



Caring for care: Online feedback in the context of public healthcare services

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ARTICLE INFO

Keywords:

UK
NHS
Digital technologies
Care
Online feedback
Qualitative interviews

ABSTRACT

People increasingly provide feedback about healthcare services online. These practices have been lauded for enhancing patient power, choice and control, encouraging greater transparency and accountability, and contributing to healthcare service improvement. Online feedback has also been critiqued for being unrepresentative, spreading inaccurate information, undermining care relations, and jeopardising professional autonomy. Through a thematic analysis of 37 qualitative interviews, this paper explores the relationship between online feedback and care improvement as articulated by healthcare service users (patients and family members) who provided feedback across different online platforms and social media in the UK.

Online feedback was framed by interviewees as, ideally, a public and, in many cases, anonymous 'conversation' between service users and healthcare providers. These 'conversations' were thought of not merely as having the potential to bring about tangible improvements to healthcare, but as *in themselves* constituting an improvement in care. Vital to this was the premise that providing feedback was an *enactment of care* – care for other patients, certainly, but also care for healthcare as such and even for healthcare professionals. Ultimately, feedback was understood as an enactment of care for the National Health Service (NHS), as symbolically encompassing all of the above.

Putting these findings in dialogue with STS scholarship on care, we argue that, in this context, the provision of online feedback can be understood as a *form of care* that is, simultaneously, both *directed at* healthcare (in the round, including patients, professionals, services, organisations, and, of course, health itself) and *part of* healthcare. We conceptualise this as 'caring for care'. This conceptualization moves beyond dominant framings of online feedback in terms of 'choice' and 'voice'. It embeds online feedback within pre-existing healthcare systems, relations and moral commitments, foregrounds the mutuality of care relations, and draws attention to the affective labour of feedback practices.

1. Introduction

Over the past decade, the number of people who go online to rate, review and provide feedback about their healthcare experiences has been slowly and steadily growing (Gao et al., 2012; Greaves and Millett, 2012; Van Velthoven et al., 2018). This trend has been met with considerable concern from healthcare professionals, with fears expressed about accuracy and representativeness, as well as implications for care relations and professional (in particular medical) autonomy (McCartney, 2009; Patel et al., 2015; Samora et al., 2016; Menon, 2017; Atherton et al., 2019). At the same time, online feedback promises to enhance patient power, choice and control, encourage greater transparency and accountability, and contribute to healthcare service

improvement in a cost effective manner (Greaves et al., 2012; van de Belt et al., 2015; Browne and Shaller, 2018).

Survey research indicates that 42 % of UK internet users (n = 1824) have read some form of healthcare-related feedback online, while only 8 % have provided feedback about their own experiences (Van Velthoven et al., 2018). This pattern is consistent with health-related social media use, where the number of people reading about healthcare experiences far outstrips those providing it (Mierlo, 2014). Thus, the feedback practices of a relatively small group has the potential to affect a much wider pool of patients, their family members and healthcare professionals.

A key concern expressed by healthcare professionals, especially doctors, is that online feedback is produced by an unrepresentative

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<https://doi.org/10.1016/j.socscimed.2021.114280>

Received 14 July 2019; Received in revised form 7 July 2021; Accepted 27 July 2021

Available online 29 July 2021

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minority expressing extreme views and, as such, is of limited value for healthcare improvement (Atherton et al., 2019; Patel et al., 2015). However, rather than being dominated by disgruntled service users and complaints, much online healthcare-related feedback is positive (Kadry et al., 2011; Lagu et al., 2013; Emmert et al., 2014, 2015; Greaves et al., 2012; Menon, 2017; Liu et al., 2018; Powell et al., 2019). This tendency has remained consistent over time, across national healthcare systems, different medical specialists and feedback platforms (Boylan et al., 2019).

Despite their central importance to the online feedback landscape, little is known about how those providing feedback in different healthcare contexts understand their own practices (Boylan et al., 2019). Drawing on 37 qualitative interviews with people who read ($n = 37$) and/or wrote ($n = 32$) online feedback about their own or a family member's experiences of the National Health Service (NHS) in England ($n = 34$) and Scotland ($n = 3$), this paper analyses experiences of and motivations for providing online feedback. It focuses on how people who posted online feedback across different platforms in the UK understood the relationship between online feedback and care improvement.

