination rates (WHO, 2020): what people think and feel, social norms, and technological affordances that impact conduct and communication, availability of vaccines, inconveniences in accessing vaccines, and much more. The Wellcome Global Monitor 2018 (Gallop, 2019) surveyed over 140,000 people in 144 countries to find that higher degrees of vaccination skepticism, specifically concerns over safety, more typically appeared in highincome regions compared to low-income regions, although there were significant national variations in this pattern. The level of education also influenced perceptions of vaccine safety differently in different regions. In Northern Europe and Northern America, people with higher levels of science education were more likely to agree that vaccines are safe, whereas in Eastern Europe, Central Africa, and Southern Africa, the opposite was true.

Some studies of national or local communication environments have identified social, moral, and/or political issues that have influenced public attitudes and behavior toward HPV vaccination. For example, concerns about sexuality and gender have been marked in a few countries, most notably in the United States, where attitudes were also found to be politically polarized (Kahan et al., 2010; Fowler et al., 2012; Casciotti et al., 2014; Gollust et al., 2016; Daley et al., 2017). Later, Beavis et al. (2018), using the 2010–2016 annual vaccine monitoring surveys

conducted by the Centers for Disease Control and Prevention in the United States, found that parents chose not to have their children vaccinated because of safety concerns, lack of necessity, and lack of knowledge about the potential health consequences of HPV.

In most other countries, public controversies over HPV vaccination have revolved around the safety and effectiveness of HPV vaccination. The Japanese HPV vaccination crisis, for example, followed sensational news stories about a cluster of adverse events suspected to be linked to HPV vaccination. The government subsequently suspended its recommendation of the national HPV immunization program, and the vaccination rate dropped to nearly 0% (Tsuda et al., 2016; Okuhara et al., 2018). Ireland also experienced a decline in national HPV vaccination rates, which were linked to widespread concerns over suspected adverse events reported in the press, on social media, and in a TV documentary aired in December 2015 (Corcoran et al., 2018; Mynthen and Sørensen, 2019). The same story can be told for countries such as Romania, France, and Denmark (Fagot et al., 2011; Penta and Baban, 2014; Suppli et al., 2018), but not for Australia, which seems set to be the first country to completely eliminate cervical cancer (Hall et al., 2019). Germany, Italy, Norway, the United Kingdom, and, in fact, most high-income countries for various reasons report less-than-adequate HPV vaccination uptake; yet, globally, national income level remains a strong determinant for HPV vaccination acceptance and uptake (Bruni et al., 2016).

#### The Danish Debate Over HPV Vaccination

In 2008, the Danish Parliament (Folketinget), following the advice of the Danish Health Authority (Sundhedsstyrelsen), introduced HPV vaccination into the Danish childhood immunization program. The process leading up to the decision involved a 2007 medical technology assessment report produced by an interdisciplinary team (Sundhedsstyrelsen, 2007). The report emphasized cervical cancer risk prevention as the main reason for introducing HPV vaccination. It estimated that successful implementation of HPV vaccination could prevent  $\sim\!\!70\%$  of all cases of cervical cancer, which led to approximately 175 deaths annually in Denmark. By January 1, 2009, the quadrivalent HPV vaccine Gardasil was freely available to girls aged 12 years (cohorts born in 1996 or later). In addition, HPV vaccination was offered to girls aged 13–16 years (cohort born 1993–96) in a catch-up campaign.

The HPV vaccination initially received favorable press coverage, and the vaccination rate was high compared to other developed countries (European Centre for Disease Prevention Control, 2012). Then, in 2013 and again in 2015, critical stories about HPV vaccination began to emerge (Smith, 2018). Journalists reported on general physicians, named as well as unnamed, who openly recommended HPV vaccination, but also received payments from two pharmaceutical companies producing HPV vaccines, namely Safino Pasteur (through their joint venture vaccines operation with Merck & Co.) and GlaxoSmithKline. In addition, stories about suspected adverse events, reported by some of the girls who had received vaccination, began to appear from April 2013 onwards.

On March 26, 2015, TV 2, a national public broadcasting service of Denmark, aired a documentary about suspected adverse events following HPV vaccination. The documentary called "The Vaccinated Girls – Sick and Betrayed," attracted almost 500,000 viewers, which is a substantial share for a small country like Denmark with just 5.7 million inhabitants as of 2015. The documentary and subsequent news stories on TV 2 focused on a group of named Danish girls, 47 in total, who all reported symptoms that are normally associated with postural orthostatic tachycardia syndrome (POTS) or complex regional pain syndrome (CRPS). All the girls claimed that their symptoms began or significantly worsened after HPV vaccination.

