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### Illness online

*Popular, tagged, and ranked bodies*

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## *Summary*

### **Illness Online. Popular, Tagged, and Ranked Bodies.**

This dissertation intends to contribute to the cultural study of illness and to debates about the use of social media as a vehicle for illness storytelling. More concretely, it examines how people use social media to speak about their illnesses, the types of stories they tell, and what telling these stories affords them. The results are three types of social media illness stories; namely, the stories of *popular bodies* on YouTube, *tagged bodies* on Instagram, and *ranked bodies* on GoFundMe, a crowdfunding site.

A disciplinary contribution is made by positioning social media illness stories and the types of stories I proposed, more specifically, within existing research in the humanities. I have reviewed how authors from the fields of literature, narrative studies, cultural studies, history, mass media, electronic literature, and social media studies approach the subject of illness and issues of narrating, voice, and agency. The outcome is a disciplinary context for understanding the study of illness stories on social media both in relation to concepts of narrative, voice, and agency as well as medium-specificity, platforms, affordances, and self-presentation strategies such as micro-celebrity, as developed by authors such as Zizi Papacharissi, Carsten Stage, Jill Walker Rettberg, and Ruth Page.

A theoretical contribution is made through the types of social media illness stories that I proposed; namely, of popular bodies, tagged bodies, and ranked bodies. Each type of story addresses socio-technical conditions of social media which are essential to how illness is told online. I theorize these social media illness stories as stories with specific structures and goals pertaining to recovering agency, particularly through ideas of wounded-healing, a concept proposed by sociologist Arthur Frank, and testimonial pathographies, a notion found in the work of Anne Hunsaker Hawkins. Then, I built upon such concepts by applying them to social media stories through the lens of micro-celebrity, 'hashtag publics,' and ranking cultures (digital objects handled by the methods embedded in platforms).

A methodological contribution is made by proposing digital methods techniques, which are research techniques native to social media, to study the stories of popular, tagged, and ranked bodies. Digital methods, as developed in the work of Richard Rogers, are techniques developed by repurposing the digital elements and methods already present in platforms. Through the use of digital methods I illustrated productive ways for conducting medium-specific, data-driven social media research on the subject of illness. And, more precisely, I performed a 'filtered reading' to the study of vlogs on YouTube,

undertook co-hashtag network analysis on Instagram, and studied the 'website biography' of [www.gofundme.com](http://www.gofundme.com) using the Wayback Machine of the Internet Archive.

Chapter 2 engages with the stories of *popular bodies*. These are the stories of patients who vlog on YouTube and practice micro-celebrity. Popularity is both a status (to be well-known and liked) and a product of accumulating views and comments, which, in turn, lead to vloggers ranking high on YouTube's search engine. The chapter analyzes the vlogs of these two cancer patients, Sophia Gall and Daniel Toms, who accumulated millions of views on YouTube before passing away. I offered insights on how illness is narrated using lifestyle vlogging, a format vernacular to online media, and how becoming popular online, as was the case of Sophia Gall and Daniel Toms, shapes both storytelling and illness experiences. The vlogs were studied through a 'filtered reading,' that means that the vlogs were analyzed, first, chronologically, which corresponds to 'seeing' the vlogs filtered 'from older to newer'. Second, the vlogs were analyzed based on engagement, that is, as reorganized from 'most engaged to least'. Vlogging and popularity afforded the vloggers a sense of agency over their life stories and became a lifeline to the world. Through vlogging Sophia and Daniel also challenged expectations about sick people's passivity; in fact, Sophia and Daniel were entrepreneurial patients. At the same time, the public nature of their communication made them the subject of the scrutiny. As their health worsened, Sophia and Daniel became unable to vlog steadily. Some viewers grew concerned about the vloggers and others questioned, publicly, the value and sincerity of their online activities. Responding to these accusations and managing this concerned audience became, too, part of vlogging at the end of life, demanding the reevaluation of ideas of agency *vis a vis* the demands of popularity.

