Talking about decisions: The facilitating effect of a celebrity health announcement on the communication of online personal experiences around decision-making

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Abstract

This study examines how posters on an online forum discussed their own current and past decision-making in response to a celebrity health announcement. We examined messages in response to a celebrity narrative, and extracted those explicitly related to decision-making around genetic testing and preventative surgery. Using deductive coding we identified different types of decision-making narratives, and with inductive coding we examined how users discussed decision-making activities. Guided by the literature on narrative content types in decision-making, and on celebrity health narratives, we found that the celebrity decision

announcement facilitated social sharing in relation to two key decision-making activities. First, identifying with the celebrity allowed people to reflect and compare their own personal health circumstances. This empowered readers to appraise and select options about their current decision-making regarding preventative surgery. Second, the announcement allowed an extension of the discussion beyond the celebrity, and acted as a catalyst encouraging other people to share their own previous decision-making experiences. These experiences contained a mix of narratives content types, and provided an opportunity for posters to evaluate their decisions, and to contribute to a repository of decision-making examples for others. Health narratives act as communication devices in decision-making, and we discuss the findings in relation to the extension of the educational and persuasive function of celebrity health narratives.

Celebrity health problems draw attention to illnesses, raise awareness and motivate the public to take action (Borzekowski, Guan, Smith, Erby, & Roter, 2013; Lerner, 2006). News coverage surrounding the death of a celebrity from cancer, for example, often serves as a health campaign in itself. It raises awareness of the disease, and encourages social sharing of relevant information (Myrick, 2017). The publicity generated by celebrity announcements of a cancer diagnosis can also lead to huge increases in media coverage of the particular health condition. Increased information searching by the public and changes in behaviour are also noted. The publicity following Kylie Minogue's diagnosis of breast cancer saw mammography screening bookings rise 40% in the 2 weeks following the announcement (Chapman, McLeod, Wakefield, & Holding, 2005). This phenomenon, dubbed the 'Kylie effect', and similar effects have been reported in relation to other celebrities. The diagnosis, and subsequent death from cervical cancer, of celebrity Jade Goody led to an increase in

internet search patterns related to cervical cancer. A modest increase in screening was observed around Jade Goody's death (Metcalfe, Price, & Powell, 2010), and 40% of women, in particular younger women, thought Goody's story had influenced their decisions about cervical screening (Marlow, Sangha, Patnick, & Waller, 2012).

More recently, Angelina Jolie's announcement of her double mastectomy after testing positive for the faulty BRCA1 gene led to a relatively short-lived but intense period of increased online information seeking about breast cancer, genetic testing, and procedures for treatment (Lebo, Quehenberger, Kamolz, & Lumenta, 2015; Sabel, & Cin, 2016; Noar, Althouse, Ayers, Francis, & Ribisl, 2014; Dean, 2016). Data from the UK suggests a similarly short-lived behavioural effect with referrals to family history clinics and genetics services showing a 2.5-fold increase in June and July 2013 (Evans et al., 2014).

Celebrity health narratives

Celebrity health narratives in the public sphere perform a number of key functions including education, inspiration, and activism (Beck, Aubuchon, McKenna, Ruhl, & Simmons, 2014). Celebrities may recognise the potential in publically revealing their health status or treatment decisions in relation to reducing stigma, promoting early detection or diagnosis or simply encouraging more informed debate and discussion. There is a rich literature on celebrity health narratives (see for example the extensive work by Beck, Chapman, Simmons, Tenzek, & Ruhl, 2015). This work theorizes about the processes that make celebrity narratives so powerful. One important concept is that of identification - the amount of overlap between one person's experience and another's. Identification and personal relevance are important predictors of public responses to celebrity narratives. Those who identify with a celebrity or perceive their health status as more personally relevant are more likely to share news about a celebrity's health narrative (Myrick, 2017; Basil & Brown, 1994).

