Illness online
*Popular, tagged, and ranked bodies*

Sánchez Querubín, N.

**Publication date**
2020

**Document Version**
Other version

**License**
Other

**Citation for published version (APA):**

**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.
Chapter 3 Tagged Bodies and Wounded Healers
If you are on Instagram, you might learn about one of your friend’s pregnancies through an announcement post. These posts typically include the photograph of a sonogram or a positive pregnancy test, a caption, and hashtags such as #pregnant and #babyclub. To create these hashtags on Instagram, one simply places the number sign (#) before a word.

Later on, your friend will upload time-lapse videos to share the growth of her stomach and take the “perfect pregnancy selfie” (Austin, 2014, para. 7). She will also use online services that make tracking the fetus “a playful, creative and fulfilling experience” (Lupton & Thomas, 2015, para. 2). For instance, Baby Sizer is a service that helps expectant parents visualize the size of the fetus using familiar objects. According to the initiators, a fetus is like “a rainbow sprinkle in week 6 of pregnancy, a golden snitch in week 10, or a stick of travel-size deodorant in week 15” (Baby Sizer, 2020, para. 1). If you query Instagram for the hashtag #babysizer, you will find people posting screenshots from the service to update their followers.

Days (or hours) after the birth, you will see photos of your friend’s newborn on your content feed and, from then on, snippets of her life as a parent. When the publication of the child’s life is too detailed, people might call it ‘sharenting’ (Blum-Ross & Livingstone, 2017). There is also the chance that your friend will gain a sizable online following and become a ‘mommy influencer.’ She could offer tips about caretaking and promote brands on her Instagram account (Abidin, 2015).

Practices like these have led scholars to describe Instagram and other social media as spaces for the performance and “self-construction of pregnancy” (Tiidenberg & Baym, 2017, p.1), “mediation of childbirth,” and the articulation of “networked maternal subjectivities” (Das, 2017, p.1). There is also academic interest in discourses developing on social media around pregnancy and motherhood. For instance, Tiidenberg and Baym describe pregnancy today as “highly visible, intensely surveilled, marketed as a consumer identity, and feverishly stalked in its celebrity manifestations” (2017, p.1). With this in mind, they ask whether, on Instagram, women “rely on and reproduce pre-existing discourses aimed at morally regulating pregnancy, or reject them and construct their own alternatives” (2017, p.2).

Tiidenberg and Baym found, for example, that the selfies that Russian pregnant women post often emphasize their ability to remain attractive. This is known as the ‘yummy mummy’ phenomenon. Other studies, in comparison, identify counter-discursive practices, such as breastfeeding online activism (Locatelli, 2017; Mecinska, 2018; Meer, 2019).
In this second chapter, I, too, discuss pregnancy, birth, and motherhood on Instagram, though from a different perspective. I am interested in how women use Instagram to speak about stillbirth, which is the birth of an infant that has died in the womb after twenty-four weeks of gestation.

Stillbirths are linked to congenital problems, with or without a chromosomal abnormality, issues with the placenta, and conditions such as preeclampsia ("Causes" 2019). They are relatively frequent in western industrialized societies. For example, in the United States, it is reported that 1% of all pregnancies result in stillbirth ("What is Stillbirth? | CDC" 2019) and in England, 1 in every 200 births ("Stillbirth" 2019). At the same time, stillbirth remains a disenfranchised and invisible birth narrative. That is to say, the event is usually “not openly acknowledged, publicly mourned or socially supported” (Doka, 1989, p.4; Kelley & Trinidad, 2012; St John, Cooke, & Goopy, 2006; Murphy, 2012; Brierley-Jones et al., 2015).

With this social reaction in mind, it is intriguing to see how Instagram has become a tool to ‘break the silence’ about stillbirth and other forms of perinatal death. For example, maternity blogs advise readers to go to Instagram and use hashtags such as #stillbirth and #stillbornstillloved (‘stillborn still loved’). The goal is to “find other momma’s who may have had the same type of loss” (Mannegren, 2018, para. 8). Other similar hashtags include #bereavedmothersday (‘Bereaved Mother’s Day’), #angelmommies (‘angel mommies’), and #1in4. The last hashtag refers to the claim that “as many as 1 in 4 known pregnancies end in miscarriage, also known medically as spontaneous abortion” (Starr, 2018, para. 4).

Stillbirth and its alienation have inspired distinctive posting and hashtag practices, of which I will be discussing three. I identified these three practices by analyzing a collection of Instagram posts on the subject of stillbirth and explore them further using co-hashtag network analysis. Co-hashtag network analysis is a technique that combines the study of the cooccurrence of hashtags with the close reading of content.

In the first practice, bereaved patents participate in hashtag campaigns that help create rituals and render otherwise invisible grief ambient and networked. An example is Wave of Light, a candle-lighting ceremony for deprived parents that takes place during International Pregnancy and Infant Loss Remembrance Day. The organizers of the event instruct participants to “take a photo of [their] candle and post it to Facebook, Twitter or Instagram using #WaveOfLight” (“Get involved with” 2018, para. 5).

In a second hashtag practice, hashtags not only aid information discovery but also meaning-making, and help frame pregnancy loss and birth as journeys. For example, a person will experience pregnancy differently when their previous
pregnancy resulted in stillbirth or miscarriage. Through hashtags such as #pregnancylossjourney (‘pregnancy loss journey’) women share their personal histories encompassing multiple events—and the need to recognize and discuss them together—including miscarriage, infertility, stillbirth, and live birth.

Lastly, hashtags related to stillbirth and pregnancy loss are used commercially by an industry of makers to reach potential consumers and promote a material culture around loss. In many instances, the Instagram accounts using these promotional hashtags are run by small entrepreneurs who have themselves experienced some form of loss.

By ‘telling the story’ and tagging it in the ways I describe, women who have had a stillbirth, I argue, are practicing a form of ‘wounded healing’ (Frank, 2013). The latter is a concept from the field of illness narrative that describes how people who suffer regain agency as healers, create publics, and function as educators, in this case, through online storytelling and tagging. I call these stories, stories of tagged bodies.

Numerous studies have explored the formation of communities and tagging practices around health issues on Instagram and similar platforms. These studies address, for example, Instagram communication about fibromyalgia (Berard & Smith, 2018; Isika, Mendoza & Bosua, 2020), endometriosis (Melander, 2019), mental health (Feuston & Piper, 2018), Celiac disease (Meleo-Erwin et al., 2019), HIV (Nobles et al., 2020) and, on Tumblr, chronic pain (Gonzalez-Polledo, 2016).

My research contributes to this cluster of work. It has been argued that the narratives of pregnant women “can be seen within the wider context of illness narratives because they do share many of the same features, such as interactions with medical professionals and institutions, and sometimes unpleasant or traumatic interventions and practices” (Davis, 2014, p.260). Examples of these experiences are postpartum depression (Montgomery et al., 2012), illness resulting in infertility (Neville-Jan, 2004) fetal issues (Sandelowski & Corson Jones, 1996), and, indeed, stillbirth and other forms of perinatal death (Miller, 2005; Bailey, 2001). Like people who are seriously ill, women who have had a stillbirth face the challenge of making sense of their experiences as more than medical events.

Instagram also inspires investigations on what Tamar Leaver and Tim Highfield (2020) call lifespans. This involves the study of Instagram in terms of “uses and use practices that span an entire lifetime, from the cradle to grave,” with case studies on the very young and recently deceased (Leaver & Highfield, 2020, p.175). On the earlier spectrum are the studies on birth and maternal subjectivities that I referenced earlier. Leaver and Highfield have researched people’s motivations for posting sonograms on Instagram and the documentation of childhood. On the end side of the spectrum, are practices related to the end of life such as taking
funeral selfies, a new Instagram ritual for celebrating life and death, also researched by Leaver and Highfield. Stillbirth collapses such distinctions between the very young and the diseased, thus opening a different interrogation about mediated lifespans and the use of social media.

