
Terry Pratchett, Alzheimer's, and the Role of the Author

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Abstract

Terry Pratchett is one of the most prolific genre writers of the last century, but over the last decade of his career he gained renown for publicising Alzheimer's UK and the assisted dying campaign. This article aims to evaluate his wide impact and how it affected the remainder of his publishing career. It brings ideas from theories of authorship and of celebrity authors, discussing Pratchett's career, the changing paratext around his books, and examines his social activism and the response to it.

KeyWords

Terry Pratchett; Discworld; Alzheimer's Disease; Authorship; Marketing; Celebrity authors,

Introduction

"The world changes, but slowly." (Pratchett, 2011). Thus ends the final piece in *A Slip of the Keyboard*, Pratchett's collected essays and non-fiction, with his article from the *Independent* about the response to his documentary on Dignitas. Pratchett initially became well known for his Discworld series; a fantasy series that ultimately consisted of 41 books, about a flat world that travelled through space on the back of a giant turtle.

His writing was characterised by a sharp satire, casting a mirror on the quirks and injustices of our own bizarre reality. Between December 2007 and his death in March 2015, Terry Pratchett morphed from being an acclaimed and prolific fantasy writer to a public figurehead, championing both Alzheimer's patients and the assisted dying campaign in the public eye. During this time, he was criticised for this by religious groups, as well as by those who thought that it was not the place of a fantasy author to broach such topics. It is worth noting early on that he also received an incredible amount of support about his decision to speak up about his illness, and the injustices and stigmas surrounding it. As Pratchett eloquently puts it in an article from 2008, "It's a fact, well enshrined in folklore, that if we are to kill the demon then first we have to say its name."

This article will take a critical look at the changes that occurred after Pratchett announced his illness, both to his career as an author and as a consequence of his public campaigning to increase awareness on issues that made him "furious" (Gaiman, 2014). The article will then aim to evaluate whether authors have a social responsibility to openly discuss topics not related directly to the subjects of their writings, and to apply theory of both authorship and marketing to the way Pratchett publicly navigated the last eight years of his life whilst continuing to be an esteemed and decorated writer.

The Role of the Author

One of the most interesting and multi-faceted topics under the vast umbrella of publishing studies is that of the author. What is their role, where do they fit, and what value do they add (or take away from) their text? Roland Barthes' esteemed essay "The Death of the

Author" (1967) argues that the author's intentions cease to have relevance once the text is available to the public, and to try and link any meaning of a text back to its author is limiting. "A text's unity lies not in its origin but in its destination" he explains, giving the autonomy of understanding to the reader and disregarding the contexts and cultures that would have influenced the original text. This concept is expanded on and made significantly more complex in "What is an Author?" (Foucault, 1980). Foucault assumes Barthes' conclusion of the death of the author as an inevitability and looks deeper into the social functions of the author, without coming to any meaningful conclusions. In "Star Authors", Moran (2000) summarises their arguments thus:

Both Barthes and Foucault, then, are criticizing not so much the common-sense notion that individual authors write texts, but the kinds of mystical associations which cluster around them in capitalist societies, naturalizing them as the only authoritative source of textual meaning and as a locus of power and authority within a culture. (Moran 2000)

Moran's book goes on to discuss the role of celebrity within culture, applying those theories to authors and examining the ways that a celebrity culture changes the way a book is marketed and read. Towards the end of the book, he concludes that "literary celebrity [...] works as much through the sphere of textual representation as it does through the material processes of cultural production and consumption." In practice, this means that the famous author has as much say over how the work is perceived and presented as the work itself has alone.

Terry Pratchett was undoubtedly a "literary celebrity" by the late 1990s. Having started publishing in 1971 with *The Carpet People*, the more prolific era of his career began in 1983 with the publication of the first Discworld book, *The Colour of Magic*. By 1987 he had become a full-time author and was writing and publishing two or three books a year. Smythe (2011) says in his online biography of Pratchett's career that:

As far as Britain is concerned Terry was the 1990s' best-selling living fiction author (but this was before the Potter phenomenon). His sales now run at well over three million books a year. In 2001, it was reported that during the first 300 weeks' existence of the British Booktrack's (now called Bookscan) weekly bestselling chart, over 60 titles had continuously been in the top 5,000 bestselling titles, and the author with the most titles in this listing was Terry with twelve novels.'