Investigating the effects of celebrity narratives on the social sharing practices of individuals in particular has relied on a number of different methodologies in the past including survey and interview. However, as celebrities and non-celebrities begin to occupy shared online spaces it becomes possible to witness the functioning of celebrity health narratives in naturalistic interactional spaces. Observing online posts in this context allows us to understand more about the "disclosure of personal health narratives enacted in public forums beyond interactions about celebrity health" (Beck et al., 2014, p252). Of particular interest here is the question of how people who strongly identify with the celebrity and/or those facing the same health issue react to the celebrity narrative in order to reflect upon and disclose details of their own experiences. We can start to see how personal health narratives are provoked and shaped by the original celebrity narrative, and how these personal narratives can be seen as an extension of the education and persuasive function of celebrity narratives. We know that reading about others' experiences, not just celebrities', has the ability to influence how people feel about their own health conditions, their understanding of the condition, and their subsequent behavioural choices (Ziebland & Wyke, 2012). Thus, celebrity health narratives around decision-making are particularly pertinent and worthy of studying in further detail.

Narratives and decision-making

Narratives vary in their content and effect on decision-making. Shaffer and Zikmund-Fisher (2013) provide a taxonomy of patient narratives based on their purpose, the content of the message and the evaluative valence. Within the taxonomy, they developed a framework for the narrative content that identifies the process, experience, and outcome elements. This PEO framework is useful when developing and analysing narratives, and has been applied to 'experimental' narratives, i.e. those used within hypothetical decision-making tasks. Shaffer and colleagues have shown how different elements of personal narratives affect decision-

making. Fictional narratives that convey the *outcome* of health decisions may affect or bias treatment choices (Shaffer & Zikmund-Fisher, 2013), while those containing information about the *process* of decision-making may encourage further information seeking (Shaffer, Hulsey, & Zikmund-Fisher, 2013). In natural settings such as online support forums, people are exposed to a wide range of experiences and decision-making accounts (Sillence & Mo, 2014). Overall, we know that these personal narratives can be useful to people across a number of decision-making activities including selecting options, and evaluating and living with decisions already made (Entwistle, et al., 2011). However, relatively little is known about the composition of these natural narratives other than they are likely to contain a mixture of process, experience and outcomes information (Sillence, 2016).

The current study context and rationale

Angelina Jolie's original announcement of her decision to have preventative surgery first appeared in an editorial opinion piece to a USA based newspaper, both in print and online. The announcement, presented as a personal narrative, set out the circumstances leading up to the decision, an account of the decision-making *process*, the *experience* of the treatment, and initial *outcomes*. Within the online site, readers could post their own comments below, and these discussion posts form the basis of this paper. These health narratives are shared within a naturalistic setting, and so provide an opportunity to focus directly on the voices of online posters. This allows us to go beyond survey data to examine how readers respond to celebrity narratives as part of their own sense making around their health decision.

We aim to examine how celebrity health narratives encourage the disclosure of personal health narratives that begin to extend beyond interactions about celebrity health per se. In doing so, we take a very specific example of decision-making to explore in depth how the celebrity narrative generates the sharing of decision narratives among non-celebrities. The

decision to have preventative surgery following genetic testing is relatively uncommon at least in relation to mastectomy following a cancer diagnosis. Stigma and a lack of awareness around the surgery persists making it more difficult for people to discuss their current and past decision-making in this context. The celebrity announcement thus provides a unique opportunity to understand more about personal health narratives around this decision.

Overall approach

In this study, we focus on two key decision-making stages as identified by Entwistle and Watt (2006); namely current decision-making: Appraising options and making a selection; and past decision-making: Evaluating decisions made. Previous research has indicated that personal experiences may support both of these stages (Entwistle et al., 2011, Sillence & Bussey, 2017). We then apply the PEO narratives framework (Shaffer & Zikmund-Fisher, 2013) to the decision-making activities. This allows us to examine posters' own decision-making messages, and to reflect on their own past decision-making around preventative surgery. To our knowledge, this is the first use of this framework in relation to naturally occurring decision narratives within this health context. In summary, this paper aims to examine how posters on an online forum discussed their own decision to have preventative surgery in response to a celebrity health announcement. Specifically the paper aimed to answer the following questions:

1. How do people draw on the celebrity narrative in relation to their own current decision to undergo preventative surgery?

2. What narrative content types are present in messages reporting on past decisions to undergo preventative surgery, and how do they relate to the celebrity context?

Method

The data for this study consists of the readers' comments posted online in response to Angelina Jolie's original announcement of her treatment decision in the New York Times.