Stillbirth and, more generally, pregnancy loss also complicate discussions about personhood and grief. In my analysis, I follow the approach put forward by Lind (2017) and Earle et al. (2012), which rejects an a priori hierarchy of grief based on fetal growth and, instead, places the experience of the “gestating subject” at the center (Lind, 2017, Introduction). That means that choices about grief and its impact should be made by the person who was pregnant and not by the researcher. Accordingly, I follow closely the language of the online communities whose activities I study and describe how they identify their unborn and grief, rather than intending to settle any form of debate about grief hierarchies, or in other words, about whose grief matters the most.

On the following pages, I expand on concepts of disenfranchisement of stillbirth, social-media tagging in relation to illness storytelling, and wounded healing. Specifically, I review and build on Gonzalez-Polledo’s (2016) work on the tagging practices of Tumblr users who suffer from chronic pain and on Zappavigna’s (2018) theory of hashtags as ‘searchable talk’. Next, I explain the technique of co-hashtag network analysis and how I have employed it and present an account of each of the hashtags practices I mentioned above; namely, hashtags for making grief visible and networked; hashtags that articulate journeys; and hashtags for promoting commerce around pregnancy loss. In the conclusion, I return to Frank’s (2013) theory of wounded healing.

Tagging pain and loss

People with chronic pain are subject to testimonial and hermeneutical injustice (Carel & Kidd, 2014). When they share their experiences in health contexts or with peers, often, these are “met by prejudice [and] their frames to communicate about illness are deemed irrelevant, time-consuming, emotional, insufficiently articulate, or unhelpful” (Gonzalez-Polledo, 2016, p.2). Moreover, chronic pain is difficult to describe and it challenges dominant health narratives about a cure and progress. As a result, the experience becomes disenfranchised.

Gonzalez-Polledo studied chronic pain communication on Tumblr and Flickr, two visual social-media platforms. In both, she found people living with pain who “actively resist epistemic injustice and create inhabitable pain worlds” (Gonzalez-Polledo, 2016, p.2). People do so, for instance, by sharing visual metaphors and pain memes. A case in point is the photograph of a man, edited to appear as if his head was engulfed by flames. Many of these memes, Gonzalez-Polledo remarks, “elaborate recurrent themes of being ‘stuck’ in pain, ‘lost’ or
incommunicated, and on the idea that being overcome by pain is like being ‘out of control’” (2016, p.5).

The infrastructures of Tumblr and Flickr are crucial to create this shared pain vocabulary. Their public nature enables people to speak “about chronic illness in their own language” (Gonzalez-Polledo, 2016, p.7). In addition, “tagging images makes them searchable by keyword, meaning they may be encountered out of context, near other images with the same tag” (Gonzalez-Polledo & Tarr, 2014, p.1458). Thus, the result of this meme-making and tagging is a user-generated system of classification for content about pain. To study this folksonomy, Gonzalez-Polledo collected memes tagged with ‘chronic pain,’ ‘pain’, ‘hurt,’ ‘migraine,’ and ‘fibromyalgia,’ and conducted a visual thematic analysis.

Moreover, Tumblr activity around chronic pain helps sustain the ‘spoonie networked public’. A public is a collection of people who have “a common understanding of the world, a shared identity, a claim to inclusiveness, [and] a consensus regarding the collective interest” (Livingstone, 2005, p.9). In the case of ‘spoonies,’ a shared identity emerges around the term ‘spoon,’ which reworks the pain theory formulated by Miserandino (Cristol, n.d.). The theory states that “living with a chronic illness means one has a limited amount of spoons (units of energy) which have to be carefully administered” (Gonzalez-Polledo, 2016, p.5).

The work involved in acting as a ‘spoonie public’ – that is, in creating a shared identity – is “restructured by networked technologies” (boyd, 2010, p.39). In the case of spoonies, a shared identity is the result of posting, making memes, and tagging content about chronic pain. This public is not either on- or offline: it exists simultaneously in “the space constructed through networked technologies ... [and]... the imagined collective that emerges as a result of the intersection of people, technology, and practice” (boyd, 2010, p.39).

In Gonzalez-Polledo’s study, networked content became “a key unit of analysis” (2016, p.3). Here, it seems important to understand the reblogging practices of spoonies. To unpack these, Gonzalez-Polledo used Tumblr’s API to collect posts tagged with ‘chronic pain’ and “metadata about the post (such as the user name, the post date, the post URL) [...] and a ‘reblog key’” (2016, p.5). Then, she produced a series of ‘re-blogging trees’ and analyzed them. In these trees, “each ‘nerve branch’ depicts how content (i.e. image, animation, video, etc.) is re-blogged throughout a community of people with chronic pain on Tumblr. When clicking on different ramifications of a branch a pop-up window will show a different context (a blog) in which the same piece of content has been re-blogged” (n.d. para. 1).

The Instagram activity around stillbirth that I study is also an example of social-media users creating networked publics and resisting testimonial injustice. About
stillbirth, feminist studies remark that “women whose infant children have died struggle to reconcile a pregnancy and state of motherhood that does not follow a standard narrative for pregnancy: conception, growth, and birth” (Bhave, 2017, chapter 5). Since the only expectation is birth and ‘reproductive success,’ women experience pregnancy loss and stillbirth as personal failures and deviations (St John, Cooke & Goopy, 2006).

Feminist scholar Karen O’Donnell (2017) elaborates on this idea of failure while writing about her full-term pregnancy loss. After the event, she remembers telling herself: “You have failed many times at this whole motherhood thing: you can neither produce a living child nor deliver her properly [...] You yourself almost certainly killed your baby by not paying enough attention” (O’Donnell, 2017, chapter 11).

Traditionally, pregnancy loss is not only framed as a failure, but also as inconsequential. Many people “view stillbirth children as never living” (Bhave, 2017, chapter 5). Accordingly, the dominant script is that after a stillbirth those involved should “return to normal life more quickly than following other kinds of bereavement” (Brierley-Jones et al., 2015, p.152) and avoid too much discussion about the death (Davidsson Bremborg, 2012). In other words: repairing the narrative wreckage caused by stillbirth needs to be quick and private.

The perceived right of a person to call themselves a ‘mother’ after a stillbirth is also contested and lacks nomenclature (Browne, 2016; Brierley-Jones, Crawley & Lomax, 2014). Elaborating on this “ambiguous space of motherhood,” feminist scholar Maya Bhave asks: “what happens if you lose a child in utero or near delivery? [...] Are you called a non-mother or post mother after such an event? [...] and, how to "continue mothering a child that is not present"? (Bhave, 2017, chapter 5). The dilemma “is troubling and is not voiced within society” (Bhave, 2017, chapter 5). Bhave argues that this leaves women limited options for discussing “what mothering with loss looks like” (2017, chapter 5).

Telling personal stories helps break the silence about stillbirth and expands the perceptions and ‘scripts’ available for making sense of it. Stillbirth storytellers include parents and the organizations that support them. Examples in the United States are the Angel Names Association (ANA) and the charity-funded “Stillbirth Stories,” a digital archive that offers “interviews with parents and clinicians talking about their experiences of stillbirth” (Stillbirth Stories, 2017, para. 1). News media also offer sharing platforms: in 2015, the New York Times asked readers to share their experiences and published the compilation, Stillbirth: Your Stories.