Smythe also notes that in 1997, *Reaper Man* became Britain's "eighth fastest-selling novel for the previous five years: a remarkable achievement for any book at that time, let alone a so-called 'genre' novel." According to the ITV's website, Pratchett was the UK's highest earning author in 1996, and "at one point he held the dubious honour as the most shop-lifted author in Britain". He was awarded an OBE for services to literature in 1998, and was later knighted in 2008 after beginning his campaign for Alzheimer's awareness and donating £700,000 to research. The *Independent* praised him and how suitable his knighthood was, saying, "In a period of personal adversity, Mr Pratchett has shown genuine courage. The knighthood of this modest man is an example of what our honours system should be about - and the best reason of all not to scrap it."

Having published 41 Discworld books, numerous standalone novels, and co-authored approximately another 50 books (Smythe, 2011) by the time of his death, Pratchett was undoubtedly prolific, and no doubt had had much influence over many more people than he could have possibly imagined. Moran's theories that the celebrity author influencing the way their work is perceived does ring true with Pratchett's influence around it, and his theory that we live in a "meet-the-author" culture may be why Pratchett was able to have as wide a reach as he did. In an article for *The Author* in 1993, Pratchett had this to say about the aspect of celebrity author culture that encouraged people to write to him asking for signed photographs:

This beats me. I mean who cares what an author looks like? You finish a book, perhaps the gripping narrative has left white-hot images snugly mindfitting into the

brain – and then you turn to the back flap and there's this short bald guy with a pipe...

His amicable, approachable style in articles such as these, as well as his fantastic ability to present the everyman in his novels is undoubtedly what qualified him to be a spokesperson for Alzheimer's awareness later in his life. Recalled by someone who met him at a convention as a 'jolly old elf' (Gaiman, 2014), it is unsurprising that he became somewhat of a national treasure.

Changes in Paratext

The paratext surrounding Pratchett's books did, unsurprisingly, change throughout his career, but kept a consistent brand throughout. Considering the paratext as "what enables a text to become a book and to be offered as such to its readers, and, more generally, to the public" (Genette, 1997), the fonts, language, images, and vivid colours found on Pratchett's book jackets easily establish them as part of a series and as genre books. The distinctive cartoon style of the books denotes the offbeat tone of the narrative within, and, as many well-branded books do, continues to prove that whilst you cannot judge the quality of a book from its cover, it is often designed so you have a good idea about what you are going to get.

Take, for example, the two different covers for *Equal Rites*, the first published in 2012 and the second in 1987. The books themselves are of notably different sizes, with the older edition being much smaller, with smaller font and thinner paper, whereas the newer edition is the same size as a standard modern paperback with a larger font. In the example above, the artwork remains thematically similar with the newer one slightly sparser in content, which is consistent throughout updated artwork in Pratchett's books.

The artwork and the thin, serif all-caps font maintains a brand identity, but in the newer covers, Pratchett's name is larger than the title of the book. By 2012, he was more than established as a brand in his own right, and his name was more likely to sell a book than the title itself. They are both easily identifiable as fantasy books (the wizard on the right is a bit

of a giveaway), and as Gardiner (2000) says, “the publisher insists that it is the book’s *circulation* that must be represented – its destination – the market it is to find by analogy with books of the same genre, the futurity of its appeal.” The artwork and font immediately make it obvious that these are Pratchett titles, or, to the uninitiated, titles that are recognisable as fantasy.

The epitext surrounding the books changed massively throughout his career. The blurbs are very different from the earlier novels to the later. In the earlier editions, the blurb appears in a box only slightly larger than the box the title is in and is two sentences long, with an extra sentence explaining its part of the Discworld series. In the later edition, the blurb is significantly longer and features pull review quotes from authors such as A. S. Byatt

The epitext that is most relevant to this article, however, is the author biography inside the book. In the early editions of the Discworld books, the biography can be found taking up half a page opposite the half-title, with a three-paragraph biography of Pratchett’s career, written in a typically comedic style. The 1993 edition of *Equal Rites* biography begins, “Terry Pratchett was born in 1948 and is still not dead. He started work as a journalist one day in 1965 and saw his first corpse three hours later, work experience *meaning* something those days.” The biography is then followed by a bibliography. Comparatively, looking at an edition of *Thud!* published after his death in 2015, the author biography appears on the inside of the front cover and features a full colour picture of Pratchett that takes up the top half of the page.