Reports about adverse events dominated the Danish media coverage of HPV vaccination throughout 2015 (Smith, 2018). In November 2015, the European Medicines Agency published a review of HPV vaccination and suspected adverse events. The review, produced at the request of the Danish Health Authority, concluded that the available evidence did not support the conclusion that POTS and CRPS are caused by HPV vaccination (European Medicines Agency, 2015). The debate over vaccination safety, however, persisted, and vaccination rates continued to decrease. Statistics produced by the State Serum Institute (Statens Serum Institut, SSI) in early 2017 showed that by 2016, only 54% of the 2002 cohort (due to HPV vaccination in 2015) and only 29% of the 2003 cohort (2016) had completed the full dose HPV vaccination schedule (Statens Serum Institut, 2017).

In response to what was perceived as a national crisis, the Danish Health Authority with the Danish Cancer Society (Kræftens Bekæmpelse) and the Danish Medicines Agency (Lægemiddelstyrelsen) in May 2017 launched a campaign under the heading "Stop HPV, stop cervical cancer" (in Danish, "Stop HPV, stop livmoderhalskræft"). Around the same time, there was a change in media coverage (Smith, 2018). Most news articles reported favorably on the "Stop HPV" campaign, recommending the effort to do something about the decline in the HPV vaccination rate. Some journalists took a critical stance on the media's coverage of HPV vaccination, and criticized TV 2 for their 2015 documentary, although the documentary previously had been nominated for the Cavling Prize, a prestigious Danish journalism award (Lynard, 2018). Vaccination rates began to rise in 2017, and the trend continued in 2018 (Statens Serum Institut, 2019).

The "Stop HPV" campaign was based on a general concern about the spread of misinformation, particularly on social media. Søren Brostrøm, Director of the Danish Health Authority, worried that the Internet and social media spawned post-factual tendencies skewing the debate about HPV vaccination. Brostrøm said: "When I look into my crystal ball to see the future of health services, I clearly see the post-factual society as one of the biggest challenges we face right now. You should not underestimate how big a challenge this is. It worries me." (Rasmussen, 2017, authors' translation).

References to the post-factual condition pervaded the public discussion about what is wrong with the HPV controversy. The notion of post-factual was closely linked to the idea that the social media spread sentimental and counter-factual information,

which led to the decline in HPV vaccination uptake (Andersen, 2017). Facebook, the most widely used social media platform in Denmark, was depicted as one of the main sources of (mis)information. "Much of the debate about the HPV vaccine takes place on Facebook, and this is where many parents get their information," explained Louise Hougaard Jakobsen, consultant to the Danish Cancer Society (quoted in WHO, 2018). The "Stop HPV" campaign, therefore, had to be particularly visible on social media such as YouTube and Facebook to counter post-factual tendencies.

#### MATERIALS AND METHODS

# Sampling

We aim to study the strands of criticism related to HPV vaccination on selected Pages in Denmark. To narrow our object of study, we identified in the following way what we believe are the three most prominent Pages that have been vocal in the debate over HPV vaccination. First, we typed in simple keywords, "hpv" and "hpv adverse event\*" (in Danish, "hpv bivirkning"), and browsed the results for Pages that would meet both of the following two criteria:

- Primary subject matter is HPV vaccination (treatment of other vaccines or vaccination in general should be secondary to HPV vaccination).
- Skepticism to HPV vaccination is the dominant attitude.

We located several relevant Pages that failed on one of the two criteria. The "Stop HPV" Campaign mentioned above certainly has HPV vaccination as its primary subject matter, but Admins mainly post messages aimed to counter skepticism about HPV vaccination. Another Page, "Make HPV vaccination free to ALL citizens" (authors' translation of "Gratis HPV-Vaccine til ALLE statsborgere"), criticized the government's original decision to limit the HPV vaccination scheme to girls of a certain age group, but the Page in general was very positive about HPV vaccination. Finally, we excluded Pages such as "Vaccination Forum" (authors' translation of "VaccinationsForum") that featured skeptical views about vaccination in general, but did not specifically focus their skepticism on HPV vaccination.

We were able to identify only three Pages that met both criteria. Apart from these, we also identified some groups that seemed to apply to both criteria. All, except for one, were closed groups, meaning that access to the content could only be granted if Admins allowed. To respect the privacy of the visitors, we excluded the closed groups. As this left us with only one additional group, we decided to exclude this one as well to keep the data material as simple as possible by focusing on Pages only.

The three Pages that we identified were all created by Danish groups, or organizations that emerged during the early days of the HPV controversy. All the three Pages focus exclusively on HPV vaccination, and all call for a skeptical attitude toward HPV vaccination. However, the skeptical views offered are diverse. In the following paragraphs, we first describe the three Pages, that is, our sources, and the three social groups or organizations that administer them. We then proceed to describe in detail how we have made sense of the diversity of the three Pages' skeptical posts

and comments. For the sake of simplicity, we refer to the three groups as Groups A, B, and C, and to their Pages as Page A, B, and C, respectively.