Chapter 3 engages with the stories of *tagged bodies*. These are stories about people who suffer from disenfranchised conditions and use Instagram to share (and tag) their personal experiences. The goals of this public storytelling are to fight stigmas and create communities. By adding tags, otherwise 'invisible' personal experiences can be found by other Instagram users and placed into networks. In other words, on Instagram, breaking the silence involves patients making themselves searchable and networked. To develop these ideas, the chapter uses co-hashtag network analysis to examine the communication and tagging practices of women who have suffered stillbirth. The analysis reveals three hashtag practices. The first is the use of hashtag campaigns to coordinate expressions of grief and make them ambient. The second is to use posts and hashtags to share personal histories of pregnancy loss using tropes of journeys and sisterhood. The third practice pertains to how brands use hashtags related to pregnancy loss to target bereaved women and sell them products. This storytelling and tagging activities (and their relevance) were theorized as media-specific manifestations of wounded healing, a concept relevant in the field of illness narrative. Wounded healing refers, in this context, to how women who have suffered stillbirth regain agency as educators and issue makers through online storytelling and tagging.

Chapter 4 engages with the stories of *ranked bodies*. These are stories of sick people in financial distress who use crowdfunding sites such as GoFundMe to raise funds to pay for their medical treatment. The chapter presents an analysis and subsequent critique of medical crowdfunding's on-sided advice to market personal illness stories as cure-oriented, or as restitution stories in the language of survivors. This one-sidedness may

come to exclude conditions which cannot be narrated in relation to a cure such as terminal illness or chronic conditions. Also, too much emphasis on personal responsibility downplays the systemic issues and inequalities which lead people to crowdfund. In doing this GoFundMe recreates long standing economies of deservingness. In addition, the chapter explores how campaigns and the illness stories told in them will not only be evaluated by potential donors, who decide who they want to fund. They are also ranked (that is, given a status amongst other stories) by GoFundMe's algorithms. To study this ranking culture the chapter presents an historical investigation – a website biography—about the different ranking criteria GoFundMe has used in its website in the last ten years. The current emphasis on trending, equates popularity with deservingness, once again creating potential inequalities. In a regime of 'trending,' people with less marketable conditions and limited digital literacy are at risk of not receiving funds.

I conclude the dissertation by drawing together insights from the different case study chapters and using them to reflect on how platform-enabled visibility as well as the sociotechnical conditions of popularity, tagging, and being ranked both enhance but also diminish the political potential of illness storytelling. I also reflect on the digital debate in the health humanities: engagement with medium-specific research, as the one I have developed, can further the study of illness storytelling as it continues to develop online.

# Samenvatting

## *Ziekte online.*

### *De populariteit, tagging en ranking van lichamen op sociale media.*

Dit proefschrift beoogt bij te dragen aan de culturele studie van ziekte en aan debatten over het gebruik van sociale media als middel voor *storytelling* over ziekten. Concreet wordt onderzocht hoe mensen sociale media gebruiken om over hun ziekte te praten, het soort verhalen dat ze vertellen en wat het vertellen van deze verhalen hen biedt. Drie prominente vormen van zulke ziekteverhalen op sociale media staan in deze studie centraal; de verhalen van populaire lichamen op YouTube, van getagde lichamen op Instagram en van gerankte lichamen op GoFundMe, een crowdfunding website.

Een disciplinaire bijdrage wordt geleverd door het positioneren van bovengenoemde typen ziekteverhalen op sociale media binnen bestaand onderzoek in de geesteswetenschappen. Ik heb in kaart gebracht hoe auteurs uit de literatuurwetenschap, narratieve en culturele studies, geschiedenis, massamedia, elektronische literatuur en social media studies het onderwerp ziekte benaderen in relatie tot narratieve strategieën, inspraak en handelingsbekwaamheid. De onderzoeksresultaten bieden inzicht in verhaalstructuren en in de prominente actoren op sociale media. De handelingsbekwaamheid van actoren wordt mede bepaald door mediums specifieke eigenschappen van platformen, hun 'affordances', en de strategieën van gebruikers voor zelfpresentatie middels bijvoorbeeld micro-beroemdheid, zoals ontwikkeld in het werk van onder meer Zizi Papacharissi, Carsten Stage, Jill Walker Rettberg en Ruth Page.