We wanted to examine how this first-hand account, published on its original platform, generated discussion around decision-making. As outlined above, we focussed our attention on two key stages of decision-making: Current decision-making and past decision-making. Below, we outline the method for examining these two different stages.

The process for identifying the message sample was as follows: 1) We collected all 1712 comments posted on the site and then read and re-read for meaning. 2) Comments that referenced genetic testing and preventative surgery, as a result of this testing, were identified for analysis. 3) Those comments were split into messages referencing i) current decision-making and ii) past decision-making.

Current decision-making (appraising options and making a selection)

Thirty-three messages fell under this category. Only messages that explicitly reported current, ongoing decisions regarding preventative surgery following genetic testing were included in this sample. For example, "*I too, tested positive. Now, at nearly 32 years old and the mother to 3 young boys, I am faced with the decision to remove my breasts to decrease my chances.*" We examined these inductively, and developed codes to capture the ways in which posters described the role of the celebrity disclosure on their current decision-making.

Past decision-making (evaluating decisions made)

The original data set was re-examined, and we identified 69 messages that contained a report of the poster having made the decision to have preventative surgery following genetic testing in the past. For example, *"I made this same tough decision 13 yrs ago and have had no regrets!"* To explore these messages further we used a hybrid approach. This incorporated both data-driven inductive and the theory-driven deductive approach of data analysis. First, we analysed messages deductively based on the process, experience, outcome framework (Shaffer & Zikmund-Fisher, 2013). We coded messages that contained explanations of the

process by which people had arrived at their decisions as *process* content; we coded messages containing detail of the procedures or side effects as *experience* content, and messages that detailed an evaluation of the decision as *outcome* content. Using an inductive approach, we then identified themes in each of the content categories to provide more detail about the nature of these content types. Due to the anonymous nature of the site, demographic data were not available except those spontaneously offered by message senders.

Results

Current decision-making: Appraising options and making a selection

The first part of the data analysis focused on those messages that reported a current decision concerning preventative surgery following genetic testing. Of these 33 messages, 29 were posted by people facing the decision themselves, and 4 related to a family member or close friend facing the decision. In response to the first research question, the examination of these messages led to the identification of eight separate ways in which the celebrity announcement had played a role in current decision-making: Empowerment, helping to tell the story, increased insight, remind or prompt to contact doctor, confirmation, reduced fear, unspecified thanks and increased information (see Table 1 for examples).

<insert Table 1>

Across all eight categories, we saw readers discuss the importance of the celebrity announcement explicitly with people naming Angelina directly or in some cases addressing their comments directly to her *"Your straight forward account."* In the remainder of this section we discuss how the celebrity announcement assisted with current decision-making in relation to the three most common categories in Table 1 (empowerment, helping to tell the story, and increased insight), and provide illustrative examples.

In some cases, e.g. [60], posters acknowledged explicitly the importance of the announcement in strengthening their resolve, providing support, and *'empowering'* them to make the decision.

> *While waiting to leave for my doctors appointment this morning the news about Angelina came across the television. My husband said it was a "sign". I too have the Braca gene and have been faced with the decision to have a preventative bilateral mastectomy, today was my appointment with the plastic surgeon!! Angelina's news gave me the courage I needed to make the decision final and proceed with setting up the surgery. [60]*

In this post, we see the timing of the announcement coincide with the poster's 'decision day' regarding surgery. For some, the celebrity narrative was evoked with immediate effect, for others it was to be used in the near future e.g. taking *'Ms. Jolie's letter into their next doctor's appointment'*. In other posts, the announcement was a useful way of bringing up the discussion of their current decision-making with friends and family – it provided a way of *'telling the story'* of their decision-making. Bringing the topic into the open and associating it with a popular, well-known face provides people with a reference point with which to frame their discussions. Being able to refer to the celebrity announcement made discussions of their decision more accessible, less threatening for others. As [99] explains, she hopes the celebrity announcement will raise awareness of the procedure and normalise it to some extent.