When the same stories are shared online, the storytelling can have various functions. When it comes to personal blogging, researchers have found that
motivations include therapeutic benefits and making available the “less frequently discussed possibilities in the journey to parenthood” (Sohr-Preston & et al., 2016, p.17). Instagram, as I have mentioned, is another online medium for speaking about stillbirth and contesting the disenfranchisement of its grief. An investigation is warranted to understand better how women are using the platform to re-articulate their experiences beyond medical events and deviations from normative narratives of reproductive success. It helps us to answer the question: how is storytelling on Instagram becoming a vehicle to consider motherhood, birth, and death in a “redefined scope?” (Bhave, 2017, chapter 5)

In what follows, I start my analysis by introducing the research methodology. Like Gonzalez-Polledo, I explore tagging and posting practices as meaningful for storytelling about health and as tools for resisting disenfranchisement. However, while Gonzalez-Polledo mapped re-blogging trees, I employ hashtags and co-hashtag networked analysis. A co-hashtag network analysis has similarities with co-word analysis, a content-based bibliometrics technique that employs “structural features of the network” to gain insights from a textual corpus (Chiu & Lu, 2015, p.1). Researchers use, for example, the technique to examine “the co-occurrences of the term/keyword pairs from titles, abstracts, keywords field, and/or the full text in order to reveal themes, structures, and development of a field” (Chiu & Lu, 2015, p.2). While co-hashtag network analysis similarly uses structural features to gain insights, the network is not made of words but of hashtags. To understand the network, one also needs to understand hashtags.

Hashtag theory: what do hashtags do?

In her book *Searchable Talk* (2018), linguist Michele Zappavigna, who I mentioned earlier in my introduction, explores how hashtags have captured both the public imagination and academic interest. The “practice of tagging, once an act of classification,” she argues, also “has emerged as a means of forging and contesting social bonds” (Zappavigna, 2018 p.1). By this, Zappavigna means that hashtags are tags and forms of user “generated metadata,” which facilitate information discovery, management, classification, retrieval, navigation, and the description of content. Moreover, tagging supports a “decentralized practice by which individuals and groups create, manage, and share terms” (Zappavigna, 2018, p.4). In Gonzalez-Polledo’s study, as I already explained, this type of folksonomy was a meaningful feature in the communication of people with chronic pain on Tumblr.

As Zappavigna demonstrates, in addition to classification hashtags have meaning-making and social-bonding capacities. That is to say, people use them to create semiotic meaning by adding context and extra-experiential information and referencing perspectives. With this capacity in mind, people think carefully about which hashtag is “most appropriate for the task of promoting visibility” (Page,
2012, p.183). That is, “using a particular hashtag presupposes that there exist other texts that may contain the same tag, as well as putative listeners who might ‘tune in’ via the social stream” (Zappavigna, 2015, p.288).

By bringing together information discovery and meaning-making affordances hashtags make “searchable talk” (Zappavigna, 2015, p.274) and invite “potential interaction with other members of the site” (Page, 2012, p.184). These interactions are not conversational. Instead, they are forms of “ambient affiliation” and “communing affiliation” (Zappavigna 2011, p.790; Zappavigna & Martin, 2017, p.4). With these terms, Zappavigna describes how knowledge about others and the co-presence and identification with these ‘listeners’ become tangible when one clicks on a hashtag and is redirected to thematic streams and networks of related content.

Hashtags help users, in this sense, in inserting themselves into thematic spaces and aligning “around values in social media” (Zappavigna & Martin, 2017, p.4). To track these acts, one can perform positioning analysis by “locating and placing the actors’ purposive keyword choice (or issue language) vis-à-vis that of others” (Rogers, 2018 p.12). An example: in the context of the same-marriage debate in the United States, Rogers was interested in the hashtags #lovewins (‘love wins’), favored by liberals, and #jesuswins (‘Jesus wins’), favored by conservatives. He saw an opportunity to determine “who is joining a program and who is joining an antiprogram” (Rogers, 2018, p.461-62) and use this information to describe the formation of “ad-hoc publics,” “calculated publics,” “hashtags publics,” and “networked publics” (Bruns & Burgess, 2015; Bruns, Moon, Paul & Münch, 2016; Papacharissi & Oliveira, 2012). These terms refer to the assemblages of users and content and communities of interest that are sustain by hashtag-usage.

The different ways in which Zappavigna approaches hashtags — information discovery, semiotic, and grouping devices—guide the co-hashtag network analysis, which is the technique I employ in my own work.

Co-hashtag network analysis

As mentioned, I began my analysis by creating a collection of Instagram posts. To accomplish this, I employed the software tool ‘Visual Tagnet Explorer’ to query Instagram and collect posts that contain either the keyword or hashtag #stillbirth. I performed the query on 3 July 2017 and collected 7,433 posts that had been published between February and July 2017. The quantity of posts corresponds to a randomized selection determined by Instagram’s API. The posts collected were authored by a total of 1537 unique public Instagram accounts. Most of them were run by women based in the United States, the United Kingdom, and Australia. In the ‘bios’ or posts, they disclose their connection to stillbirth. The authors have either experienced one or they are engaged in commerce or charity.
For each of the posts, the ‘Visual Tagnet Explorer’ captured the number of comments and likes, the text found in the caption, geolocation, timestamp, and hashtags. The tool makes this data accessible as a spreadsheet. The ‘Visual Tagnet Explorer’ also outputs a co-hashtag network based on the data. In this network, nodes are hashtags and edges appear between them to indicate that they cooccur, that is, that they are used together in a post. I used this co-hashtag network (and Gephi, a software for network analysis) as tools for making sense of the data and guiding my exploration of tagging practices in the stillbirth community.

In more detail, with Gephi, I ‘cleaned’ the network by eliminated #stillbirth, which is the query node to which every other hashtag in the network is connected. Then, I filtered the network to remove hashtags with a low frequency. In the case of the stillbirth co-hashtag network, I eliminated hashtags below a frequency of 10. Next, to explore the topography of the network, I used Force Atlas 2. This algorithm pulls to the centre of the graph the nodes with a higher degree count, which is the number of edges that are adjacent to the node. Then, with Gephi’s modularity function, I identified clusters of tightly connected nodes/hashtags. When applied to the stillbirth network, this function resulted in 14 clusters, numbered 0 to 13. Gephi provides an additional table in which one can clearly see which nodes (hashtags) belong to which clusters.

Below, in Figure 3, I share the co-hashtag network, with the main clusters differentiated by color. The resulting network is closely knitted, that is, there is no extreme polarization between the clusters, thus they remain close to each other in the graph. This distribution indicates that the occurrence of hashtags is frequent. The topography of the network — the clusters— support a form of ‘distant reading’ of the dataset and the discovery of a combination of hashtags and patterns significant for the analysis.