The paper foregrounds four aspects of the relationship between online feedback and care improvement as articulated by interviewees. One, understandings of how online feedback might improve healthcare were premised on pre-existing embodied, emotive and, at times ambivalent, relationships with the NHS. Two, healthcare professionals and services were positioned as both subjects and beneficiaries of online feedback. Three, a major motivation for providing feedback was to improve care for other patients and their families, with whom interviewees felt a strong identification and communality. Fourth, interviewees wanted online feedback to, ideally, take the form of a two-way 'conversation' between service users and healthcare providers. Across all four, the public and anonymous nature of online feedback were foregrounded as crucial facilitators of care improvement.

In what follows, we put these findings in dialogue with Science and Technology Studies (STS) work on the ethics of care. Through our analysis we suggest online feedback be understood as a way healthcare service users (patients and their family members) *enact care* for other patients and their families, but also, significantly, for healthcare practitioners and services – what we conceptualise as 'caring for care'. A key way interviewees hoped online feedback could facilitate this particular form of care is through publicly available (often anonymous) digitally mediated feedback 'conversations'.

Most extant research and health policy has framed online feedback in terms of patient 'choice' or 'voice', or a conjoining of the two with capturing the patient 'voice' seen as a means of enhancing 'choice' (Adams, 2010; Powell et al., 2019). We argue that even when modelled on systems used by commercial enterprises, online healthcare feedback cannot be conceptualised as consumerist behaviour aimed at reinforcing patient choice; nor as a means of democratising the technocratic instrument of quality control through harnessing the patient's voice. Instead, we propose 'care' and 'conversation' as alternative framings for understanding online feedback practices in the context of public healthcare systems. This dual conceptualization foregrounds the mutuality of care relations and highlights the affective labour of feedback practices. Furthermore, it draws attention to two ways online feedback can improve care: first, through prompting tangible changes to healthcare services – online feedback *for* healthcare improvement; second, as a form of care improvement in its own right – feedback *as* healthcare improvement.

2. Online healthcare feedback: going beyond 'choice' and 'voice'

Much academic literature on online healthcare-related feedback has come from the US and Germany, but there is a growing body of work in different healthcare systems, including free at point of use systems like the NHS in the UK (Boylan et al., 2019). The link between feedback and patient-consumer choice is, unsurprisingly, a common theme in studies

from countries with private healthcare systems, like the US, and in relation to elective procedures such as plastic surgery (Hanauer et al., 2014; Menon, 2017; Yaraghi et al., 2018). However, health policy in the UK (especially England) similarly positions online feedback (and digital technologies more generally) as both a key facilitator of patient choice and a tool for care improvement through harnessing the patient voice (Department of Health, 2012; Department of Health and Social Care, 2016, 2015).

The blurring of 'choice' and 'voice' in this manner is not limited to online feedback (Adams, 2010). It is characteristic of a wider healthcare landscape where discourses around the democratisation of healthcare and patient empowerment overlap with and mutually reinforce an emphasis on health consumerism and patient choice (Greener, 2008). Thus, the subject (usually but not exclusively the patient) addressed in public health discourse emerges simultaneously as 'consumer' and 'citizen', despite the different logics and styles represented by these archetypes (Mol, 2008).

Associating online feedback straightforwardly with the articulation of an emancipatory patient 'voice' is problematic for a number of reasons. The dramatic growth of people sharing health experiences (including feedback) online can play a role in patient empowerment. But, digital media is not a neutral conduit. It influences the forms health activism takes, contributing to an increased alignment with mainstream biomedicine and commercial enterprises (Petersen et al., 2019). Furthermore, concerns have been raised about the commodification of health experiences, the lack of transparency around surveillance, privacy and data ownership, and the potentially coercive and disciplinary effects of digital health technologies based on individualised notions of self-care (Lupton, 2012, 2014; Millington, 2014; Schüll, 2016; Petrakaki et al., 2021).

Framing online feedback as primarily a facilitator of patient 'choice' is similarly problematic. While 'choice' is widely endorsed as a value in healthcare, people's ability to enact healthcare choices is constrained and context dependent (Coulter, 2010; Powell and Boden, 2012; Fotaki, 2014). Type of healthcare service, the state of one's health, socio-economic status, education level, the attitude of medical professionals, geographic location and practical considerations such as transportation and family responsibilities, all influence one's ability to choose healthcare services and professionals (Damiani et al., 2005; Dent, 2006; Fotaki, 2013; Greener, 2003). A number of scholars have furthermore questioned the validity of foregrounding choice at the expense of other values in healthcare, such as 'trust' (Fotaki, 2014) and 'care' (Mol, 2008) – a critique we build on in relation to online feedback specifically.

