



UvA-DARE (Digital Academic Repository)

Illness online

Popular, tagged, and ranked bodies

Sánchez Querubín, N.

Publication date

2020

Document Version

Other version

License

Other

[Link to publication](#)

Citation for published version (APA):

Sánchez Querubín, N. (2020). *Illness online: Popular, tagged, and ranked bodies*. [Thesis, fully internal, Universiteit van Amsterdam].

General rights

It is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), other than for strictly personal, individual use, unless the work is under an open content license (like Creative Commons).

Disclaimer/Complaints regulations

If you believe that digital publication of certain material infringes any of your rights or (privacy) interests, please let the Library know, stating your reasons. In case of a legitimate complaint, the Library will make the material inaccessible and/or remove it from the website. Please Ask the Library: <https://uba.uva.nl/en/contact>, or a letter to: Library of the University of Amsterdam, Secretariat, Singel 425, 1012 WP Amsterdam, The Netherlands. You will be contacted as soon as possible.



NATALIA SÁNCHEZ-QUERUBÍN

ILLNESS ONLINE

POPULAR, TAGGED & RANKED BODIES

Illness Online. Popular, Tagged, and Ranked Bodies

ACADEMISCH PROEFSCHRIFT

ter verkrijging van de graad van doctor
aan de Universiteit van Amsterdam
op gezag van de Rector Magnificus
prof. dr. ir. K.I.J. Maex

ten overstaan van een door het College voor Promoties ingestelde commissie,
in het openbaar te verdedigen in de Aula der Universiteit
op woensdag 16 september 2020 te 14.00 uur
door Natalia Sánchez Querubín
geboren te Bogotá D.C

Promotiecommissie:

Promotor:

Prof. dr. R.A. Rogers Universiteit van Amsterdam

Copromotor:

Prof. dr. E. Rutten Universiteit van Amsterdam

Overige leden:

Prof. dr. M.S. Parry	Universiteit van Amsterdam
Prof. dr. E. Peeren	Universiteit van Amsterdam
Prof. dr. R. Boast	Universiteit van Amsterdam
Prof. dr. M.J.P. Deuze	Universiteit van Amsterdam
dr. M.P. Stevenson	Universiteit van Amsterdam
Prof. dr. S.S. Orgad	London School of Economics and Political Science

Faculteit der Geesteswetenschappen

Table of contents

ACKNOWLEDGEMENTS	- 5 -
LIST OF FIGURES	- 6 -
LIST OF TABLES	- 7 -
CHAPTER 1 INTRODUCTION: SOCIAL MEDIA ILLNESS STORIES	- 8 -
STUDYING ILLNESS AS A HUMANITIES SCHOLAR	- 13 -
<i>Illness and stories</i>	- 13 -
<i>Illness and Narrative Studies</i>	- 16 -
NARRATIVE TYPES AS LISTENING DEVICES	- 20 -
<i>Applied Narrative and Other Interventions</i>	- 24 -
<i>Other Perspectives</i>	- 25 -
STUDYING ILLNESS AS A MEDIA SCHOLAR	- 29 -
<i>Mass Media and the Representation of Illness</i>	- 29 -
<i>Electronic Literature and illness</i>	- 33 -
<i>A definition of networked selves and online stories</i>	- 38 -
<i>A Short History of Online Illness Stories</i>	- 43 -
<i>A Typology of Social Media Illness Stories</i>	- 47 -
<i>Digital methods and social media as research machines</i>	- 51 -
A RISING DIGITAL HEALTH HUMANITIES AGENDA	- 59 -
CHAPTER 2 POPULAR BODIES: VLOGGING AT THE END OF LIFE	- 62 -
SICK MICROCELEBRITIES	- 63 -
TO STUDY POPULAR BODIES, ADJUST THE FILTER TWICE	- 70 -
READING 1: BECOMING TERMINALLY ILL IN FRONT OF AN AUDIENCE	- 71 -
READING 2: LOW PRODUCTIVITY, DEATH, AND A CONCERNED AUDIENCE	- 76 -
THE DIFFICULTIES OF POPULAR BODIES	- 80 -
CHAPTER 3 TAGGED BODIES AND WOUNDED HEALERS	- 84 -
TAGGING PAIN AND LOSS	- 88 -
HASHTAG THEORY: WHAT DO HASHTAGS DO?	- 91 -
CO-HASHTAG NETWORK ANALYSIS	- 92 -
USING HASHTAG CAMPAIGNS TO MAKE #GRIEF AMBIENT	- 97 -
LOSS AS A #JOURNEY	- 102 -
REACHING BEREAVED #MOTHERS THROUGH PROMOTIONAL HASHTAGS	- 106 -
TAGGED BODIES, WOUNDED HEALERS, AND LIFESPANS	- 109 -
CHAPTER 4 CROWDFUNDING AND THE RANKED BODY	- 112 -
GoFUNDMe's PLOTS AND ADVICE FOR TELLING STORIES	- 115 -
STUDYING GoFUNDMe's RANKINGS THROUGH A WEBSITE BIOGRAPHY	- 122 -
RANKING CAMPAIGNS ACCORDING TO FRESHNESS, SOCIALITY, AND TRENDING	- 126 -
RANKED BODIES, DESERVINGNESS, AND CALCULATED SPACES OF CARE	- 132 -
CHAPTER 5 CONCLUSIONS: ALGORITHMIC VISIBILITY, EDITED SELVES, AND LIVENESS	- 134 -
CASE STUDIES AND LESSONS ABOUT ILLNESS ONLINE	- 139 -
CONTRIBUTING TO A DIGITAL AGENDA IN THE HEALTH HUMANITIES	- 144 -
SUMMARY	- 146 -
SAMENVATTING	- 149 -