To contextualize the clusters and the patterns they evoke, I zoom into posts associated with the hashtags in each of the clusters, perform a close-reading of them, and, then, label the clusters. It is worth emphasizing that, in other forms of analysis, researchers study the entities first and then group them based on similarities. In this case, Gephi’s modularity function did the clustering of the hashtags. I looked into the clusters to answer the question: what do the hashtags in these clusters have in common? And what activities do they sustain? Ultimately, in co-hashtag network analysis, the topography of the network is used as a map for the qualitative exploration of data, taking into account content and hashtags, while the mathematical functions of the graph are “bracketed” (Venturini et al., 2017, p.156). Here, the concern is not so much with the exact value of gravity or connectivity but with “the stories that [networks graphs] evoke” through close reading (Venturini, Bounegru, Jacomy & Gray, 2017, p.157).
I characterized and labelled the 14 clusters taking into account the network topography and the associated hashtags and posts. To ensure the legibility of these findings, which I present below, I label and describe the clusters and hashtags practices without using the standard format for writing hashtags - the number symbol (#) before a word. Instead, I present hashtags in plain text in the table and between single quotations in the rest of the chapter. In table 2 I outlined the labels for each of the clusters and included a sample of the hashtags (nodes) that belong to them.
<table>
<thead>
<tr>
<th>Cluster</th>
<th>Examples of hashtags found in the cluster</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 Makers &amp; Support</td>
<td>Crochet, help others, cherished gowns UK, charity, bereaved parents, stillborn awareness, stillbirth support, still loved, baby loss support, neonatal death, angel baby, wrapped in love, volunteers, wedding dress, wrapped in love blankets, wedding dress upcycle, knitting love, cherished gowns</td>
</tr>
<tr>
<td>1 Hope &amp; Pregnancy Loss</td>
<td>Faith, angel mommy, infertility, hope, ivf, strong women, ttc journey, ttc sisters, miracle baby, ivf journey, forever loved Happy Mother’s Day, rainbow babies, ivf sisters, surviving stillbirth, infertility sisters, April’s fools, gestational surrogate</td>
</tr>
<tr>
<td>2 Rituals</td>
<td>Grief journey, what heals you, support, Mother’s Day, mama grief, 1 in 4, bereaved mother, life after loss, stillbirth awareness, still born still loved, may we all heal, Bereaved Mother’s Day, International Bereaved Mother’s Day, capture your grief, wave of light 2017</td>
</tr>
<tr>
<td>3 Motherhood in Loss</td>
<td>Stillborn but still loved, pregnancy loss awareness, angel babies, motherhood, still a mother, parents of angels, miscarriage matters, stillbirth matters, grieving mom, still mother, no more taboo, pregnancy loss group, I miss my son, always remembered, I am a mother, I am a father, Mother’s Day 2017</td>
</tr>
<tr>
<td>4 Art &amp; Charity</td>
<td>Postcards to heaven, angel gowns, artist, handmade, still birthday, pencil drawing, keepsakes, non-profit, keepsake, angel gown project, hand crafted</td>
</tr>
<tr>
<td>5 Grieving Out Loud</td>
<td>Grieving parents, grieving father, stillbirth break the silence, say their names, still a mama, grief and loss, grieving, bereavement, grieving mother, child loss, mourning, wish you were here, in loving memory</td>
</tr>
<tr>
<td>6 Pregnancy After Loss</td>
<td>Third trimester, parenting after loss, pregnancy, pregnancy after loss, pregnancy, rainbow baby, born too soon, NICU, living with hope, birth trauma, breastfeeding, life after baby loss</td>
</tr>
<tr>
<td>7 Unfiltered</td>
<td>Mom life, raising, toddler, candid childhood</td>
</tr>
<tr>
<td>8 Identity</td>
<td>I am the 1 in 4, grieve out loud, loss and love, miscarriage survivors, empty arms, rainbow mama, baby loss mamas, miscarriage survivor, grief support, I had a miscarriage, grieving mama, bereaved moms</td>
</tr>
<tr>
<td>9 Connecting</td>
<td>Pass it on, soul tears, we understand, be you, life quotes, compassion, kindness, saying goodbye, you are not alone</td>
</tr>
<tr>
<td>10 Religion &amp; Inspiration</td>
<td>Wave of light, writers of Insta, authors life, I am writing, empowering women, Jesus cares, expecting sunshine documentary, Jesus heal, Jesus is lord</td>
</tr>
</tbody>
</table>
### Table 2: Clusters with examples of hashtags

The 14 clusters found in the co-hashtag network are labelled included in the table, along with examples of hashtags associated with them.

<table>
<thead>
<tr>
<th>Cluster</th>
<th>Example Hashtags</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rituals</td>
<td>Recovery, grief, therapy, healing rituals, and bereavement.</td>
</tr>
<tr>
<td>Grieving Out Loud</td>
<td>Posts celebrating events such as ‘Bereaved Mothers’ Day 2017’ and campaigns like ‘may we all heal,’ a photography challenge. Other hashtags and images evoke the memorial iconography specific to infant loss; examples are ‘tiny feet’ and ‘angel babies’. Similarly, in Motherhood in Loss, the content and hashtags emphasize the right to grief and claim the title of mother despite the loss of the stillborn child. In this cluster, one finds hashtags such as ‘still a mom,’ ‘I am a mother,’ ‘I am a father,’ and ‘Mother’s Day 2017.’ Closely related, in the clusters Identity and Awareness, are hashtags and content about self-identification and disclosure. These include ‘I had a miscarriage,’ ‘I am the 1 in 4,’ ‘baby loss mamas,’ and ‘breaking the silence.’ I return to some of these grief and awareness oriented clusters and hashtags when discussing the first hashtag practice: the creation of rituals that make grief ambient.</td>
</tr>
<tr>
<td>Memorization</td>
<td>Posts discussing and sharing experiences about stillbirth, infertility, and other instances of perinatal death such as miscarriage, as well as the hope for a live birth. These posts make reference to journeys and communities: they include such hashtags as ‘pregnancy loss journey,’ ‘ttc journey,’ ‘recovery,’ ‘ivf journey,’ ‘ttc sisters,’ ‘infertility sisters,’ ‘strong women,’ and ‘ivf community.’ In the cluster Pregnancy After Loss one finds, instead, discussion about becoming pregnant after a stillbirth. Hashtags include ‘there is hope’ and ‘rainbow baby’. Rainbow baby is the term used to describe a live birth after a previous loss. That is to say, the rainbow after the storm. I return to these journey-oriented hashtags and the storytelling they support when discussing the second hashtag practice.</td>
</tr>
<tr>
<td>Awareness</td>
<td>Education for awareness, awareness for prevention, still aware.</td>
</tr>
</tbody>
</table>

In the clusters Rituals, Grieving Out Loud, and Memorization one finds posts about recovery, grief, therapy, healing rituals, and bereavement. These clusters include hashtags celebrating events such as ‘Bereaved Mothers’ Day 2017’ and campaigns like ‘may we all heal,’ a photography challenge. Other hashtags and images evoke the memorial iconography specific to infant loss; examples are ‘tiny feet’ and ‘angel babies’. Similarly, in Motherhood in Loss, the content and hashtags emphasize the right to grief and claim the title of mother despite the loss of the stillborn child. In this cluster, one finds hashtags such as ‘still a mom,’ ‘I am a mother,’ ‘I am a father,’ and ‘Mother’s Day 2017.’ Closely related, in the clusters Identity and Awareness, are hashtags and content about self-identification and disclosure. These include ‘I had a miscarriage,’ ‘I am the 1 in 4,’ ‘baby loss mamas,’ and ‘breaking the silence.’ I return to some of these grief and awareness oriented clusters and hashtags when discussing the first hashtag practice: the creation of rituals that make grief ambient.

In the cluster Pregnancy Loss and Hope one finds posts discussing and sharing experiences about stillbirth, infertility, and other instances of perinatal death such as miscarriage, as well as the hope for a live birth. These posts make reference to journeys and communities: they include such hashtags as ‘pregnancy loss journey,’ ‘ttc journey,’ ‘recovery,’ ‘ivf journey,’ ‘ttc sisters,’ ‘infertility sisters,’ ‘strong women,’ and ‘ivf community.’ In the cluster Pregnancy After Loss one finds, instead, discussion about becoming pregnant after a stillbirth. Hashtags include ‘there is hope’ and ‘rainbow baby’. Rainbow baby is the term used to describe a live birth after a previous loss. That is to say, the rainbow after the storm. I return to these journey-oriented hashtags and the storytelling they support when discussing the second hashtag practice.