In this paper we move beyond an emphasis on 'choice' and 'voice' in the context of online feedback, proposing 'care' and 'conversation' as alternative framings. Our approach is informed by STS scholarship that has interrogated the relationship between care and technology in contemporary healthcare (Mol, 2008; Mol et al., 2010; Roberts et al., 2012; Pols, 2015). This work foregrounds care as a set of sensibilities and a mode of engagement with phenomena rather than an a priori theoretical framework (Mol et al., 2010). It approaches its subject(s) as intrinsically relational, attending to the embodied experiences, emotions, tensions and moral commitments within care practices. In a departure from a more traditional feminist ethics of care, it treats technology as part of, rather than opposed to, care relations (Mol et al., 2010; Pols, 2015). A key contribution has been to draw attention to the different, often overlooked or invisible, forms of labour implicated in digitally mediated healthcare (Oudshoorn, 2011; Roberts et al., 2012). This includes research which proposes the *moderation* of online feedback be thought of as care work (Ziewitz, 2017; Petrakaki et al., 2021). We bring the aforementioned sensibilities and insights to bear on practices of *providing* online feedback, putting our empirical findings in dialogue with social scientific literature on technologically mediated care practices and online feedback specifically.

3. The online healthcare feedback landscape in the UK

'Online patient feedback' is used as a catchall term to describe a variety of practices and technologies, each with its own associated norms and expectations (Dudhwala et al., 2017). In the UK, patient and other relevant service users' experiences are collected and ideally used to improve care through numerous mechanisms: from surveys and questionnaires to the collection of 'real time' feedback in hospitals and online platforms that allow unsolicited feedback (Marsh et al., 2019). Furthermore, the four (English, Scottish, Northern Irish and Welsh) devolved National Health Services conceptualise and manage feedback differently, with considerable regional variability.

Healthcare service users can provide online feedback through systems and mechanisms fully or partially managed by the NHS – such as the friends and family test (FFT) (<https://www.england.nhs.uk/fft/>) and NHS Choices (<https://www.nhs.uk>) in England. The latter was rebranded after we had completed the research and is now simply called the NHS website. They can also use third party dedicated feedback platforms, such as Care Opinion (www.careopinion.org.uk) – the feedback platform of choice for the Scottish NHS (Scottish Government, 2013) – and iWantGreatCare (<https://www.iwgc.org>). NHS Choices (<https://www.nhs.uk>) is the most commonly used online platform for writing feedback in the UK, followed by Care Opinion (Van Velthoven et al., 2018).

In addition to 'feeding back' experiences through dedicated feedback systems, patients and their family members comment about their experiences on social media (e.g. health forums, Facebook, blogs, Twitter, and YouTube) and post ratings and reviews on commercial platforms (e.g. Google Reviews and Yelp). Facebook is the most commonly used social media outlet for writing feedback in the UK, followed by Google reviews (Van Velthoven et al., 2018). While this form of feedback may not always be directed at a healthcare provider, it is nonetheless *about them* and we thus include it here as a form of feedback.

We adopt an inclusive approach to online feedback, using the term loosely to describe publicly available comments, ratings, reviews and feedback about healthcare service experiences provided through one or more digital technology or platform. This includes both solicited (e.g. collected through the FFT) and unsolicited (e.g. posted on social media) feedback. Rather than predetermining what constituted online feedback, we asked interviewees to tell us about their experiences using and providing online feedback, ratings and reviews. We took this broad approach intentionally: first, to develop a nuanced, empirically grounded understanding of online feedback from the perspective of those providing it in the UK; second, to situate feedback practices within the wider 'digital patient experience economy' within which they are embedded and co-constitute (Lupton, 2014).

The people we interviewed provided online feedback in relation to their own or (sometimes multiple different) family members' healthcare experiences. Because of this, when presenting our findings, we refer to 'service user' (rather than 'patient' or 'carer') feedback. We recognise that the term 'user' (like 'patient', 'carer', 'customer' and 'citizen') carries particular associations and assumptions (Petrakaki et al., 2021). When referring to or quoting directly from an interview, the capacity in which the interviewee was providing the relevant item of feedback is made clear (e.g., as a patient or a parent, etc.)