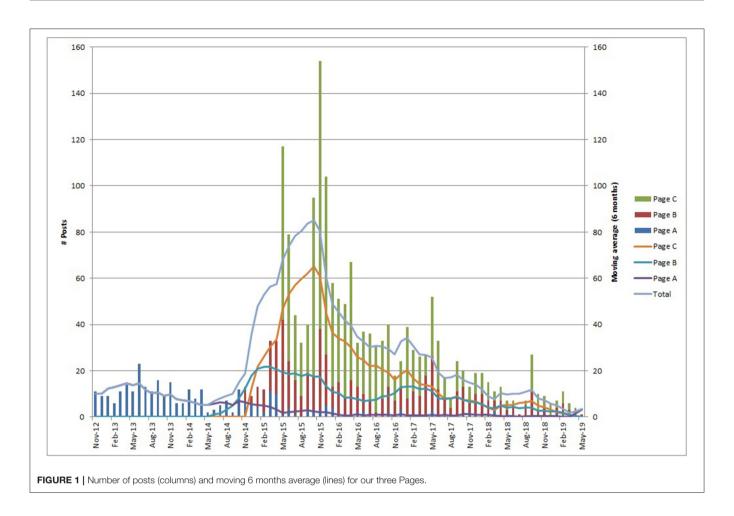
#### Sources

We accessed the three Pages in May 2019. We collected information about the number of all Admin posts from the Pages' respective launch date up until May 2019 (see Figure 1). In a previous study, we coded around one-third of the posts using quantitative content analysis. The results have been reported elsewhere, enabling us to discern differences between the Pages as well as prevalent topics and means of communication on the three Pages (Agergaard et al., 2020). We found that the three Pages' Admins and Editors assembled many different sources-media reports, personal narratives, scientific information, political assertions, and more—to construct their central message about HPV vaccination. They were all skeptical of the way in which the Danish health authorities responded to the legitimate concerns over the safety of HPV vaccination and to the demands for proper treatment voiced by the girls afflicted, their families, and many others. We also found that the posts were highly contextual in nature as they remained closely related to actors, events, and opinions in the unfolding Danish controversy. Despite their common cause, the three Pages also differed significantly.

Page A belongs to Group A, known as "HPV Vaccine Info-Fighting for Just Information about the HPV Vaccine" (authors' translation of "HPV Vaccine Info-Til Kamp for Retfærdig Oplysning om HPV-vaccinen"). The group consists of an unknown number of "passionate writers" (HPV Vaccine Info, 2020, authors' translation). The group emerged due to alleged censorship on behalf of the Danish Cancer Society, which did not allow skeptical views about HPV vaccination on its Facebook Page. Group A accuses the Society of manipulation of facts about HPV vaccination, arguing that the Society intentionally and systematically disregards critical information about the lack of effect of HPV vaccination and the high rates of adverse events. Group A also suggests that the Society has conflicts of interests, and will not allow information that could "impact the revenue of the Society's business partners in the pharmaceutical industry" (HPV Vaccine Info, 2020, authors' translation).

Group A launched Page A in November 2012. In June 2013, activity on Page A peaked at 23 posts. Since May 2015, the number of posts per month has remained below six, and months have gone by with no posts at all. We last accessed Page A in May 2019, where it was still moderately active, and had about 5,900 likes. Posts on Page A most frequently announced new articles on Group A's homepage, which typically discusses suspected adverse events following HPV vaccination and alleged conflicts of interests between main stakeholders such as public authorities, patient organizations, and pharmaceutical companies.

Group B and C, respectively, are "HPV Update" and "The National Association for Those Afflicted by HPV Adverse Events" (authors' translation of "HPV update" and "Landsforeningen HPV-Bivirkningsramte"). In contrast to Group A, they were both established by family members for patients who suspected HPV vaccination to have led to adverse events. In early



2015, Group B gained recognition as a special group under the Danish Association of the Physically Disabled (Dansk Handicapforbund), a Danish NGO working to ensure rights and accessibility for all persons with physical disabilities (HPV-update, 2020). Group C remained independently associated (Landsforeningen HPV Bivirkningsramte, 2020). Both the groups disseminate information about HPV vaccination and its suspected adverse events to patients, their relatives, and the public.

Group B launched its Page in November 2014. Page B activity peaked in May 2015 with 41 administrator posts. When we last accessed Page B in May 2019, it had about 1,700 likes, and administrator posts appeared regularly. Posts on Page B usually spoke out about the difficult position that the girls afflicted with suspected adverse events found themselves in, trying to ensure that they were heard in the debate. Page B became a mouthpiece for the political and epistemological representation of the community around the girls.

Group C launched its Page in May 2015. Page C was by far the most active of the three Pages studied. Activity peaked in November 2015 with 116 posts. Although the activity level has dropped significantly since then, the Page was still active till May 2019 with about 8,100 likes. Posts on Page C, like those on Page B, focused on the girls afflicted with suspected adverse events.

Page C also served for community-building purposes by sharing personal content such as narratives and images. Posts on Page C emphasized that the "afflicted" community deserved recognition and respect.

#### Data

For the present study, we accessed all the posts and comments on the three Pages. We carefully read as many posts and comments as necessary to identify what we considered as stable semantic discourses through a process of saturation: discourses were considered stable when we were unable to locate posts and comments that would allow us to develop new assumptions and thereby new discourses (see section below).

