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Populist discourse on a British social media patient-support community: The case of the Charlie Gard support campaign on Facebook

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ABSTRACT

This article analyses discourse on a new and ongoing online patient-support community to demonstrate how it performed populism. It demonstrates how the more than sixty thousand strong social media ‘Army’ formed around a terminally ill baby at the centre of a parent-judiciary-hospital legal battle, used key tropes and devices of populist rhetoric to establish lay-expertise in its performance of support for the ordinary patient and their family, de-recognizing and vilifying medical expertise and publicly funded healthcare systems built on socio-democratic ideals. The article shows how users’ mobilization of populist rhetoric to reject professional expertise and public institutions, made use of established architectural features of the online community’s socio-technological design, such as immediacy, remediation and protective gatekeeping. The paper argues that this fed into and out of an environment of disdain for public services and expertise in contemporary UK.

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1. Introduction

This article draws from an ethnographically motivated non-participant observation of an ongoing and very young online patient support community in the UK, to present an analysis of its discursive practices. It demonstrates how it performs populism (c.f. Canovan, 1982, 1999; McRae, 1969), and both draws upon and contributes to a climate of opinion fuelled by what has recently been described as media populism (Krämer, 2014). Using the theoretical lens of populism and climate of opinion, it demonstrates how the more than sixty thousand strong social media ‘army’ (61,337 members at the time of writing this paper) formed around a terminally ill baby at the centre of a parent-judiciary-hospital legal battle in Britain in 2017, uses key tropes and devices of populist rhetoric to establish lay-expertise in its performance of support for the ordinary patient and their family, de-recognising and vilifying medical expertise and publicly funded healthcare systems built on socio-democratic ideals. The article also demonstrates how ordinary users’ mobilization of populist rhetoric to reject both professional expertise and public institutions, make use of established architectural features of the online community’s socio-technological design (c.f. Escobar et al., 1994; Ley, 2007), such as immediacy, remediation and protective gatekeeping. Populism has, till now, been used largely for the study of politics and medi-

ated political communication (c.f. Meyer, 2006; Hameleers & Schmuck, 2017). By drawing upon this body of work to inform the analysis of a patient-support community (see also Loader et al. 2002; Preece, 2010; Armstrong et al., 2011 on online patient communities), this paper also discusses the public implications of these findings, calling for considerations of the impact of digitally mediated populist ideologies, campaigns and rhetoric on public perceptions and expectations of healthcare systems and professionals.

The patient support group in question is called Charlie’s Army – the official, family-created Facebook support page for a terminally ill baby who was born in the UK in summer 2016 and was in the care of the UK’s leading Great Ormond Street Hospital for children (henceforth GOSH). Charlie had an extremely rare genetic condition called encephalomyopathic mitochondrial DNA depletion syndrome (MDDS) and was left with severe brain damage and an absolute inability to perform any normal physiological functions including breathing on his own or crying. Doctors at GOSH declared it in his best interests to turn off his life support (see The Guardian, 2017 for an overview of the case). His parents claimed it in his best interests to take him abroad for an experimental treatment for which they have crowdfunded vast amounts of money but for which there is very scant and dubitable evidence. A legal battle ensued between the parents and the hospital over the child’s ‘best interests’, and the parents lost their case three times to argue for experimental treatment for the baby, at the British High Court, the Supreme Court and the European Courts, who all agreed

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with medical teams that Charlie's life support needed to be switched off to prevent any further suffering for him. The Pope, President of the USA, a Republican Senator from the USA and a controversial pro-life faith preacher also from the USA became involved in arguing for extending treatment for Charlie, with a Facebook group called 'Charlie's Army' (maintained by the Gard family) organising a variety of demonstrations, protests and sale of merchandise across the UK and other countries like Spain and Italy. The 'Charlie's Army' Facebook page opened up in spring 2017. Membership of the group and activity within the group increased manifold in the months of June and July 2017 as the legal battle between the parents and GOSH (the hospital Charlie is at) progressed. At the time of analysis in early July 2017, there were 61,337 members, 10,150 posts, 3454 authors, 12,893 commentators, and 31,183 reactors. The group seamlessly connected with on and offline media, and its actions spilled across the online and the offline. In the short period since its inception, the group has seen approximately 3500 photos, 610 videos, 436 links, 5500 new statuses and the organization of 84 events. These numbers continued to grow as this paper was written. While the membership and administration of the group is predominantly British, and the moderators include the Gard family members, occasional contributions can be found from other countries, especially those where public figures have spoken out in support of Charlie's continues medical treatment, such as the USA and Italy. Since Charlie Gard's death, the group has continued to survive, but primarily as a memorial site which is, first, continuing to fundraise, and second, continuing to witness digitally produced artefacts of outpouring of anger, sorrow, love and other similar strong emotions, from posters. The primary purpose of fund-raising, having already raised a huge amount of money, is no longer relevant, but the fundraising attempts continue on the group. At the time of concluding this paper, the group is arranging the sale of Charlie Gard themed Christmas baubles, to 'raise money for Charlie's Foundation' (see Fig. 1).