Acknowledgements

My time as a Ph.D. candidate begins and ends surrounded by mentors and friends. My sincere gratitude goes to my supervisor Richard Rogers and co-supervisor Ellen Rutten. I thank Richard for encouraging me to pursue a Ph.D. and supporting me in every stage of the process. Richard taught me the nitty-gritty of academic writing and research and how to make findings out of a sea of information. The trust that he placed in me has, quite literally, shaped the course of my life. Ellen has been a kind supervisor and source of inspiration. I am thankful for her detailed feedback and genuine interest in my career and future.

My paranymphs are Sabine Niederer and Marloes Geboers. Sabine is not only an unstoppable source of energy but also a lovely friend. Marloes and I have had parallel Ph.D. journeys. She has been a fantastic travel companion. I am grateful for their support with the task of finalizing and defending this dissertation and friendship along the way.

The web of people around me, I am lucky to say, is broad. I am especially grateful to the members of the Digital Methods Initiative: Esther Weltevrede, Erik Borra, Anne Helmond, Liliana Bounegru, Jonathan Gray, Fernando van der Vlist, Marc Tuters, Lonneke van der Velden, Carolin Gerlitz, Bernhard Rieder, Micheal Stevenson, Stefania Milan and many others. Our yearly summer and winter schools, data sprints, publications, travels, and friendship have given rhythm and much meaning to my time as an academic. I am also thankful to The Visual Methodologies Collective and colleagues at the HvA: Sabine Neiderer, Marloes Geboers, Carlo de Gaetano, Gabriele Colombo, Federica Bardelli, Loes Bogers, Geert Lovink and others. Each of you are creative and fun and always uniquely challenge me to step out of my comfort zone in the most productive ways. I also say a heartfelt ‘thank you’ to my colleagues at the University of Amsterdam Alex Gekker, Niels van Doorn, Stijn Peeters, Charles Forceville (and many others) and my friends from the ‘Ph.D. room’. When I go to work and look around, I see some of the smartest, most hardworking, and kindest people I know.

Behind the scenes in the making of this dissertation is my husband, John Haltiwanger. He incessantly reminds me that I am capable of tackling all the challenges that I put my mind towards -- and that everything will work out just fine. He is always happy to say: I told you so. My parents Jorge and Adriana, my brother Alejandro, and aunt María Eugenia are my most devoted supporters. This accomplishment is dedicated to you. To my family-in-law, Dona, Curt, Julia, Anne, and Brett: I am grateful for your love. Maya Livio, Liliana Bounegru, and Johnathan Gray and I have kept each other company in our academic journeys and grown together during the past decade. For you, my gratitude.

Amsterdam 2020

List of figures

Figure 1: Sophia 's vlog	74
Figure 2: Daniel's vlog	75
Figure 3: #stillbirth co-hashtag network	94
Figure 4: Capture your grief 2017	99
Figure 5: Motherhood in loss	100
Figure 6: Hope and pregnancy loss	103
Figure 7: Meme encouraging women to speak up	104
Figure 8: Motherhood after loss	105
Figure 9: Pregnancy after loss selfie	106
Figure 10: Mama bear T-shirt	107
Figure 11: Angel baby figurine	108
Figure 12: Why crowdfund for medical expenses?	118
Figure 13: Tell your story	119
Figure 14: Help by sharing	121
Figure 15: A campaign's public metrics	122
Figure 16: www.gofundme.com in the Wayback Machine	126
Figure 17: Ranking donations according to 'liveness	127
Figure 18: Recent donations	127
Figure 19: Ranking campaigns according to sociality	128
Figure 20: Trending in medical crowdfunding in 2018	131

List of tables

Table 1: Comments on Sophia's and Daniel's videos.	74
Table 2: Clusters with examples of hashtags.	92