The clusters Makers and Support, Religion and Inspiration, and Art and Charity include posts promoting the work of crafters, businesses, and charity enterprises dedicated to supporting grieving parents. These posts feature, in combination with the hashtag ‘stillbirth’, hashtags such as ‘donate a wedding dress,’ which refers to a
A campaign looking to up-cycle wedding dresses into outfits for (diseased) newborns. Similarly, the hashtags ‘wrapped in love’, ‘handcraft,’ and ‘volunteers’ are included in posts published by Cherished Gowns UK, which “provides the families of babies that are stillborn, miscarried or pass away shortly after birth with items of clothing that they are able to be dressed in for their funeral” (‘Cherished Gowns’, 2020, para. 2). Here one also finds clothing brands that sell t-shirt with slogans such as ‘rainbow momma’, and post promoting Expecting Sunshine, a documentary that “chronicles the anticipation and anxiety of expecting a baby while still grieving for the child that came before” (Chute, 2017, para. 3). I use examples from these clusters to discuss the third hashtag practice: the creation of material and commercial cultures around pregnancy loss.

The last three clusters in the network are somewhat generic and dispersed and, thus, are labelled lightly, and left out of the analysis. The cluster Unfiltered reunites hashtags such as ‘keep it real,’ which are used for speaking about everyday life as a mother, but also about the realities of grief. In Spanish, one finds hashtags similar to the ones in the other clusters, but in the Spanish language. The frequent combination Spanish and English is most likely a product of the presence of users from the United States, where the two languages are spoken. Connecting includes miscellaneous hashtags and content such as ‘life quotes’.

In the next section, I describe and analyze in more detail the three hashtags practices that have my interest, using selected examples from the 14 clusters. In presenting my findings, I have isolated clusters from the co-hashtag graph in order to make legible the stories that they elicit. When refereeing specific posts, I chose not to include the names of individual Instagram users, with the exception of businesses. The few images I use to illustrate the main points of the analysis, have been edited to show only the silhouettes. On the practice of image editing that I follow in doing so, see Tiidenberg and Baym (2017) and Cesare and Branstad (2017).

Using hashtag campaigns to make #grief ambient

Parents create memorial websites for their stillborn babies. These websites feature portraits taken at the hospital, accounts of the birth, sonograms, and artworks. According to visual researcher Margaret Godel, materials such as these helps tell an imagined story “of the baby’s life, not from birth onwards, but from conception to birth which is also a death” (2008, p.263). Creating the website also helps parents integrate the birth into their social world and “work through grief and mourn” (Godel, 2008, p.260). This therapeutic function of memorial sites is important, considering that “there are few rites for those who have been born but never lived” outside of the womb (Godel, 2008, p.258).
Memorial websites support forms of reciprocal acknowledgment. According to Godel, memorial websites tend to link to each other and parents leave entries on each other’s guestbooks and ‘grant awards.’ These awards “are a form of recognition for the stillborn baby [and] take the form of virtual plaques” (Godel, 2008, p.264). Their presence increases “traffic to particular sites and perpetuates the spread of virtual networks of interest” (Godel, 2008, p.264).

Activity around stillbirth on Instagram resembles, to some extent, the web practices that Godel describes. Posting photographs and stories of the stillbirth integrates the event into a person’s (Instagram) biography. The content is visible to the person’s followers, who can leave comments expressing their sympathy. One could, like Godel, conduct a visual study of the images, placing them in lineage with practices of memorial photography.

My interest lies, however, with the hashtag practices emerging around stillbirth and grief. The first recurring practice is the use of hashtag campaigns to express grief. In these cases, the acknowledgment of grief is not voiced by hyperlinking or inscribed in guestbook entries. Instead, on Instagram, hashtag campaigns organize networks of related content and make grief, in Zappavigna’s terminology, “ambient.”

Hashtag campaigns are initiatives “usually meant to gain social media attention, to create engagement, or drive traffic for a specific topic, product or idea” ("The Importance of” 2019, para. 2). Social media users participate in them by including a pre-determined hashtag into their own content. For example, the Ice Bucket Challenge was a successful campaign for raising awareness about ALS. People poured cold water on themselves and shared the documentation online, using the hashtag ‘ice bucket challenge.’ By including the hashtag, they contributed to and affiliated themselves with the theme and values of the campaign.

Participation in such campaigns is, likewise, a matter of clicking on the hashtag and navigating through the content that other users have created and that also includes it. These practices lead Instagram users to develop an ambient awareness about the theme of the campaign and the participants – or, put differently, a peripheral knowledge about their environment and networks of likeminded people. While fragmented, this form of knowing can lead “to a coherent representation of social others” (Levordashka & Utz, 2016, p.1).

Scholars have employed the term ‘ambient’ in various media contexts. For example, the notion of ‘ambient journalism’ describes how “lightweight and always-on systems are enabling citizens to maintain a mental model of news and events around them” (Hermida, 2010, p.297). A sense of ambient awareness has also been observed in online debates about the pervasiveness of sexual abuse and the suffering of victims, among those following (and participating in) the #metoo
movement. In scenarios like the #metoo discussion, participation in hashtag campaigns can lead “an ambient audience to align with their bonds” (Zappavigna, 2011, p.801).

Ambient, I argue, is also an appropriate term to describe how Instagram users who have had a stillbirth share their grief and learn about the grief of others. The hashtag campaign ‘Capture Your Grief’ (in the cluster Rituals) neatly demonstrates why. This campaign, launched by blogger Carly Marie, encourages people to complete a list of daily grief-related challenges and to share the documentation using the hashtag ‘capture your grief’. One challenge is sharing a photo of yourself before the loss and then taking an ‘after loss self-portrait.’ On day fifteen of the campaign, people were invited to “light a candle at 7 pm to help create a continuous wave of light around the world for 24 hours” (Marie, 2016, para.18). According to Marie, the campaign “is a mindful healing project for anyone who is grieving the death of a baby or child of any age or gestation child” (2016, para.1).

Hashtag-enabled rituals such as these are not necessarily occurring at the same time or space. Nevertheless, because the posts include the same hashtags, Instagram aggregates them and allows users to discover and follow the content as it accumulates over time. For example, querying Instagram for the hashtag ‘capture your grief’ returns an (at the time that this book was written) ongoing series of images of homemade altars, pictures taken during the earlier months in the pregnancy, and crafts featuring the names of the diseased infant. Examples of these post can be seen in Figure 4.

![Figure 4: Capture your Grief 2017. Querying Instagram for the hashtag ‘capture your grief’ returns posts associated with the hashtag campaign. These posts include photographs of homemade altars, pictures women took during the earlier months in the pregnancy, and crafts featuring the names of diseased infant. Source: Instagram.](image)

Hashtag campaigns about stillbirth and grief acquire a more political tone in connection with issue days. For example, as can be seen in Figure 5, in the cluster
“Motherhood in Loss,” three sub-clusters, framed in blue, gravitate around the hashtag ‘pregnancy loss awareness.’ In these sub-clusters, one finds the hashtags ‘grieving mom’ and ‘October 15.’ October 15 is International Pregnancy and Infant Loss Remembrance Day. These issue days (and its corresponding hashtag) become an opportunity to make individual grief known and educate people about common missteps.