Een theoretische bijdrage wordt geleverd via de voorgestelde typen ziekteverhalen op sociale media; die van populaire lichamen, getagde lichamen en gerankte lichamen. Elk type verhaal wordt bestudeerd in de context van de socio-technische aspecten van de platformen die essentieel zijn voor de manier waarop verhalen over ziekte online worden verteld. Ik theoretiseer deze ziekteverhalen als verhalen die ten doel hebben keuzevrijheid en handelingsbekwaamheid te herstellen dan wel te vergroten, met name door strategieën die voortborduren op de noties van 'wounded healing', een concept van socioloog Arthur Frank, en 'testimonial pathographies', een begrip uit het werk van Anne Hunsaker Hawkins. Vervolgens heb ik voortgebouwd op deze concepten door ze toe te passen op sociale media verhalen die zich afspelen in de context van typische sociale media fenomenen: micro-beroemdheden, 'hashtag publics' en 'ranking cultures' (deze fenomenen zijn het resultaat van methoden die zijn ingebed in platformen en die resulteren in digitale objecten zoals de hashtag).

Een methodologische bijdrage wordt geleverd door de ontwikkeling en toepassing van *digital methods*. Digital methods, zoals ontwikkeld in het werk van Richard Rogers, gaat uit van het gebruikmaken van digitale elementen en methoden reeds aanwezig in de infrastructuur van een platform. Door het gebruik van digital methods heb ik productieve manieren ontwikkeld om verhalen over ziekte op sociale media te bestuderen met oog voor de mediums specifieke, datagedreven dynamieken van platformen. In de studie van vlogs op YouTube pas ik een 'gefilterde lezing' toe, deed een co-hashtag-netwerkanalyse

op Instagram en bestudeerde de 'website-biografie' van [www.gofundme.com](http://www.gofundme.com) met behulp van de Wayback Machine van het Internet Archive.

In het tweede hoofdstuk behandel ik de verhalen van populaire lichamen. Dit zijn verhalen van patiënten die vloggen op YouTube en daar micro-beroemdheden zijn. Populariteit is zowel een status (bekend en geliefd zijn) als een product van opeenvolgende views en commentaren, die er op hun beurt toe leiden dat vloggers hoog scoren in de zoekmachine van YouTube. In dit hoofdstuk analyseer ik de vlogs van twee kankerpatiënten, Sophia Gall en Daniel Toms, die miljoenen views op YouTube verzamelden voordat ze stierven. Deze analyse biedt inzicht in hoe ziekteverhalen worden verteld met behulp van *lifestyle vlogging*, een format dat in sociale media wordt gebruikt en waarmee Sophia Gall en Daniel Toms zeer populair werden. Dit format beïnvloedt zowel de inhoud van *storytelling* als de ervaringen van het ziek-zijn.

Door middel van een 'gefilterde lezing' zijn deze lifestyle verhalen bestudeerd. Dit betekende dat ik eerst de vlogs chronologisch heb geanalyseerd, beginnend bij de oudste vlog. In tweede instantie werden de vlogs geanalyseerd op basis van betrokkenheid, dat wil zeggen gereorganiseerd van 'meest betrokken naar minst betrokken'. Vloggen en populariteit gaven de vloggers een gevoel van keuzevrijheid in de vormgeving van hun levensverhalen en fungeerden als een reddingsboei. Door te vloggen gingen Sophia en Daniel ook in tegen het beeld van passieve zieken; in feite waren Sophia en Daniel ondernemende patiënten. Tegelijkertijd werden ze door het openbare karakter van hun communicatie kritisch bekeken. Naarmate hun gezondheid verslechterde, konden Sophia en Daniel minder vaak vloggen. Sommige kijkers maakten zich zorgen over de vloggers en anderen vroegen publiekelijk naar de waarde en oprechtheid van hun online activiteiten. Reageren op deze beschuldigingen van inauthenticiteit en het onderhouden van dit bezorgde publiek werden onderdeel van het vloggen aan het einde van hun leven. Dit vraagt om reflectie op onze ideeën over handelingsbekwaamheid in relatie tot een cultuur die populariteit prioriteert.