Terry Pratchett was the acclaimed creator of the global bestselling Discworld series, the first of which, *The Colour of Magic*, was published in 1983. His fortieth Discworld novel, *Raising Steam*, was published in 2013. His books have been widely adapted for stage and screen, and he was the winner of multiple prizes, including the Carnegie Medal, as well as being awarded a knighthood for services to literature. He died in March 2015.

As previously established, Pratchett became a mainstream public figure for being a campaigner for Alzheimer's awareness and assisted dying, and it is quite telling that his publishers made the decision to not mention this at all in the epitext for his novel. There are two probable reasons as to why this decision was made: a) to separate Terry the Campaigner from Pratchett the Writer, or b) to avoid negative connotations by people who may be put off buying books from someone who actively advocated for assisted dying. This ties into a lot of Barthes' ideas about the necessary divorcing of the author from the text and, from the publishers' perspective, would be an intentional effort to allow the text to stand on its own. However, if this is the case then it does create a subtextual discourse between minimising Pratchett's social influence whilst using his name as a brand to market the book, as mentioned before.

Social Impact

As an author, I've always tended to be known only to a circle of people – quite a large one, I must admit – who read books. I was not prepared for what happened after I 'came out' about having Alzheimer's in December 2007, and appeared on television. (Pratchett, 2009)

(Image from the *Guardian*, 2014)

It has, for a long while, been impossible to visit the science fiction and fantasy section of a bookshop and not escape the wall of Pratchett books before you. As already discussed, his books were successful and widely popular, and anyone aware of that aspect of culture from the 1990s onwards would find it hard to avoid his commercial influence. According to the Reading Agency (2014), 64 percent of UK adults read for pleasure, whereas the Department for Culture, Media and Sports 2013/14 free time survey estimates that number as closer to 69 percent, with 91 percent of UK adults spend their free time watching TV – a significantly higher number, meaning a significantly wider audience.

Pratchett discusses this transition from fantasy author to a TV persona in great length, through the form of op-eds and interviews and essays. Several of these are presented

together in the last third of *A Slip of the Keyboard* (2014a), his non-fiction collection. He describes the increase in the amount of people contacting him and sharing their stories and fears, or stopping him on the street thanking him for what he was doing.

One of the things Pratchett often returned to when discussing his condition was how it impacted his writing. "For me, living with posterior cortical atrophy began when I noticed the precision of my touch-typing getting progressively worse and my spelling starting to slip. For an author, what could be worse?" (*The Guardian*, 2014b) This is a typical example of how he would link his illness back to his career – to the thing that he was initially renowned for. A lot of the awareness he raised was directed at encouraging people to discuss their fears and reducing the stigma around dementia.

In his now infamous speech at the Richard Dimbleby Lecture (2010), he discussed the change in attitudes towards cancer in the last 50 years. Recounting how, in 1965 when he was beginning his career as a journalist, cancer was referred to as "a long illness", and when Richard Dimbleby's family referred to it by name after his death, "the war on cancer began in earnest". It is commonly believed that Pratchett being so open about his Alzheimer's has had the same social impact on the disease.

More tangibly, Pratchett himself donated the equivalent of \$1,000,000 to Alzheimer's UK after learning that Alzheimer's research funding receives 3 percent of what cancer research receives (Alzheimer's Research Trust, 2008). This money was used to create an international research group to further understand what causes Alzheimer's disease, what can be used to cure symptoms, and, ultimately, what can cure it. A combination of the advances in research that were facilitated by his donation, and the political effects of both his forcing Alzheimer's into the public's social consciousness as well as an increase in focused research mean that the G8 "promised to aim to develop a treatment or cure by 2025" (Serpell, 2015).