As said, people frequently offer support in ways that deny the importance of a bereaved parent’s loss and grief. About this problem, one Instagram user writes in a post: “to the women who mean well, to those who are trying to help the hurt […] may I ask in all sincerity and without any malice, please never say the phrase don’t worry you will get pregnant again.” This same person then explains that it is not possible to guarantee that someone will get pregnant again or that the next baby will be full term. Her post includes the hashtags ‘moms of angels,’ ‘one in four,’ ‘angel parents,’ ‘stillbirth,’ ‘miscarriage matters,’ ‘see you in heaven,’ and ‘October 15.’ Another woman, in a different post, debunks the equally hurtful assumption that living children automatically remove the grief derived from previous losses. Her post reads: “I find comfort in the babies I do have but I still grieve the ones I do not.” She includes the hashtags ‘one in four,’ ‘angel parents,’ ‘stillbirth,’ ‘miscarriage awareness,’ and ‘October 15.’

Figure 5: Motherhood in loss. In the graph three sub-clusters, framed in blue, gravitate around the hashtag ‘pregnancy loss awareness’, which has the largest number of edges. In the sub-clusters, there are hashtags such as ‘one in four,’ ‘angel parents,’ ‘miscarriage matters,’ and ‘October 15,’ which address parental subjectivity and contest the assumption that grief derived from stillbirth and pregnancy loss is inconsequential.
There are also in the cluster *Motherhood in Loss* hashtags that affirm parental subjectivity, that is, the right to call oneself a mother. Two of these hashtags are ‘angel babies’ and ‘motherhood.’ The iconography of angels is widespread in the discourse of perinatal loss. Indeed, it “is one of the most frequent responses to the realness problem of pregnancy loss and the question of how to visibly represent a lost child” (Keane, 2009, p.160). Close to these two hashtags, on the left-upper and right-lower corners of the graph (again, Figure 5), are hashtags such as ‘stillborn but still loved’, ‘still a mother’, ‘still birth still loved’, and ‘no more taboo.’ These hashtag campaigns help parents position themselves against the perceived notion that stillborn children do not matter and are not missed, thus making their grief known and affirmed. This is one of the cases in which hashtags are worn like a “coat of arms” (Yang, Sun, Zhang & Mei, 2012). Yang and her co-authors use this notion to describe how hashtags can work as “a unique indicator of both the topic of the content and the membership of a community” (Yang, Sun, Zhang & Mei, 2012, p.262).

The hashtags ‘Mother’s Day,’ ‘Mother's Day 2017,’ ‘International Bereaved Mother’s Day’ and ‘Bereaved Mother’s Day’ are also present in the cluster *Motherhood in Loss*, as well as in the clusters *Identity* and *Rituals.* While it might be too schematic to describe Mother’s Day and Bereaved Mother’s Day as program and anti-program, the activity occurring on those days does constitute an example of how women who grieve pregnancy loss and stillbirth use hashtags to reclaim visibility for their experiences.

For grieving women, posting and tagging content during Mother’s Day is a way to participate and reclaim the day. One Instagram user writes, for example, “Ah Mother’s Day. Such an awesome day right? Well, for some momma’s Mother’s Day isn’t a kind day.” She also describes how her daughter made her a "mom in the physical sense.” However, she has spent the past five years “dreading and wishing for that innocent day that is loved by so many to just be over.” Regardless of her feelings, she asks other people to please include in their celebrations women who are affected by miscarriage, stillbirth, and child loss. Her post includes the hashtags: ‘Mothers’ Day,’ ‘grief,’ ‘pregnancy after loss,’ and ‘rainbow baby.’

Other Instagram users echo this call for inclusion. One of these user writes, “happy Mother's Day to every kind of beautiful mother out there. Some of us don’t have our babies to hold in our arms, but we’re still mothers.” Similarly, another person explains: “I became a mother multiple times before I held a baby in my arms [...] I think about all my children all the time.” The posts include the hashtags ‘my babies,’ ‘stillbirth,’ ‘stillborn,’ ‘infant loss,’ ‘baby loss,’ ‘miscarriage,’ ‘multiple losses,’ ‘life goes on,’ ‘International Bereaved Mother’s Day,’ ‘may 7th,’ ‘Mother’s Day,’ and ‘pregnancy loss awareness’. This type of post often includes photos at grave-sites and Mother’s Day cards.
The content that I have so far referenced is posted on personal Instagram accounts and is visibly to the account owner’s followers and to the people following the hashtags. In addition to these personal accounts, one finds accounts which are dedicated to amplifying and aggregating individual messages and grief. The account @ihadamiscarriage is a case in point. This account is managed by a psychologist specializing in maternal mental health. She created the hashtag campaign ‘I had a miscarriage’ and has 37.1k followers. Another example is @Stillbornstillmatters, an account that works towards breaking taboos around stillbirth. Finally, @graysonproject_birthdaywishes is dedicated to celebrating ‘angel’ birthdays.

Loss as a #journey

The same person who has had stillbirth may have also had miscarriages. People undergoing fertility treatments will, likely, experience multiple events of pregnancy loss – stillbirth may happen more than once. Maintaining hope for a live birth is necessary, however; there are no guarantees. In the words of Pamela Meredith, expert on occupational therapy, “the consequences of previous perinatal loss may extend to a subsequent pregnancy. Women who become pregnant again may doubt their ability to maintain a successful pregnancy, and fear a reoccurrence of perinatal loss” (Meredith et. al., 2017, para. 9).

On Instagram, women speak about the reappearance of these events (e.g., miscarriage, stillbirth) and frame reproductive loss and birth, accordingly, as journeys. Some posts have images and captions in which the person explicitly discusses the recurrence of events and also includes hashtags that express the metaphor of the journey (e.g., the hashtag ‘infertility journey’). In other occasions, neither the caption or image are explicit about the person’s multiple losses. It is only because they include, in the same post, numerous hashtags that reference the different events — a sort of running list—that a sense of journeying is communicated. In these cases, hashtags function as “both metadata and metadiscourse” (Zappavigna, 2018, p.2). Below, I illustrate these journey-making hashtag practices.

The meeting of events such as stillbirth, miscarriage, and infertility (and the need to speak about them together) is perceptible in the cluster Pregnancy Loss and Hope. As can be seen in Figure 6, two journeys come together, each forming a sub-cluster. In the first sub-cluster (red inset) the hashtag ‘pregnancy loss journey’ cooccurs with ‘surviving stillbirth,’ ‘miscarriage,’ and ‘medically terminated.’ The second journey (blue inset) is about infertility and trying to conceive. Hashtags in this sub-cluster include ‘infertility journey,’ ‘infertility,’ ‘IVF warriors,’ ‘IVF journey,’ ‘TTC journey,’ and ‘infertility sucks.’ The abbreviation IVF stands for in vitro fertilization, the medical procedure whereby an egg is fertilized by sperm.
outside the body. TTC stands for ‘trying to conceive.’ Pregnancy loss journeys and infertility journeys are connected by the hashtag ‘hope.’

In one of the posts that belongs to this cluster, a woman writes about her recent stillbirth, which is one of the many losses she has experienced. In the post, we see her holding the hand of her baby, who was stillborn. The caption reads: “I honestly never thought I would have to do an update like this again. But here I am.” She includes the hashtags ‘stillborn still loved,’ ‘stillbirth,’ ‘pregnancy loss,’ ‘supposed to be our rainbow baby,’ ‘sorrow,’ and ‘second stillbirth.’