We also accessed information about the pertinent social context. This entailed a lot of reading "beyond" the material provided on the Pages. We systematically tried to access contextual information about public actors and events mentioned in the posts and comments. Out of ethical concerns (see below), we did not pursue more information about any individuals mentioned. We followed the links provided in the posts and comments, and we consulted relevant media coverage using Infomedia, the leading Danish provider of full-text electronic articles from all Danish newspapers, broadcast media, and online media.

To follow the Pages chronologically, we also placed posts and comments on the controversy's timeline as indicated by the number of posts in **Figure 1** and the amount of media coverage provided by Suppli et al. (2018). The posts and comments in correlation with contextual data allowed us to proceed with the discourse analysis.

# **Discourse Analysis**

Using posts, comments, and contextual data, we performed a discourse analysis of the material. According to Fairclough (Fairclough's, 2003), discourse refers to the relatively durable semantic structures of language that form a part of the relatively durable social structures and relations. We focused our discourse analysis on the range of recurring meanings that we were able to locate in our corpus of posts and comments on the three Pages. We also attempted to interpret these meanings in relation to what we know about the groups and organizations behind the Pages and in relation to the key actors and events in the wider social context. In doing so, we relied on Fairclough's (2003) concepts of underlying assumptions and intertextuality as tools to connect posts and comments to the larger communication environment.

Following Fairclough's (2003), we sought to identify discourses that hold assumptions about what exits (existential assumptions), what is or can be or will be the case (propositional assumptions), and what is good or desirable (value assumptions). We operationalized our discourse analysis in the following way. In our data, we first identified the existential assumptions in the statements referring to personal experiences with HPV vaccination, one's own or others', the existence of which should be taken for granted. We then identified the propositional assumptions in the statements that are concerned with assessing possible future developments in relation to HPV vaccination, that is, statements that are more political in nature. Finally, we identified value assumptions in the statements that emphasize social relations (including parent-child relations) defined or affected by HPV vaccination, and the values that such relations imply. We discussed all the assumptions identified in this way, and then gradually articulated and adjusted in a recursive manner that we agreed were the most important and meaningful assumptions until we reached a point of saturation.

We grouped all assumptions into overarching discourses, broad enough to accommodate existential, propositional, and value assumptions. This was probably the hardest part of the discourse analysis. Several iterative processes of definition, description, and discussion are required. For each set of assumptions, we identified several exemplary posts and/or comments. We sought to define discourses that would not only apply to our examples, but also make meaning for many more posts and comments.

As mentioned, the proliferation of discourses takes place in a communicative environment, which is potentially relevant for the configuration of meaningful discourses. We paid particular attention to intertextuality by identifying connections from our Pages' comments to other means of communication, such as the news media or information on HPV vaccination provided by the health authorities. Following Fairclough's (2003), we approached intertextuality as a way of producing difference

and/or dialogue. Differentiating, that is, using language to mark a difference, is a semantic tool essential to the construction of meaning. Establishing dialogue means the inclusion of other voices through direct, indirect, implicit, or even absent reference. All discourses have their blind spots, and it is important that we as discourse analysts look at what is being said, but also at what is not being said.

We operationalized the notion of intertextuality as follows: for each of our discourses, we would identify several intertextual elements such as links, images, stories, and/or videos. These elements were located in posts and/or comments. We assessed the intertextual elements as integral to our discourses, which meant that they would support the meaning built into the underlying assumptions.

#### **Data Ethics**

By default, Pages are visible to anyone on the Internet. The data used in this study are publicly available, and we did not collect personal data on individuals. Public accessibility, however, is not an excuse to ignore ethical assessments of using social media data. Even in a public forum like Pages, there is a reasonable and valuable expectation of privacy on behalf of social media users and visitors (Zimmer, 2010; Nissenbaum, 2011). Following Townsend and Wallace (2016), we took steps to protect the anonymity of the Pages' visitors by paraphrasing rather than quoting comments with potentially vulnerable information, such as details about visitors' health condition. Furthermore, we omitted all personal information that could be used to identify individual visitors both in this article and in our datasets. We made no attempts to seek information about the named individuals encountered (except for public actors such as politicians, researchers, etc.) beyond the Pages that we studied.

#### **RESULTS**

We were able to identify three overarching discourses of HPV vaccination skepticism: loss, doubt, and betrayal. Before we present our results about each of these in turn, we will try to clarify the underlying basis of the three discourses in terms of existential, propositional, and value assumptions.

We classified the following observations as existential assumptions about HPV vaccination: what had happened to some girls just after HPV vaccination; close ties between the health care providers and the pharmaceutical companies; and the systematic failures of the health care system and the political actors leading to the exclusion of critical discussion or outright skepticism. Reports about what was commonly referred to as the "afflicted" girls were often narrative accounts about individuals, often named girls, and they occurred in both the Admin posts and visitors' comments. The stories all confirmed that these girls had been struck by an "affliction" changing their lives for the worse. The HPV vaccination was most often depicted as a crucial turning point in the narrative, and the health care system failed to acknowledge the affliction. Moreover, the health care system was often depicted as being immune to criticism,

and all people expressing skepticism regarding HPV vaccination were marginalized.