Hoofdstuk 3 gaat in op de verhalen van getagde lichamen op Instagram. Deze zijn afkomstig van mensen die lijden onder erbarmelijke omstandigheden en Instagram gebruiken om hun persoonlijke ervaringen te delen en te taggen. Doelen van deze openbare verhalen zijn het bestrijden van stigma's en de creatie van gemeenschappen. Door tags toe te voegen, kunnen persoonlijke ervaringen gevonden worden door andere Instagram-gebruikers en in netwerken worden geplaatst die anders 'onzichtbaar' zouden zijn. Met andere woorden, op Instagram houdt het doorbreken van de stilte in dat patiënten zichzelf vindbaar maken in het zoekstelsel en zichzelf onderdeel maken van een netwerk. Om deze ideeën te ontwikkelen, gebruikt het hoofdstuk 'co-hashtag network analysis' om de communicatie- en *tagging*-praktijken (de manieren waarop hashtags strategisch worden gebruikt in posts) van vrouwen die een doodgeboorte hebben meegemaakt, te onderzoeken. De analyse onthult drie hashtag-praktijken. De eerste is het gebruik van hashtag-campagnes om uitingen van verdriet te coördineren en ze te introduceren als onderdeel van sociale media *feeds*. De tweede is om *posts* en hashtags te gebruiken om persoonlijke verhalen van doodgeboortes te delen met behulp van vaker voorkomende uitdrukkingen (*tropes*) rond 'journeys' en 'sisterhood'. De derde praktijk heeft betrekking op hoe merken hashtags gebruiken, die verband houden met zwangerschapsverlies, om nabestaanden te bereiken en producten te verkopen. Deze

*storytelling* en *tagging*-activiteiten (en hun relevantie) werden getheoretiseerd als mediaspecifieke manifestaties van ‘wounded healing’, een concept relevant in het gebied ziekteverhalen. ‘Wounded healing’ verwijst in deze context naar hoe vrouwen die een doodgeboorte hebben meegemaakt, hun handelingsvermogen kunnen herpakken door educatief-informerend op te treden en aandacht te vragen voor dit onderwerp via *storytelling* en *tagging*.

In het vierde hoofdstuk ga ik in op verhalen van gerankte lichamen. Dit zijn de verhalen van zieke mensen in financiële nood die crowdfunding websites als GoFundMe gebruiken om geld in te zamelen voor hun medische behandeling. Het hoofdstuk zet de analyse van deze verhalen uiteen en geeft kritiek op de eenzijdige nadruk van medische crowdfunding op verhalen die gaan over persoonlijk herstel. Daarnaast onderzoek ik hoe campagnes en de daarin vertelde ziekteverhalen niet slechts worden geëvalueerd door potentiële donoren die beslissen wie ze willen financieren. Ze worden ook gerangschikt (dat wil zeggen, tussen andere verhalen een bepaalde status verleend) door de algoritmen van GoFundMe. Om deze ‘ranking cultures’ te bestuderen, deed ik historisch onderzoek - in de vorm van een website-biografie - naar de verschillende rangschikkingscriteria die GoFundMe de afgelopen tien jaar op zijn website heeft gebruikt. Verhalen van genezing of overleving worden op het platform gepropageerd en zijn meer succesvol. Deze eenzijdigheid kan ertoe leiden dat aandoeningen die niet kunnen worden verteld in de context van genezing, zoals terminale ziektes of chronische aandoeningen, uitgesloten worden. Teveel nadruk op persoonlijke verantwoordelijkheid bagatelliseert ook de systemische problemen en ongelijkheden die mensen bewegen tot crowdfunding. Door deze eenzijdigheid versterkt GoFundMe een op merites gebaseerde economie. De huidige nadruk op *trending* stelt populariteit gelijk aan merites en creëert daarmee potentiële ongelijkheden. In een regime van *trending* lopen mensen met minder (goed) behandelbare of onbehandelbare aandoeningen en beperkte digitale geletterdheid het risico geen geld te ontvangen.

Ik sluit het proefschrift af door inzichten uit de verschillende hoofdstukken en uit de case studies samen te brengen en te gebruiken om na te denken over hoe zichtbaarheid op platformen en de sociotechnische voorwaarden van populariteit, tagging en ranking het politieke potentieel van ziekteverhalen kunnen versterken, maar ook kunnen verminderen. Met dit proefschrift wil ik daarnaast aantonen dat betrokkenheid van gezondheidswetenschappen bij mediums specifiek onderzoek, zoals ik dat heb ontwikkeld, de studie van online ziekteverhalen en *storytelling* kan bevorderen.

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