> *When people hear about me doing something, they may be more like, "Oh yeah, I have heard about people doing that before" as opposed to, "That's crazy talk." [99].*

Finally, hearing a first-hand account of the experience had given some posters an increased '*level of insight'* into the process, allowing them to see what making the decision

would actually entail. This reinforces the importance of experiential detail as being a key feature of personal accounts. The fact that the personal account in this case belongs to a celebrity, and as such is far more accessible via media coverage, is a point acknowledged in post [9]:

> *Your straight forward account has provided me with both insight and information that I doubt I would have encountered elsewhere, and that in and of itself is pretty powerful. [9]*

Past decision-making: Evaluating decisions made

Overall, 69 people posted to the online space indicating they had made the same decision in the past (prophylactic surgery following genetic testing). In all but three of these 69 posts, the author provided details of their personal experience regarding that decision-making process. Of these, 5 were stories about someone else e.g. wife or sister-in-law. We carried out a deductive coding analysis, and coded the narratives according to the content types they contained. This indicated that of the 66 messages containing personal narratives, 52 included 'process' content in their accounts i.e. information about why they made the decision, 20 contained experiential content i.e. what it was actually like, and 38 contained outcome content i.e. a value judgement regarding the decision. Here, in an echo of the celebrity announcement itself, we see an emphasis on process content i.e. people describing how and why they made the decision to have prophylactic surgery following genetic testing. These different types of content often appeared in combination, for example, there were 17 cases of process and outcome content, 13 cases of process, experience and outcome content, and 4 cases of process and experience content.

Inductive analysis

We undertook an inductive analysis of the process, experience, and outcome (PEO) content of the messages.

Process content

Looking at the process content, (see Table 2) we see that there were five types of process content identified: Family history, personal risk, to see children/family for longer, to reduce fear, and to spare children and family.

<div align="center">**<insert Table 2>**</div>

The posts below illustrate the three most common types of process content, family history, personal risk, and to see children/family for longer. Many posters referenced their family history as part of their decision-making. Narratives included details of close family members who had been diagnosed with, or who had died as a result, of breast cancer. "*I too, have a BRCA1 mutation and watched my mother die of breast cancer at 42.*" Other references included family timeline information, and family members undergoing genetic testing. Posters also reflected on the choices available to them in comparison to previous generations.

Often posters described their personal risk of developing breast cancer following genetic testing. In some messages, posters indicated that they had the same 'chances' as Angelina, in others, posters were more detailed about their personal risk. Given the genetic component involved, personal risk and family history were often both cited as part of the decision-making process.

> *Thank you, Angelina Jolie, for writing this op ed piece. I too am BRCA1+ and I had my permanent implant surgery this past Friday (following a double mastectomy) ....Yes, I did rely on statistics to make my decision; a 50-80% chance of breast cancer and 44% chance of ovarian cancer, before age 70, did not sound good to me. I also relied on the knowledge that I never knew my grandmother, who died at age 52 of breast cancer when I was one. And my aunt, my mother's youngest sister, who had breast cancer twice and beat it [47]*

Another main reason cited as part of the decision-making process was the importance of living as long as possible for the sake of dependents. This focus on the future was a key concern for mothers with young children in particular.

I applaud you on your decision. It was an easy choice for me.... I also chose life, to be able to see my children grow up and be a part of their children's lives. I am also BRCA positive and had both of my surgeries before I turned 37. [43]

Many of the posts captured the ways in which narratives often incorporate multiple explanations or rationales for decision-making. Narratives often coupled personal statistical risk figures with references to fear, emotion or loss.

Outcome content

Table 2 highlights five categories relating to a value judgement on the surgery. In four of the categories, the tone of the outcome was positive, 'lack of regret', 'right choice', 'peace of mind', 'would do it again'. There was just one category, 'regret' that indicated a negative outcome or evaluation. Where outcomes were positive, the two most common types of outcome content were 'no regrets' and 'the right decision'. Many people indicated they had no regrets about the decision to have surgery.

I was afraid that after doing it I might regret it. But, as it happened, neither my husband nor I have ever felt even one moment of regret [83].

Positive outcome messages were also careful to acknowledge that the decision remains a very individual experience, while emphasising the belief that making the decision was the right thing for them.

Obviously this choice is not for everybody, but it was right for me and 7 years later I am still 100% sure that I made the right decision. [70]

The messages were often tempered by discussion of the fear preceding the surgery or the challenges of recovery but concluded with a positive message indicating that on balance the decision was right and would be repeated if necessary (e.g. [37]).