Propositional assumptions included statements about the potential outcome of individual and institutional decisionmaking processes. At the individual level, such assumptions were often tied to the narratives of afflicted girls and the question of how parents would make decisions about HPV vaccination. Some Admin posts and visitor comments expressed worry that the available knowledge and advice were insufficient, implying that the established means of knowledge production and dissemination were lacking. At the institutional level, propositional assumptions were linked to broader problems in the health care system. The assumption that the health care system and, in particular, the health authorities could not be trusted, was a prevalent feature of many posts, comments, and intertextual elements. Two reasons, both of which were related to the two existential assumptions mentioned above, were given: first, there was an unsound alignment of interests between public health care providers and pharmaceutical companies; second, the health care system failed to provide due care to the afflicted girls.

In terms of value assumptions, we identified three different values. First, basic human values were important to posts and comments that expressed sympathy or compassion in relation to the afflicted girls. Trust in the narratives about afflicted girls was stipulated as a basic value, which then led to moral appraisal of the fundamental necessity for human relationships and dependencies for human existence. Second, epistemological values included the expression of doubts about certain kinds of expert advice and evidence. As Carrion (2018) observed in her study of mothers' arguments about vaccination, we found tensions between experts' and lay people's ways of knowing that seemed to promote a kind of standpoint epistemology: parents' intuitions about vaccination should be valued because they are intimately tied to the lifeworld of their children. Third, social value assumptions were established in posts, comments, and intertextual elements that made judgments about the proper functioning of the health care system. There was a broad consensus that the health care system had failed to provide proper treatment for afflicted girls, but focused too much on cancer treatment and the commercial interests of pharmaceutical companies.

#### The Discourse of Loss

The discourse of loss pertained to the many posts and user comments on the three Pages that addressed the lived experiences of the girls who reported feeling seriously ill after HPV vaccination. Posts and related comments reported on, but also referred to, other reports about individuals and often named girls, many of which originated from the news media. All the reports had one feature in common, namely the portrayal of HPV vaccination as a crucial turning point in the girls' lives. Admins or Editors posted news media reports with headlines such as the following: "Rebecca wanted to protect herself from cancer—crippled by the vaccine;" and "Simone was vaccinated against HPV: I feel pain every single day." At the heart, such reports dealt with the disabling loss of a good life as an existential condition.

Page A and Page C especially provided links to many first-hand reports from afflicted girls and their relatives. Some administrator posts contained lengthy quotations from private letters or posts from private Facebook accounts, reporting intimate stories about the consequences of personal loss. The intertextuality of the loss discourse, therefore, was not limited to the incorporation of news media on the Pages. One post on Page A shared a private Facebook status from a mother who reflected upon the moment when a homeopath told her that her daughter's symptoms had been caused by HPV vaccination. Suddenly, she said, her daughter's loss made sense. She added that HPV vaccination had made her daughter's life miserable.

The personal stories about losing one's abilities and quality of life also appeared in the visitors' comments—again on Page A and C in particular. One common denominator of such stories was an existential assumption stemming from bodily experienced events. At some point in time, the girls in question had lost physical and/or mental capabilities such as strength, energy, memory, or, in some cases, even mobility or vision. The experienced loss was real, and, therefore, had to have a real cause. "It is possible that HPV vaccination has caused my symptoms," one visitor said, after reporting on her newly emerged visual impairment, the diagnosis for which her physician had been unable to come up with. Such statements, we argue, related HPV vaccination to the experience of loss, but also to the process of making sense of the loss.

As indicated by the interrogative structure of the comment in this example and others, we noted that some visitors were careful not to make claims that affirmed HPV vaccination as a certain cause of their own or their family members' symptoms. Regardless of whether comments were committed to strict causality, we nevertheless found that all individual reports on adverse events reiterated the same temporal chain of events. In other words, all comments reporting on the girls' lived experiences shared the same narrative structure before and after HPV vaccination. All such comments associated the "before" with the bodily experience of being fit, active, and happy, whereas the "after" was rendered distinctively negative as a state of illness, dissolution, and sometimes even helplessness. In this temporal narrative elucidating chains of events, HPV vaccination demarcated the "before" and the "after." It was the narrative point of no return in the discourse of loss.

The discourse of loss consisted of individual reports on loss, but also included elements of shared social values and even proposals for political action. Recognizing and understanding loss thus became much more than an individual affair. Some of the stories about the afflicted girls connected loss to values of compassion and parenting. For example, comments included compassionate expressions in response to a post with a status update from a private Facebook profile, where a young woman told her story about the life she led before (happy and active) and after HPV vaccination (sick and frustrated). Visitors on Page C reacted to the post by calling it a sad, yet important message. One visitor stated that their heart was bleeding for anyone suffering badly.