4. Methods

The research presented here formed part of the Improving NHS quality using internet ratings and experience (INQUIRE) project funded by the National Institute for Health Research (NIHR) Health Services and Delivery Programme (14/04/48).

The paper is based on 37 semi-structured qualitative interviews with people who used online platforms to read and/or write feedback about healthcare experiences. We recruited interviewees in a number of ways. Information about the study was posted on the project website and social

media. We drew on the professional network of project members (including the study's Patients, Carers and Public Reference Group) and colleagues to advertise the study as widely as possible. Care Opinion circulated the study to users who had agreed to be contacted for research purposes. Through Google searches, SK identified bloggers and other individuals who had commented about their healthcare experiences online. She approached those with publicly available contact details to ask if they would like to participate in the study.

People who expressed interest in the research were sent an information sheet. Those who agreed to take part were interviewed in their own home, or elsewhere, if they preferred. Written consent was sought on the day of the interview; participants were later sent a verbatim transcript of their interview to review before final consent and copyright was agreed for publication of extracts from the interviews to be used online (e.g. for teaching, trigger films and a toolkit). Data were stored according to the requirements of the Data Protection Act 1998 and the University of Oxford's governance requirements. Ethical permission was given by the University of Oxford's Medical Sciences Inter-divisional research ethics committee (R47871/RE001).

We aimed for a maximum variation sample (Coynne, 1997) that included different ages, genders and ethnicity, as well as people who had used a variety of online platforms and had commented on, or read about, different healthcare services (including primary, emergency, maternity, chronic, and specialist services). A topic guide was used to explore interviewees' general use of digital technologies, and their motivations and experiences of engaging with online healthcare-related feedback. The protocol was reviewed by the project's Patients, Carers and Public Reference Group and adjusted based on their feedback. It was used as a guide in the interviews, but participants were encouraged to speak freely about their experiences, including in relation to topics not explicitly included in the protocol.

An inductive approach was taken with two researchers (SK and FM) reading, discussing and coding the interviews throughout the data collection process. Interviewing was stopped when we ceased to identify new analytic codes and concluded the data were 'saturated'. See Table 1 for participants' basic demographic information (age, gender, ethnicity, health condition, and services used).

Interviewees had used numerous, in some cases multiple, different feedback platforms. The most commonly used formal feedback platforms were Care Opinion (n = 11) and NHS Choices (n = 6). Interviewees had also provided feedback through Healthwatch (n = 1), the NHS Friends and Family test (n = 1), and various NHS websites (n = 8). With regards to social media, interviewees had read and written feedback on Twitter (n = 21), blogs (n = 9), Facebook (n = 10), and forums (n = 9). The high number of people using Twitter and blogs is most likely because we advertised the study through Twitter and also because we were specifically looking for active feedback providers, a number of whom blogged about their healthcare experiences.

Transcripts were coded thematically using NVivo 10 software. We conducted an initial high-level analysis where we coded the data according to *motivations for, experiences of, and perceived effects of* reading and writing online feedback. We also coded for each platform mentioned (e.g. NHS platforms, Twitter, blogs, Facebook, Care Opinion etc.) and emergent themes such as anonymity, the public nature of feedback, and relationships with healthcare professionals. During the coding process we were struck with how interviewees articulated the relationship between their feedback practices and care improvement. In particular, how they consistently framed their online feedback as aimed at improving care for other patients and healthcare professionals.

To explore this in more depth, we did a second round of coding focused on unpacking the relationship between feedback and care improvement as described by interviewees. This resulted in themes focused on: i) online feedback and relationships with the NHS and healthcare professionals; ii) online feedback to improve care for other patients; iii) online feedback to support services, staff and the NHS; iv) conversational metaphors and care improvement. Although we were

Table 1

Basic participant information (age, gender, ethnicity, health condition, services).