Figure 7 is another example of a person highlighting the recurrence of loss and journeys and using hashtags to support this information. The post is a meme with the text “don’t be ashamed of your story. It will inspire others.” The caption states: “Your struggle and your journey make you who you are. Never be afraid to share it. You never know when someone is experiencing something similar. Your story could give them hope and inspire them.” It includes the hashtags ‘pregnancy journey,’ ‘infertility journey,’ ‘infant loss,’ ‘stillbirth,’ and ‘miscarriage.’ Here it is worth noting that without these hashtags, the connection and meaning of the meme in relation to pregnancy loss and its stigma could not be inferred.
Figure 7: Meme encouraging women to speak up. A meme includes the caption: “Your struggle and your journey make you who you are. Never be afraid to share it. You never know when someone is experiencing something similar. Your story could give them hope and inspire.” To make the connection of the message explicit to pregnancy loss the meme includes the hashtags ‘pregnancy journey,’ ‘infertility journey,’ ‘infant loss,’ ‘stillbirth,’ and ‘miscarriage.’

In another cluster, Motherhood After Loss, two other events come together, forming a different journey: pregnancy loss and (potential) rainbow babies. The cluster, as seen in Figure 8, unites hashtags for speaking about ‘typical’ pregnancies with hashtags specific to pregnancy loss. Typical hashtags include, for example, ‘pregnancy journey,’ ‘second trimester,’ and ‘third trimester.’ These hashtags “guide viewing through the temporality of pregnancy […] which invites searches from people interested in this particular content (presumably other pregnant women)” (Tiidenberg, 2015, p.1752). Alongside these ‘typical’ hashtags are the hashtags ‘pregnancy after loss,’ ‘parenting after loss,’ ‘rainbow baby,’ ‘stillbirth,’ and ‘always be someone missing’.

As part of Motherhood After Loss, one finds a posted photograph that follows the visual conventions of a typical pregnancy selfie, the woman poses in front of a mirror with a hand placed on the stomach. The author of this post writes, “I have my check and scan at the obstetrician […] This time I actually don’t feel nervous (yet) […] everyone expects me to get scared […] when I reach the point in the pregnancy where [he] died.” The author is referencing her previous stillbirth and reflects on how the experience frames her pregnancy as well as how other perceive it (e.g., the expectation of fear). The post also includes the hashtags ‘pregnancy loss journey,’ ‘pregnancy,’ and ‘pregnancy after loss.’
In the cluster *Motherhood After Loss* one also finds hashtags that thicken and modify the narrative that the photos tell us. The post below, Figure 9, is another pregnancy selfie. The caption reads, “36 weeks. Seven days left. We can do this.” The author includes the hashtags ‘pregnancy after loss,’ ‘rainbow baby,’ ‘stillbirth,’ ‘child loss,’ ‘stillborn,’ ‘infertility,’ ‘baby girl,’ and ‘born still but still born.’ The presence of these hashtags adds context and alters the meaning of the image significantly. They lead one to infer — a conclusion that is confirmed by reading additional posts by the same author — that she has experienced a stillbirth and is, now, expecting her rainbow baby. In the same post, the hashtag ‘born still but still born’ also tells us that the previous pregnancy mattered. In these cases, hashtags such as ‘infertility,’ ‘stillbirth,’ and ‘born still but still born’ do not merely reiterate information that can also be found elsewhere in the accounts: they offer and “aid,” in Zappavigna’s words, “pragmatic inference” (Zappavigna, 2018, 44-45). In the context of stillbirth, love is not automatically inferred but, rather, needs to be re-affirmed. These are cases where hashtags more explicitly become storytelling devices.

**Figure 8: Motherhood After Loss.** The cluster Motherhood After Loss brings together hashtags typical to communication of pregnancy on Instagram (e.g., ‘third trimester) with hashtags about loss such as rainbow baby. The term and hashtag ‘rainbow baby’ refer to a baby expected and/or born following a previous loss.
As the examples which I have offered in this section illustrate, Instagram is a space to discuss and share personal histories about overlapping journeys and anxieties. In the posts I described earlier, the tropes of the ‘journey’ and a shared sisterhood resonate in the hashtags. However, the same concepts of the journey and sisterhood – and this is a crucial point – are not always present in the captions or in the images. The diversity of hashtags helps storytellers share complex identities that acknowledge loss as recurrent and render themselves visible to women in different, yet related, circumstances.

Reaching bereaved #mothers through promotional hashtags

In the introduction of this chapter I discussed online commercial practices around pregnancy. These included mommy influencers prompting products and brands and services targeting pregnant women. A promotional post of this kind, typically, uses hashtags that are unique to a brand (e.g., the name of the brand) along with other more generic baby-related terms. An example: to promote baby clothing, a brand will make a hashtag from its own name and include it alongside hashtags such as ‘mom life’ or ‘pregnant.’ We also witness commercial hashtag usage among Instagram users who share the products that they buy with their networks. For instance, a mom-to-be might post about the outfits she just bought and tag the brand. Tiidenberg and Byam (2017) relate this type of activity to the discourse of consumerist pregnancy. Their conclusions suggest that doing pregnancy well involves buying the right products. Ergo, a “caring mother must be a well-informed and discerning consumer, shopping for the safest pram [and] the most natural food” (Keane, 2009, p.155).
The third and last practice I discuss involves charities and brands using loss-related hashtags to target bereaved mothers. Indeed, throughout the ‘stillbirth’ network, and especially in clusters Arts and Charity and Inspiration we also find posts created by brands, makers, and organizations. These actors address bereaved mothers as consumers and use the (now familiar) loss-related hashtags, but for promotional ends. Real Woman Real Journey (RWRJ) is a good example. This network of female professionals is committed to women’s wellness. RWRJ uses Instagram to promote their events. In one of their posts, they thank their guest speaker and author Alexis Marie Chute. Her book Expecting Sunshine (2017) “chronicles the anticipation and anxiety of expecting a baby while still grieving for the child that came before” (Chute, 2019). The post reads: “Get your copy of Expecting Sunshine!”. It includes the hashtags ‘expecting sunshine,’ ‘art heals,’ ‘PTSD recovery,’ ‘rainbow baby,’ ‘angel baby,’ ‘pregnancy loss,’ and ‘stillborn’. A woman searching for content related about stillbirth using any of these hashtags might, by default, encounter also Chute’s book.

The RWRJ post is no isolated case. The clothing brand Loved by Hannah And Eli offers a mama bear t-shirt. In a promotional post, see figure 10, they say: “Tomorrow at 7 am PST is the next release of the #rainbowmamabear items!!!” The post includes the hashtags: ‘loved by Hannah And Eli,’ ‘mama bear shirt,’ ‘bereaved mother,’ ‘miscarriage awareness,’ ‘rainbow mom,’ ‘infertility,’ and ‘bereavement gift.’

Figure 10: Mama bear T-shirt. The brand Loved by Hannah And Eli uses hashtags related to pregnancy loss to market its ‘mama bear’ T-shirt.

Similar hashtag strategies are used by crafters who sell specialized keepsakes, such as jewellery, drawings, and dolls. The artist behind the account @athreadrunstrruit, for instance, “creates memorial gifts & keepsake dolls to remember special people & occasions.” She uses Instagram to promote an angel baby figurine (Figure 11). The caption under the image reads: “Sweet sleeping angel. I just love how all the colors.” Hashtags include ‘baby loss,’ ‘pregnancy
loss,’ ‘infant loss,’ ‘miscarriage awareness,’ ‘miscarriage,’ ‘stillbirth,’ ‘life after loss,’ ‘grieving mother,’ and ‘my baby has swings.’