Pratchett, here, is using his success as an author, both in terms of cultural and economic capital, as a form of self-publicity but for some form of greater good. Moran (2000) states that although "the activity of writing may be bound up in varying degrees with the

machinery of celebrity, it is still a more powerful tool than many other cultural workers possess". Though many authors who gain fame are criticised for using it to discuss social issues – take, for example, Twitter users who sent J. K. Rowling abuse for her anti-Trump political tweeting by calling her a “woman whose entire career is based on stories” (Markovinovic, 2017) – there seems to be a different reaction when an author uses their fame to better the world, such as Pratchett is doing here. This is possibly because of the perceived courage it takes to be so vocal about something so terrible, frightening, and personal.

Much of the online reactions to his knighthood for services to the realm, mentioned earlier, is proud in tone and mentions the fact that he was disappointed that becoming a knight did not involve being given a sword, so he decided to make his own from iron ore he found on Salisbury Plain (Pratchett, 2010).

There was, however, a small yet vocal backlash against his campaigning for assisted dying – as is often the case, an angry minority can easily make their views disproportionately loud when their size is considered. Much of this backlash was offered after the documentary *Terry Pratchett: Choosing to Die*, where Pratchett follows two men to the Dignitas Clinic in Switzerland, was aired on BBC2 on 13th June 2011. Criticisms of the documentary were typically from religious groups, attempting to preserve the sanctity of life.

Anti-euthanasia campaigners have condemned the program saying it portrayed an idealized picture of assisted suicide, and was not an honest and balanced depiction. Critics have warned that the program could lead to people wanting to follow in Smedley's footsteps without knowing the full picture (Blake, 2011).

Much of the criticisms of Pratchett's ventures into TV documentaries, and the individuals most likely to criticize his place to make such statements, came from groups such as Care Not Killing. If anything this only created free publicity for Pratchett, both as a social activist and a novelist. That sort of press is, from a publishing perspective, a double-edged sword. There's no doubt that Pratchett's newfound celebrity, his being famous for being a person

with Alzheimer's, increased interest in his books and his sales because of this. However, from an ethical perspective, no publisher would want to be seen as profiting off the back of something so upsetting that had happened to any of their authors, and, perhaps, this is why, as mentioned earlier, there is no mention of Pratchett's social influence or illness in the newer versions of his books.

Reading Pratchett's essays in *A Slip of the Keyboard* (2014a), it presents a picture of a man who does not want to die, but who wants to enjoy every lucid day he has. Someone who feels compelled to ensure that once the time comes and he feels he is nothing more than a drain of resources and emotion, the law will allow him to make his own decision on what action to take. As for the BBC2 documentary, "there had been 1,219 complaints to the BBC and 301 calls in favour, making it one of the top ten programmes this year for appreciation."

Conclusion

Towards the end of his career, Pratchett's writing style was changing. "The rapid back-and-forth dialogue of earlier books has been replaced, in very recent ones, with chunks of exposition, almost soliloquies" Tom Chivers summarises in a 2015 article for the *Times*. In the same article, Pratchett acknowledges the absence of his character Death in his later novels, too, stating he doesn't want to be viewed as a "death fetishist". As unsurprising as it is that his style changed as his thought processes did, what is more noteworthy is that he did keep writing during the illness, and produced books that continued to be bestsellers. Nielsen Bookscan shows that, as of March 2017, the final Discworld book *The Shephard's Crown* was worth over £2,000,000, a staggering feat for any author.

It is a sad irony that Pratchett will posthumously be remembered for the controversy surrounding his campaigning for assisted dying. Maybe in upcoming decades, as legislation changes and social views shift, he will be heralded as someone as influential as Richard Dimbleby was in 1965 in changing social attitudes towards cancer. That much remains to be seen. Pratchett himself never seemed to have any doubt that, to him, speaking about what was happening with his illness was a thing he felt compelled to do. From his essays, articles,

and talks, it never seemed like he was a man intending to force onto a bigger stage than the one he already possessed. He presented himself as a man who felt the duty to tell his fans his truth, and consequently, managed to leave this world having had a more tangible impact on the wider social consciousness than anyone could have imagined a decade before.