Gender		
	Male	Female
20–35	0	7
36–50	2	9
51–65	4	8
66+	6	1
Total	12	25
Ethnicity		
	White British	Other
20–35	7	0
36–50	9	2
51–65	10	2
66+	4	3
Total	30	7
Health conditions and services used (note that many of the interviewees had commented on or read about multiple conditions and services for themselves and/or family members. The list provided below is based on the <i>main</i> condition and/or service they focused on in the interview, which does not mean they did not mention other conditions or services.)		
Multiple complex conditions		10
Mental health		6
Cancer		4
No specific condition identified		3
Diabetes		3
Care of a family member (parent or spouse, not children)		3
Childbirth (no specific condition)		2
Chronic pain		1
Early onset dementia		1
Heart condition		1
Multiple Sclerosis		1
Osteoarthritis and hip replacement		1
Spinal problems		1
Total		37

familiar with STS work on care prior to the study, we had not intended to draw on it in advance of our analysis. The salience of care and conversation as lenses for thinking through online feedback emerged during the coding process. We then drew on work on the ethics of care to inform and make sense of emergent findings.

5. Caring for care: online feedback as public conversation

[...] there's lots of reasons why I do it [provide online feedback]. It's not just one. [...] in the situation that I described at the start, that was first and foremost to try and get a bloody answer out of them [healthcare service provider] about what was going to happen next but, underlying all of this, was sharing it with other people, letting other people know that they're not alone and, hopefully, leading to change. But there's been other times where my post has been purely to highlight good practice or to instigate change in some way. [INQ36; female; late thirties; mental health; NHS Scotland]

Interviewees' provided feedback about their own or a family member's healthcare experience for a variety of reasons: to bring about changes to their care; to resolve an on-going issue; to raise concerns about care quality; to suggest improvements; to express alarm, frustration or even anger about the care received. They also used online feedback to highlight good practice and to thank, praise and acknowledge healthcare services and staff. Not only do people have many reasons for providing online feedback, they have multiple audiences in mind, from healthcare practitioners, to other patients, to regulatory authorities.

Regardless of the platform(s) used or the healthcare experience in

question, interviewees invariably orientated their feedback toward *improving* and, in some cases, *transforming* care. We unpack how interviewees spoke about the relationship between online feedback and care improvement. First, we describe interviewees' relationships with the NHS as an essential context that shaped their understandings of how online feedback could improve healthcare. Second, we look at how healthcare professionals and services, and, third, other patients and their family members, were positioned as key beneficiaries of online feedback. Fourth, we explore the prevalence of conversational metaphors in interviewees' discussions on the potential of online feedback to improve care.

5.1. 'The NHS fails, we fail': contextualising online feedback in relation to 'our' NHS

Descriptions of how online feedback could improve care were premised on embodied, highly emotive, at times ambivalent, relationships with the NHS. Interviewees recognised there was not one NHS. They spoke of national and regional differences as well as differences between services (e.g. mental health in contrast to primary care). They were aware of considerable variability in how hospitals and other services, such as GP practices, engaged with online feedback. 'The NHS' was nonetheless referenced as a single entity that needed to be protected and supported. Interviewees said they 'loved' the NHS and were 'passionate' about it. Some worked in the NHS (or had done so in the past) or had family members who did. Criticisms and complaints, even suggestions for improvement, were juxtaposed with expressions of gratitude:

I am really, you know, very grateful that I've had life changing surgery through the NHS, which I think is a wonderful thing. So I'm not a moaner or a complainer at all, but I do think it's really important that we make this change to see patients as partners in their own care and in their own recovery and having some shared decision making. [INQ08; female; early fifties; osteoarthritis and hip replacement; NHS England]

The quotation above illustrates a recurring tension. Interviewees wanted their experiences to be used to improve services, but did not want to be perceived as 'moaners' or 'NHS bashers'. Many used the first person plural pronoun 'we' and possessive pronouns – such as 'our' NHS – to position themselves as *part of* the NHS. First person plural pronouns also indicated a sense of identification and communality with other patients and fellow service users, as well as a more nebulous British public dependent on the NHS:

The NHS fails, we fail, we need the NHS to not only survive but to thrive and keep going and any feedback, certainly I'm giving and I know a lot of people in my position are, it's constructive, not because we're being critical but because need this to work. [INQ16; female; mid-thirties; multiple health conditions; NHS England]

Sometimes this dependency was articulated in abstract terms. But many interviewees, especially those with chronic, complex or rare conditions, spoke of feeling literally dependent on specific healthcare professionals. This put them in a vulnerable position. They feared critical feedback would have a detrimental effect on their care, that they would be dismissed as a 'serial complainer', or labelled a 'bad service user'. In such cases, the promise of anonymity was a major reason interviewees turned to online feedback platforms (Speed et al., 2016; Locock et al., 2020).