Parenting values, such as care and responsibility, featured prominently in what we understand as the discourse of loss. Visitors who commented on the girls' and their parents' loss made

clear that the decision to be vaccinated against HPV infection was not a technical or a calculated decision, but a decision based on a heartfelt desire to do what is best for one's own daughter. Mothers (and the occasional father) expressed a pronounced sense of responsibility for making the decision in the first place and for dealing with what they identified as consequences. For example, we found several statements of parents who regretted having their daughter vaccinated, and who, therefore, instructed other parents to seek alternatives to HPV vaccination. We believe that such statements exhibit such values of responsibility. One visitor said that not a single day went by without her regretting having brought her daughter to the doctor to get the HPV vaccine. The same visitor carefully described her daughters' symptoms, recommending to others that they should rely on cervical screening rather than HPV vaccination to save their daughters from cervical cancer.

Individual responsibility, as also pointed out by Leach and Fairhead (2007), is closely connected to questions pertaining to the responsibilities of health authorities. Talking about what the authorities should and could do introduces a political element into the loss discourse. Typically, political issues made their way into the Pages that we studied through links to news stories posted by Admins and Editors. These posts provided an opportunity for visitors to comment on the ongoing debate about HPV vaccination, and some called for more action on behalf of the established health care system. In Page A's comment, a mother described her daughter's symptoms and her repeated attempts to cry out for help. She said that the family had been let down by their physician, the health authorities, and the government, concluding that something had to be done. Although the mother did not go into details about which political actions were needed, we would argue that the discourse of loss implies making personal experiences and shared social values political.

There are many things that are not included in the discourse of loss. We particularly note the limitations of the discourse of loss due to its narrative organization with a "before" and an "after" the point of no return aka the vaccination event. In such narratives, there is no before "before," nor an after the "after." In comments referring to the sick girls, all the girls lived good lives before HPV vaccination and bad (or at least worse) lives after. These two existential assumptions were never questioned. This may be due to the strong feelings of loss, compassion, care, and responsibility involved; the discourse of loss seemed to imply that the two states, before and after, were narrowly defined in terms of good and bad, respectively. We found no comments providing more nuanced information on the girls' condition. All the comments build on the assumption that the girls were doing fine before and much worse after HPV vaccination.

#### The Discourse of Doubt

Doubt lies at the heart of vaccination skepticism. We certainly found many doubts regarding the three Pages where Admins and visitors tried to assess HPV vaccination in the light of conflicting information from different sources. Some posts and comments, however, seemed to go beyond HPV vaccination. We found doubts that arose in connection to the three types of assumptions underlying discourses:

existential, propositional, and value assumptions. This indicates that the kind of vaccination-related doubt that informs vaccination skepticism should be seen in the context of more extensive doubts.

Some visitors' comments indicated just how difficult it was to assess and decide about HPV vaccination based on the wealth of information available, including the information that already appeared on the Pages. It often happened that the visitors addressed this decision-making process explicitly. For example, some visitors stated that the stories about the afflicted girls had led them to the decision of postponing their daughter's HPV vaccine until "they" had found out if HPV vaccination was really harmful or not, with the pronoun "they" often referring to the health care system as such. Other visitors' comments indicated that the conflicting information had caught them in a decision-making limbo, and some of them expressed their struggles in interrogative phrases like "what to do?"

The question raised pertains to individual decision-making, expressing propositional doubts about the right course of action. It also has social, even existential, ramifications. Positioning the health care system as "they" establishes an existential "we," which potentially includes everyone concerned about HPV vaccination. "They" provide decisive information on the safety and performance of HPV vaccination based on "their" objective evaluation of evidence. "We" assess that information, making sense of it in the context of "our" individual lives. This indicates that "we" all find ourselves in the same position, where it is necessary to process scientific assessment while having to engage in extended negotiations with friends, family, other parents, health professionals, and many others (see Leach and Fairhead, 2007; Lawrence et al., 2014). Here, these negotiations also seemed to involve strangers or near-strangers on Facebook.

Some users, on the other hand, explained how they had found ways to go about the propositional question of "what to do?." The solution was to build special kinds of trust relationships that stemmed from underlying value assumptions. If doubt feeds on complexity and uncertainty, trust should be a way to reduce complexity and uncertainty (Luhmann, 2017). This means that trust and doubt are not mutually exclusive, but often appear together in a codependent relationship. Some comments, in fact, seemed to address this entanglement of trust and doubt. One visitor on Page A said that she used her "gut feeling" to make the decision about whether to have her daughter vaccinated, even though her husband insisted that they should follow their physician's advice.

We see "gut feeling" as a way of expressing the complex interaction between trust and doubt in the face of uncertainties about HPV vaccination. Doubts emerged due to conflicting information, and gave rise to a kind of self-trust, namely "gut feeling." The stories about suspected adverse events only seemed to confirm what the visitor already knew, namely that the health care system had been wrong all along when "they" introduced HPV vaccination. Doubt, self-trust, and trust in the community of HPV vaccination doubters then turned into shared value assumptions when other visitors gave social credits, like, to public expressions of doubt, followed by statements of "gut feeling" to confront medical advice mediated by the husband. In fact, the

comment in mention was the most liked by other users on Page A in September 2013.