References

Alzheimer's Research Trust. 2008. "Terry Pratchett pledges \$1 million to Alzheimer's Research Trust". 13 March. Accessed 19 March 2017.

<https://web.archive.org/web/20080415210729/http://www.alzheimers-research.org.uk/news/article.php?type=News&archive=0&id=205>

Barthes, Roland. 1967. *The Death of the Author*. Accessed 15 March 2017.

<http://artsites.ucsc.edu/faculty/Gustafson/FILM%20162.W10/readings/barthes.death.pdf>

Blake, Daniel. 2011. "Terry Pratchett Pro-Euthanasia Documentary Blasted for Death Show". *Christian Post*, 14 June. Accessed 19 March 2017.

<http://www.christianpost.com/news/terry-pratchett-pro-euthanasia-documentary-blasted-for-death-show-51149/#BHeJhakSrXVPU1Xm.99>

Chivers, Tom. 2015. "Terry Pratchett interview: a fantasy writer facing reality." *The Times*, 27 August. <http://www.telegraph.co.uk/culture/books/authorinterviews/10396286/Terry-Pratchett-interview-a-fantasy-writer-facing-reality.html>

Darnton, Roger. 2002. "What is the History of Books?" In *The Book History Reader* edited by A. McCleery and D. Finkelstein, p. 9-26. London: Routledge.

Department for Culture, Media, and Sport. 2015. "Taking Part 2013/14, Focus On:

Free time activities”.

Foucault, Michel. 1980. “What is an Author?” In *Textual Strategies: Perspectives in PostStructuralist Criticism* by Josue V. Harari, p. 141-60. London: Methuen & Co.

Gaiman, Neil. 2014. “Foreword by Neil Gaiman”. Foreword for *A Slip of the Keyboard*. London: Doubleday.

Gardiner, Juliet. 2000. “Recuperating the Author: Consuming Fictions of the 1990s”. *Bibliographical Society of America, Papers*, 94:2 p. 255-274.

Genette, Gerard. 1997. *Paratexts: Thresholds of Interpretation*. Cambridge: Cambridge University Press.

ITV News. 2015. “Terry Pratchett Sold More Than 70 Million Books”. ITV News Website. 12 March. Accessed 19 March 2017. <http://www.itv.com/news/2015-03-12/terry-pratchett-sold-more-than-70-million-books/>

Markovinovic, Monika. 2017. “JK Rowling Destroys Twitter Trolls Who Burned Her Harry Potter Books”. *The Huffington Post*, 2 February. Accessed 19 March 2017. http://www.huffingtonpost.ca/2017/02/02/jk-rowling-twitter_n_14573480.html

Moran, Joe. 2000. *Star Authors*. London: Pluto Press.

Pratchett, Terry. 2014a. *A Slip of the Keyboard*. London: Doubleday.

Pratchett, Terry. 2014b. “Terry Pratchett: Those of use with dementia need a little help from our friends”. *The Guardian*, 13 May. Accessed 19 March 2017.

<http://www.telegraph.co.uk/culture/books/authorinterviews/10396286/Terry-Pratchett-interview-a-fantasy-writer-facing-reality.html>.

Pratchett, Terry. 2011. "A Week in the Death of Terry Pratchett". *The Independent*, 18 June.

Pratchett, Terry. 2010. "The Richard Dimbleby Lecture: Shaking Hands with Death". BBC1, 1 February.

Pratchett, Terry. 2009. "Point Me to Heaven When the Final Chapter Comes". *Mail on Sunday*, 2 August.

Pratchett, Terry. 1987. *Equal Rights*. London: Corgi Books.

Reading Agency. 2014. "Reading facts". Reading Agency. Accessed 19 March 2017. <https://readingagency.org.uk/about/impact/002-reading-facts-1/#fn8>.

Serpell, Louise. 2015. "Terry Pratchett gave us a million dollars for Alzheimer's research – here's what we did with it." *The Conversation*, 17 March. Accessed 19 March 2017.

Smythe, Colin. 2011. "Terry Pratchett: A Biography by Colin Smythe". *L-Space.com*. Accessed 19 March 2017. <https://www.lspace.org/about-terry/biography.html>