In addition to craft makers, doulas and grief counsellors also use hashtags to reach grieving mothers. Themed hashtags circulate, finally, in posts by organizations that help women cope with loss. An example is Madison’s Closet Shop, an online clothing platform that aims “comforting and clothing our sisters in perinatal loss.” After having a stillbirth, the creator could not bear to wear her maternity clothes. She felt unable to shop for herself. “It wasn’t because I couldn’t afford to buy a few things to wear,” she clarifies. “It was because I couldn’t face clothing a body that I hated, a body I felt failed me” (“Madison’s Closet Shop”, 2019). The clothing platform runs on donations so that women can “order clothing free of charge from the comfort and safety of their homes” (“Madison’s Closet Shop”, 2019). A post from them typically includes the hashtag ‘Madison’s closet’ together with pregnancy loss terms and recruiting hashtags such as ‘volunteers.’

The examples that I have discuss in this section reinforce that there is an online consumer culture around pregnancy loss and motherhood in loss. Brands, makers, and charities are creating a network of objects that lend materiality to the often invisible experiences of stillbirth and pregnancy loss. The existence of these products appears to be received well by the members of in this pregnancy loss communities. What heightens their appeal is that a great deal of the entrepreneurial initiatives were created by women who themselves experienced stillbirth and similar experiences. These commercial enterprises also become a way to reach out to others.

Will, just like pregnancy itself, grieving well also become a matter of buying the right things? The possibility of an online consumerist culture around pregnancy-related loss is worth exploring in further detail. So are the potential dangers of such a culture. There is a risk, of course, that targeting grieving communities
might be exploitative at the hands of unlicensed healers, or damaging, given its inevitable share of misinformation.

Tagged bodies, wounded healers, and lifespans

In this chapter, I discussed how women use Instagram to post and tag content about their experiences with stillbirth and other forms of pregnancy loss. Tagging is a pervasive activity on social media. Tags function as metadata that supports the classification of online content, navigation, and the creation of folksonomies. Tagging also supports meaning-making, bonding, and the articulation of networked publics. The practice of tagging has, in fact, become a way for social media users to express themselves and engage in politics.

Tagging (and all that it affords) is not secondary but central to contemporary online illness storytelling. The stories of tagged bodies, which is the concept I put forward, are stories about illness in which tagging is key both for how the story is told and to accomplish the goals aimed for by storytelling. In these illness stories tags work as metadata with affordances and semiotic technology that helps make meaning.

An investigation of stillbirth on Instagram, as well as of other illness stories, must therefore understand and account for tagging. To study the stories of tagged bodies, I have put forward co-hashtag network analysis, which combines the analysis of the topography of a network with the close reading of content and hashtags.

The results of my analysis I organized as three hashtag practices. The first is the participation of bereaved parents in hashtag campaigns that make grief ‘ambient,’ to speak with Zappavigna concept (2018). Through these campaigns, individual expressions of grief and memorialization – on Mother’s Day, for example – are aggregated and rendered visible to other users in the platform. The second practice involves using hashtags to create meaning and speak about loss and (in)fertility as a journey. The concepts of quests and journeys is important in illness narrative and specially release in the context of pregnancy loss. While the social expectation is that the grief derived from experiences such as miscarriages be overcome quickly or quietly (Brierley-Jones et al., 2015), on Instagram, women discuss present and past events together, creating a form of narrative coherence. Furthermore, Instagram connects bereaved parents with charities, brands, and makers who target them as consumers. These entrepreneurs – this is the third practice that I discern – employ promotional tagging to become visible and align with existing loss publics.

I see these posting and tagging activities as enabling the circulation of a coded-language and practices that make visible stillbirth and pregnancy loss and reframe
them as meaningful storytelling practices rather than isolated instances. Tagging also supports goals of raising awareness, breaking taboos, and reaching out to others in similar consequences. In light of these findings, I see an opportunity to update and expand the concept of wounded healing.

As I mentioned earlier, Arthur Frank (2013) employs the term ‘wounded healing’ to describe how people who are severely and chronically ill find goals beyond cure and meaning outside established frameworks; and how, in doing so, they embrace active roles in their communities. Personal storytelling is a vital tool for wounded healing. In fact, wounded healing is, for Frank, the work of “communicative bodies,” who share intimate details about themselves with the aim “to touch others and perhaps to make a difference in the unfolding of their stories” (2013, p.127). These narratives are not the stories of people whose suffering has ended. Instead, they are stories about finding meaning under hardship. By telling these stories people aim to convey to others the possibility that a meaningful life is possible and frame their suffering as a relevant, even against social conventions. As Frank as phrased storytelling is tool when “society is suppressing a truth about suffering, and that truth must be told” (Frank, 2013, p.121). Ultimately, “as wounded people, they may be cared for, but as storytellers, they care for others” (Frank, 2013, p. xx).

In developing his concept of ‘wounded healing,’ Frank built on literature written by patients. By applying the concept to social media activity around stillbirth, I also offer an investigation of wounded healing and communicative bodies as medium-specific and of social media affordances as conducive to wounded-healing practices. In other words, I argue that by tagging their stories and, thus, making themselves searchable and networked on social media, bereaved women work towards breaking silences and taboos around stillbirth, creating networks, and helping others. In doing so, they conduct a slightly different type of wounded healing than that outlined in Frank’s research. On social media, Frank’s ‘communicative body’ becomes a tagged body, and wounded healing is socio-technical and platform-specific.

Approaching tagging practices through the case study of stillbirth and Frank’s ideas about illness storytelling has enabled me to see familiar devices –hashtags – from a new perspective. Hashtagging also prompted me to inquire into how wounded healing may occur online and with digitally native practices, thus updating the question: what do illness stories do? The stories of tagged bodies challenge, at least to some extent, the discourse of frivolity and of passivity that surrounds tagging. As Zappavigna puts is, “hashtags have been subject to criticism and offered as evidence of the narcissistic self-involvement of digital practices” (Zappavigna, 2018 p. 5). I agree with Zappavigna that this critical-only reading of hashtagging is reductionist. In the context of stillbirth, to make oneself searchable
and aggregatable acquires an ethical dimension of responsibility and risk-taking, which is described as valuable by those involved.

This ethics of responsibility and risk is, perhaps, best felt during moments in which the interests of different social media users come into conflict. Some stillbirth storytellers have gone ‘viral’ and found themselves the object of online scrutiny. An example: The Daily Mail wrote about Morgan, who went ‘viral’ after sharing “a series of heartbreaking photos on Facebook that show her and her husband ... cradling [their daughter] who died in utero at 40 weeks” (James, 2015, para. 2.). While reporters sympathized with Morgan, her social media posting was flagged by other users because of its alleged offensiveness. Emily and Richard Staley also shared a photoshoot with their stillborn baby. The Huffington Post asked Emily about her motivations for speaking up and risking pushback. Staley said “that she hopes her photography can help break down the silence surrounding stillbirths” (Bologna, 2014, para. 1). Similarly, Jackson shared images of her stillborn baby on Instagram. She argued: “my baby had every right to be shown off by his mother just like a baby who was living” (Ritschel 2018, para. 1). While it is suggested that the fathers were also involved in posting, the women who used their personal accounts to do so become the subject of critique.

The presence of stories like this on social media will continue to reinvigorate discussion about the sequestration of experiences of illness and death – mediated lifespans-- of which stillbirth is but one example. As we speak, users are performing an active platform politics around birth, grief, and death. What aspects and stages of life are appropriate for mediation? Leaver and Highfield (2020), for example, work to redeem funeral selfies, which have caused their own share of scandals in the media. However, the funeral selfie, academic studies find rather than a frivolous act, is a form of self-mediation that has become part of new rituals to deal with death. A live birth and happy childhood (with the exclusion, perhaps, of excessive ‘sharenting’) rank as uncontested food for social media. Stillbirth and motherhood loss appear to be less uncontroversial. Just as Leaver and Highfield argue for funeral selfies, so I hope that this chapter has made a case for the value of social media communication about stillbirth and pregnancy loss.