We generally found that highly opinionated and often short comments received most of the reactions from other visitors. For example, when a post on Page A in September 2015 announced that Gardasil® would be replaced in the Danish vaccination program by the Cervarix® vaccine, most comments voiced the opinion that the replacement would not make any difference, and that HPV vaccination should be halted completely. One visitor compared HPV vaccination to playing Russian roulette, while another accused the company behind Cervarix® of "bribing" its way into the Danish childhood immunization program. These negative statements, which clearly expressed doubts about HPV vaccination and the pharmaceutical companies behind the vaccines, received 15 or more likes from other visitors, far more than other, less categorical comments.

While doubts about the safety, effectiveness, and necessity of HPV vaccination were most prominent, we also observed that a small portion of visitors challenged Admins' and other visitors' skepticism. On Page B, this share of users began to appear more and more systematically from around the beginning of 2017 onwards. During some periods, the number of provaccine comments superseded doubtful or skeptical comments. The visitors in favor of HPV vaccination challenged the skepticism perpetrated by Admins and other users by referring to epidemiological studies that found no evidence of adverse events such as POTS and CRPS after HPV vaccination (e.g., Arnheim-Dahlström et al., 2013; European Medicines Agency, 2015; Feiring et al., 2017). They claimed that doubts about HPV vaccination were unfounded since such claims were based only on second-hand information, typically anecdotes, and not on what was often referred to as proper research or real science. Importantly, these comments only countered the value assumption built into the discourse of doubt, namely that the most trustworthy sources are oneself and the community around the afflicted girls and their families, but not the existential assumption of an "us" against "them," nor the propositional assumption that we all need to educate ourselves, and make an individual decision regarding vaccination (see also Reich, 2016).

Some visitors responded negatively to the introduction of scientific studies into discourse. They retaliated that the science was still incomplete, perhaps even unreliable, since scientific experts had not yet been able to come up with robust explanations for the symptoms of the afflicted girls. Or, as a visitor put it in a comment: the negative reaction of bodies is the facts. Other comments, often with support from Page Admins and Editors, referred to other studies, indicating that science cast doubt on the safety and effectiveness of HPV vaccination. For example, Admins on Page B posted a link to the webpage Med Science Research stating as follows: "There are thousands of scientific studies in the medical literature on the dangers of vaccines." Under the tab "Gardasil," the homepage listed many studies reporting adverse events after HPV vaccination.

Visitor comments to this post varied significantly. Some visitors suggested that Page B from the outset was biased against HPV vaccination, and, therefore, chose to highlight studies to this effect. Others countered that the established science was

corrupt. Both sides seemed to place value on scientific objectivity, but there was disagreement about which side could claim to possess it. As we see, this discussion revolves around the value assumption that science should be trusted. It is a corrective to the value assumption described above that only a small community of people and oneself should be trusted for reliable information to inform personal decision-making. It adds to the diversity of vaccination skepticism that some Admins and visitors would place trust in science, albeit a marginalized part of the scientific community (Reich, 2016; Carrion, 2018). It also indicates that in this case, science seemed to maintain and even enhance, rather than reduce, doubt.

# The Discourse of Betrayal

Many posts and comments on the three Pages discussed the role the health care system played in the controversy. As the controversy unfolded, a sense of betrayal became increasingly apparent in these posts and comments. As one of our previous examples also shows, some comments used an unspecified "they" to imply the entire health care system, including the government, public health authorities, pharmaceutical companies, physicians, and/or medical research institutions. The existential assumption was that "they" had let down the afflicted girls and their families by not taking their symptoms and stories seriously enough.

In fact, some comments suggested that "they" had let down the girls twice: first, by including HPV vaccination into the immunization program; and second, by failing to understand the girls' suffering and to offer help. This implied that the first failure led to the second failure. Some visitors' comments speculated that the real reason "they" were so reluctant to recognize and treat the girls' symptoms was a mix of financial and political interests, perhaps even moral failure. One comment on Page A argued, for example, that a reason for the lack of recognition of adverse events following HPV vaccination could be the financial compensation that "they" would have to pay the afflicted girls. The comment thus implied that "they" would do anything to avoid such expenses. Another comment on Page A addressed the issue of conflicts of interests by rhetorically asking whether, according to the Hippocratic Oath, physicians ought to help the pharmaceutical industry rather than the patients.

The existential assumption is failure and corruption on the part of the health care system. We found statements to that effect in all our samples, but they became particularly prominent on Page C in the later stages of the debate. Here, Page Admins and many visitors suggested that an alliance or coalition existed, consisting of the Danish Health Authority, the Danish Cancer Society, and other actors involved in the government-supported campaign for HPV vaccination "Stop HPV." Furthermore, Admins consistently referred to the Danish Cancer Society as being partly financed by the pharmaceutical industry, and labeled the information provided by the health care authorities as "propaganda."