The legal, medical or ethical decisions involved in this complex case are outside this paper's remit, as are the causes or potentially far-reaching consequences of the discourses analysed in this paper. Rather, this paper focuses on the nature of discourse and the rhetorical strategies employed by a 61,337 strong online patient-support community, analysing the production and maintenance of populist rhetoric by using the architectural features of social media. Online patient-support communities have been at the centre of attention over the past decades in fields as diverse as medicine and communication studies, showing rich findings on the supportive and empowering aspects of their rhetoric (van Uden-Kraan et al., 2009; Bartlett & Coulson, 2011), the role of well-informed participants in renegotiating relationships between expert knowledge and lay experience (Loader et al., 2002), these

communities' impact on patients' health and social outcomes (Eysenbach et al., 2004), patterns of sociability, usability (Preece, 2010), identity and authority (Armstrong et al., 2011) and the often smooth interfaces between face-to-face and online support (c.f. Turner et al., 2001). The community in question has a specific role that is different from most support communities, in that it is formed and maintained as a campaign, in support of a single patient who is unable to speak for themselves and who is constantly produced as a nearly mythical figure – with a range of affective frameworks ascribed to him, and used of when manufacturing artefacts which aim to speak on his behalf. Contributing to, but offering a different focal point to this body of literature above, this paper analyses discursive practices in this online community in the context of a steady rise of populist ideology and rhetoric in the UK and other Western countries, and draws attention to the complexities of the unfolding relationships between public institutions and private individuals in a digitally mediated age.

This paper is organised into four major sections. The first constructs a triangular conceptual framework bringing together theorisations of populist rhetoric and media populism, the relationship between populism and theorisations of the climate of opinion in the context of remediated communication, and theorisations of the material, architectural features of networked communities. The second section presents an account of the methodology pursued in this paper. The third presents findings in three analytical strands, each mobilising different aspects of the framework proposed. The final section discusses the implications of these findings, in the context of a range of interlinking fields in communication studies and suggests areas for future research.

But equally, I note here, that the group and its dynamics are fascinating, from a social scientific perspective, and many potential inroads into analysing it are possible. How, for instance, is a very specific image of motherhood and the mother figure produced and maintained here, through the use of strongly affective frameworks? How do group members seek to conform, and self-represent themselves? How does dissent and silence operate here? Where, given the nature and purpose of this group, and the discourse it produces, does the group sit within communication studies' longstanding interests in activism and what Marichal (2013) has recently called micro-activism? Surely, the lens of populism is one of many possible inroads into what has opened up as a complex site of inquiry, and as such, this paper offers one of many possible insights into the site.

2. The mediated architectures of populism

In what follows I bring together three strands of theory to produce a fruitful intersection which is mobilized later to present findings. The first strands draws from the theorizing of populism,

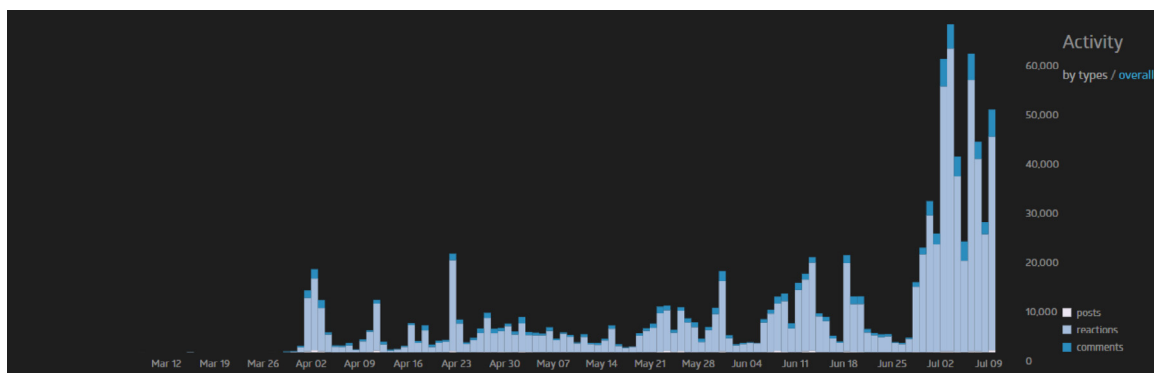


Fig. 1. The sudden rise in activity (posts, reactions and comments) in Charlie's Army.

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