Unfortunately they did not try to save the nipple and I am left looking a mess at 47 years old. Having said this, I'd still do it again so as not to orphan my 3 kids [37]

There were very few negative evaluations of the outcome. Where this was the case, ongoing pain and changing life circumstances played a key part in the evaluation.

Experience content

Most experience posts offered very little detail of the actual procedure, little or no medical information or terminology. Instead, they focused predominantly on the challenge posed by the surgery and the recovery period, and the time involved in both instances (see Table 2 for examples). In terms of 'challenge', the difficult nature of the surgery and the recovery was the most commonly referred to form of experience content. While a few messages used words such as 'painful', the majority avoided these kinds of descriptions and focussed instead on euphemisms, for example, the procedure is 'no walk in the park' or the recovery was 'no picnic' or was 'a bit challenging'. The lack of medical detail mirrors the original celebrity narrative that provided only limited details of the surgery itself, and fewer still of the recovery process.

People responding with their own messages were more explicit about the 'time' involved especially in terms of recovery. Narratives referred to the recovery process as 'long'

'slow' and 'tedious'. On one occasion, [68], a narrative combined the two themes, 'time' and 'challenge' in a more explicit way, but again avoided any medical detail.

"It was not an easy surgery and the recovery was painful and slow". [68]

Discussion

This study has demonstrated the ways in which people react to a celebrity health narrative in relation to their own decision-making around preventative surgery. All of the personal accounts displayed allow us to capture a more realistic view of the 'message' that people are can encounter in addition to the celebrity narrative. Focusing on the actual voices of the posters highlights how such narratives facilitate everyday disclosures of decision-making in online public spaces. Examining exposure to this celebrity + everyday narrative format is novel and highlights a number of important findings with respect to current and past decisions.

First, the results showed that people did draw on the celebrity narrative in relation to their own current decision to undergo preventative surgery. This occurred in a number of ways, but key among them was the issue of empowerment. For those currently facing the decision to undertake preventative surgery, reading about a celebrity's decision empowered people to make decisions (van Uden-Kraan, et al., 2008), and to discuss their decision-making processes with others (Ziebland & Wyke, 2012). For some, this sense of empowerment was affective in nature, and based on a strong sense of identification with Angelina and her health experiences. Being about to tell the story of the decision-making process, bringing up the topic, and discussing the details were all made easier when framed in the context of the celebrity announcement. The celebrity narrative also conferred some practical benefits for those currently faced with the decision. It provided a first-hand account of the treatment and recovery process itself, resonating with the educational function of

celebrity health narratives (Beck et al., 2014). Interestingly, the everyday comments contained relatively little medical detail but conveyed an evaluation of the challenge posed by the surgery and recovery period. We also saw that for some people, the celebrity announcement acted as a reminder or prompt to contact the doctor. While not the most common way in which the celebrity narrative influences current decision-making, it is still worthy of note given that it encourages patient-doctor encounters.

Second, we saw the disclosure of personal health narratives that extended beyond direct interactions about celebrity health to reflect on past decisions regarding preventative surgery. Here, the focus was on individuals sharing their own experiences and detailing their own decision-making narratives. Examining the narrative content types within these naturally occurring messages indicated a strong focus on *process* content within the narratives, i.e. messages explaining how and why readers had made their decisions. This emphasis on process suggests that this kind of resource would encourage further information searching around the topic (see Shaffer et al., 2013).

The literature on experimental narratives suggests that *outcome* content has the potential to bias treatment decisions (Shaffer & Zikmund-Fisher, 2013). We did see an overwhelming positive set of outcome messages, with few messages detailing a negative outcome from the surgery. It may be that the very positive celebrity narrative may have facilitated reflection of the decision as positive rather than negative. We know that people are often conditioned to react in a positive way to celebrity advice (Hoffman et al., 2017), and that celebrity health announcements often lead to an upsurge in enquiries about treatments (Sabel & Cin, 2016). In relation to the more 'realistic' view of the 'message' that people may encounter in addition to the celebrity narrative, it is important, however, to note that we rarely saw outcomes mentioned in isolation. Typically, messages contain outcomes alongside process and/or experience content as well. Although messages were positive in terms of their

outcome, the evaluations of the decision were often closely coupled to the reason(s) for undertaking the surgery in the first place. In this sense, the motivation provides some kind of justification for the evaluation of the outcome. In natural settings such as this, the combination of different types of content in posts gives a more rounded picture of the decision-making process.