In both posts and comments on the Page, the existence of a coalition backed by the public, non-profit, and private organizations had negative values. The coalition represented a technocratic regime with the power to enforce certain medical truths and technologies. From September 2017 onwards, the

Admins included the following part in an auto-text message in all their posts, depicting the group behind the Page as the underdog or suppressed opposition to the alliance: "We are not supported by the pharmaceutical industry; so, with a budget of 1/1,000 of what The Cancer Society and the National Board of Health spend on their propaganda program, we are engaged in an uneven fight for equity for our many seriously ill young persons."

Betrayal seemed to breed the need for resistance. Some comments extended the notion of an uneven fight to other issues. Particularly on Page A, we found reference to oppressed truths about GMOs and alternative medicine. One visitor even argued that the Danish media coverage of HPV vaccination bore resemblance to the coverage of the events in New York City on September 11, 2001, where Danish journalists "were not critical when the WORLD TRADE CENTER was teared down by NANO THERMITE and not BIN LADEN." This comment probably made an implicit reference to a Danish retired engineer who, in September 2013, went to court trying to prove that the third World Trade Center tower collapsed due to the presence of a compound known as nanothermite.

Such comments aside, we propose that comments lamenting the existence and dominance of a technocratic health care regime belong to the discourse of betrayal. The main reason we propose this term is the underlying propositional assumptions about the political power exercised by the regime on individuals. The weight of evidence and the socioeconomic resources invested in the immunization programs direct individuals toward HPV vaccination. The discourse of betrayal implies that if individuals are betrayed by those directing them, meaning that their bodies experience adverse events and thus betray the confident and powerful statements about the safety of HPV vaccination, opposition is required. Thus, betrayal has turned the question of HPV vaccination into a power struggle. As more power, more knowledge, more rules and regulations, and more money will be invested to block opposition, the betrayal becomes even more evident, and thus even more resistance is needed, so goes the argument that is fundamental to the discourse of betrayal.

# **DISCUSSION AND CONCLUSION**

Our discourse analysis of posts and comments on three Danish Pages dedicated to HPV vaccination skepticism identified three overarching discourses of loss, doubt, and betrayal. All the three discourses are founded on the underlying existential, propositional, and value assumptions that we extracted from posts and comments provided by Admins, Editors, and visitors to the Pages. We believe that these discourses, taken together or separately, provide important insights into vaccination skepticism in Denmark. We also propose that these discourses have been integral to the controversy, which means they have been closely related to the public conversation about HPV vaccination. In other words, they afford strands of skepticism related to HPV vaccination that are not exclusive to the three Pages, nor in any way exhaustive of the debate about HPV vaccination.

The three discourses were built on a variety of assumptions. Existential assumptions included personal experiences of loss, the difference between "us" (the afflicted) and "them" (experts, medical professionals, and pharmaceutical companies), and failure and corruption of the health care system. Propositional assumptions ranged from assertions over the distribution of power in society to the need and complexity of personal decisions, the potential effects of HPV vaccination, and the communal recognition of shared experiences and shared purpose. Values assumptions had to do with shared human relations, such as parenting and care, and the crucial importance of doubt and opposition. All these assumptions interacted in complex ways. The three discourses that we have distilled should be a tentative result in the joint effort to make sense of HPV vaccination skepticism that seems to be growing on social media around the world.

The strands of HPV vaccination skepticism offered by the three Pages fed on-and into-the ongoing controversy over HPV vaccination in Denmark. We observed that many posts and comments were directly related to current events. In other words, the three Pages would probably not have existed without the public and critical attention given to the safety and effectiveness of HPV vaccination. As the controversy gradually disappeared, and pro-vaccination views became more prominent in the press and on social media, the activity on the three Pages waned. At the same time, we also believe that the three Pages served as important channels of communication for those who already experienced or sensed loss, doubt, or betrayal. Rather than seeing Pages such as these as drivers of skepticism or sources of misinformation, we propose to understand them as integral elements of the total communication environment that people use as they make decisions and deliberate about HPV vaccination.

Skepticism of HPV vaccination can take many forms. The concern over anti-vaccination views spreading on social media across the world may be well-founded. We identified diverse forms of skepticism on just three Pages in Denmark that all depended to a high degree on the national debate and national media. We venture that it is important to see vaccination skepticism not as a uniform force such as implied by terms such as "anti-vaccination movement," but to understand the specificities of actors posting skeptical content online, the actual content of posts and comments, the cultural and political struggles that inform their communicative actions, and the underlying assumptions that create meaningful discourses.

# **DATA AVAILABILITY STATEMENT**

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

#### **AUTHOR CONTRIBUTIONS**

TA and KN made substantial contributions to the conception and design of the work. TA and KN performed the analysis,

drafted the work, and approved the publication and agree to be accountable for all aspects of the work. TA accessed the data.

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