While the celebrity story had led people to recount their own narrative within the online space, we were also mindful that the celebrity account increased posters' willingness and ability to share their narrative with friends and family offline. The decision to undertake preventative surgery does not represent a single event. It is life changing with lasting effects. Ongoing reflection and communication about these kinds of decisions may be important for some people, and we know that learning to tell the story of your health condition is one way in which other people's experiences affect readers' lives (Ziebland & Wyke, 2012). Future frameworks for analysing decision-making around life changing health issues may want to consider extending the notion of the 'evaluation phase' to encompass a larger timeframe, and to acknowledge the idea that decision-making should be seen as being distributed over time, across contexts and stakeholders (Rapley, 2008).

Finally, in the online data itself, we saw the development of a repository of decision-making experiences initiated by the celebrity disclosure but extending beyond celebrity to everyday people as well. This idea that celebrities and non-celebrities can thus co-author educational messages about preventative surgery and genetic is interesting (see also Beck et al., 2014), and extends the educational and sometimes persuasive function of celebrity health narratives. The resulting resource offered readers the chance to encounter a range of decision-making stories complete with information about why people had made their choices, the experience of the subsequent treatment and an assessment of the outcome. In this way, these discussions begin to mirror the exchanges common within online communities and start to act

as a collective resource for people faced with such health decisions. Online support groups are a particularly useful resource for people experiencing less common health issues or stigmatised conditions. Preventative surgery following genetic testing is less common than surgery following a cancer diagnosis, and it may be that celebrity health announcements provide an opportunity to have those conversations. Involvement in online support groups is often based around a current issue or information need (Coulson, 2013), but celebrity health narratives may provide an access point for people wishing to engage with ongoing social support around the longer term issues that often accompany such health decisions.

Narratives can help individuals connect with health messages (Dunlop, Wakefield, & Kashima, 2010), and particularly so for people experiencing the same health issue themselves (Sillence, Hardy, Harris, & Briggs 2014). If we think of these narratives as functioning as health communication devices around decision-making, we see that readers can encounter personal experiences from a very variable set of individual posters. However, there remains a strong focus on a systematic approach to decision-making with posters often citing family history or personal risk statistics as being important. In this respect our findings add to the small but growing body of work examining online decision-making accounts (Sillence & Mo, 2014), and go some way to allay concerns regarding the quality of peer-based information available online (Steginga et al., 2007). Going forward, we need to consider how such narratives might be incorporated within patient resources or online moderated discussions with healthcare professionals, and to consider how best to signpost such resources to individuals.

This study is an important first step in identifying the 'message' that people encounter when reading celebrity + everyday narratives. It also provides an indication of the ways in which 'talk about decisions' is taking place both online and offline. Future research should focus on the *impact* of these celebrity + everyday narratives. We know that peer narratives

alone are impactful upon decision-making (Sillence & Bussey, 2017; van Uden-Kraan, et al., 2008). Future qualitative work examining the impact and value of the celebrity + everyday format would be a useful next step.

In summary, to the best of our knowledge, this is the first study to examine naturally occurring decision-making narratives combined with a celebrity narrative in this health context. In this online space, we can see more clearly how people react to a celebrity health narrative around decision-making. While some people may not have read all the article or the subsequent comments, for those who did the corpus of 'personal accounts' below the article provides a more realistic view of the 'message' receivers are encountering in addition to the celebrity narrative. Applying the PEO framework to these narratives is also novel. This approach revealed that readers are encountering a predominantly positive, yet process heavy set of personal accounts suggesting that the accounts may be a useful resource for prompting further information searching. We also saw that the celebrity narrative increased the ability to discuss decision-making offline with friends and family. Taken together, exposure to this celebrity + everyday narrative content suggests readers are viewing a rich set of accounts that has the potential to act as both a persuasive and supportive health communication device.

Acknowledgements

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