When online feedback is framed in terms of 'choice' or 'voice', dependency and vulnerability are ignored or seen as problems to be resolved. The patient as consumer makes rational choices unencumbered by emotions, while the patient as citizen gives voice to their experiences without fear of reprisals (Mol, 2008). In contrast, the ethics of care recognises dependency and vulnerability (on both sides) as inherent to care relations (De La Bellacasa, 2011; Martin et al., 2015). From this

perspective, the anonymity of online feedback is not a challenge to be overcome in order to include feedback in healthcare improvement. Rather, it is one of the things that allows people to give feedback in the first place.

Interviewees provided feedback because they cared about the NHS as a national resource, which, as *citizens*, they felt a sense of responsibility for. At the same time, many interviewees or their family members were receiving care from specific services and professionals. Thus, as *patients*, they had to navigate the power inequalities, vulnerabilities and dependencies implicit in care relations (Martin et al., 2015). These two dimensions – *caring for* the NHS as a symbolic entity invested with emotional and ethical weight, whilst being dependent on *care from* NHS services and healthcare professionals – provides essential background for contextualising the practices of people providing online feedback about public healthcare services in the UK, and potentially elsewhere.

5.2. 'A public thank you': caring for healthcare professionals and services through online feedback

Feedback was seen as an important mechanism whereby patients could support, educate and inform healthcare professionals. Even when interviewees had negative experiences, they said they did not share them to be punitive, but rather, to improve professional practice. People often take considerable care when crafting online feedback (Ziewitz, 2017; Petrakaki and Kornelakis, 2021). This was certainly the case in our study where interviewees spoke of thinking carefully about what they wrote, trying to be 'constructive', balancing the bad with the good, and avoiding 'naming and shaming' staff. Rather than being done quickly or flippantly, the provision of online feedback involved considerable practical and emotional labour. Active feedback providers had usually become so over time, galvanised by a sense of frustration alongside a desire to improve healthcare services, as well as modes of communication with them. Thus, even when critical, angry or impassioned, interviewees' feedback practices were shaped by a sense of care for the NHS, or at least certain aspects of it.

This sense of care was particularly evident in discussions on positive feedback, which makes up a large percentage of online feedback (Boylan et al., 2019). Often given alongside other expressions of thanks – such as cards or chocolates – digitally recorded positive feedback performed multiple functions. Interviewees wanted to 'boost the morale' of healthcare professionals; make them feel valued and appreciated; highlight good practice; enhance professional development; and support staff in gaining resources and recognition. The *public* nature of online feedback was seen as having a crucial role to play in achieving these goals:

I kind of did the old-fashioned thing of sending off thankyou cards [...]but I think it's also important that you take the time to speak up, when things go well and say thank you, and so that's what I used Patient Opinion [Care Opinion's name at the time] for, a public thank you. [INQ23; female; mid-thirties; maternity services; NHS England]

Publicly available online feedback was perceived as reaching a wide range of audiences, be more likely to gain attention, be taken seriously and galvanise action. Online feedback was also seen as something healthcare professionals could, at least potentially, leverage as 'evidence' when needed – e.g. in negotiations with external parties or regulatory bodies, such as the Care Quality Commission (CQC). Interviewees frequently distinguished between frontline clinical staff, whom they thought were trying their best, and those they felt were undermining good care (e.g. cost-cutting bureaucrats, managers using the NHS to further a political agenda, etc.). For example, in addition to providing feedback as a 'public thank you' to maternity services, the interviewee quoted above submitted online feedback both to praise a baby weighing service and to register concern about its

decommissioning. She hoped the feedback could be used by relevant healthcare professionals to help protect the service. Online feedback was, therefore, both an expression of gratitude for care received and an act of care for a service under threat. A similar pattern was found across interviews. For example:

I want those good experiences to be acknowledged [...] for that positive experience to be a tool for them to use, I suppose, in terms of funding or, I don't know. I'm giving them that information so they can use it however they want to really. [INQ22; female; mid-thirties; mental health services; NHS England]

5.3. 'We couldn't walk away': online feedback as care for other patients and their families

A strong sense of identification and communality with other patients was clear across the interviews. While interviewees sometimes hoped their feedback would improve their own care, it was more commonly aimed at improving care for other patients, or both simultaneously. This reflects a wider phenomenon of 'digital health citizens' using online platforms to enact care for others (Petrakaki et al., 2021), as vividly illustrated by a participant whose concern about her parents' care extended to the care of other patients:

That was the trigger that, you know, when this lovely lady that we'd got to know and love as well was collapsed and had crawled into the corridor because nobody was answering her buzzer and it took my brothers nearly five minutes to find a nurse [...] I suppose for our own sanity, we wanted to feel that, well, we felt that we couldn't walk away. We felt that we could not walk away knowing what we knew. And letting other people go through that. [INQ35; female; early-fifties; mother's and father's care (separate cases); NHS Scotland]

Here, the interviewee used a combination of formal complaints, Care Opinion and Twitter to advocate on behalf of elderly patients she felt did not have a voice. In her words, providing feedback was '*not about receiving an apology, this was about change. Real and lasting change*'. Although it took over three years, the campaign received political recognition and was eventually successful in galvanising reforms to elderly care services. The interviewee contrasted her experiences of providing online feedback with other, less visible, forms of feedback (including a formal complaint), which she felt had been dismissed or ignored. As elsewhere, the public nature of online feedback was foregrounded as important for bringing about change. The above is a particularly dramatic example, but the desire for feedback to be used to make tangible improvements to care services for other patients and their families was a prevalent theme throughout the interviews.

However, feedback was also provided with the aim of improving care experiences in ways that did not necessarily require actual changes to be made. For example, some interviewees shared their healthcare experiences to help prepare others, to reassure other patients, make them feel less alone, or give them the confidence to deal with their situation:

[...]I wanted to give other patients, who might be feeling equally vulnerable and uncomfortable asserting themselves, some confidence. To be able to say, 'It's okay, you know, if you're not sure, it's okay to ask questions and to request another point of view and, eventually, you know, you would hope that you would find somebody and feel comfortable, comfortable and confident in'. [INQ08; female; early fifties; osteoarthritis and hip replacement; NHS England]

While interviewees said online feedback had *the potential* to inform their own and other patients' choices, enabling choice per se was not a major reason for providing feedback. A number of interviewees explicitly rejected the logic of choice in the context of public healthcare,

arguing that, unlike purchasing a product or going on holiday, healthcare was too complex and personal to equate with the consumer-orientated decision-making found in other sectors. Others said that, *in theory*, online feedback had the potential to inform patient choice, but that it was a struggle to actualise choice in the context of the NHS, with one interviewee describing NHS Choices as an ‘oxymoron’. Thus, online feedback was oriented toward improving services or helping other patients and their families be prepared for them, rather than toward assisting others in making decisions about what services to use.

5.4. *‘I can’t get the NHS in for a cup of coffee and say, “now look here NHS”’: online feedback as public conversation*

Interviewees regularly framed their provision of feedback in terms of a metaphorical ‘conversation’ sought with the healthcare provider, namely ‘the NHS’. They used phrases like ‘talking to’, ‘being listened to’ and ‘feeling heard by’, even while being quite clear that they were communicating with an impersonal entity (real and symbolic, singular and multiple, at the same time):

And so the reason that I blogged about the NHS, is because I felt that the NHS was not listening, that there was no way for me to talk to the NHS. I can’t get the NHS in for a cup of coffee and say, “Now look here NHS.” [INQ02; female; mid-forties; chronic pain condition; NHS England]

The metaphorical frame of ‘conversation’ (expressed in diverse ways), which pervaded interviewees’ reflections on their motivations for providing feedback adds an overlooked dimension to the more common emphasis on feedback as articulating the patient ‘voice’. Interviewees certainly wanted to give ‘voice’ to their experiences, and felt relief when they were able to ‘get something off their chest’, but this frame was used precisely if and when the preferred frame of ‘conversation’ seemed to fail:

Sometimes it’s been at moments of complete desperation and I haven’t got any other platform to turn to in the sense of we’re not getting anywhere with the NHS, the funding, we’re just constantly having to fight for basic treatment that has been denied for no reason at all. And I’ve found that it’s my way of voicing and feel like I’m being heard, when I’m not being heard when I sit down and speak to someone in person. [INQ04; female; early twenties; Post Traumatic Stress Disorder (PTSD); NHS England]

However, a feedback platform was evaluated especially positively if users received a response that addressed their comments and if action(s) was taken as a result:

I think getting a response on some level is always important. It’s always nice to know you’ve been heard. I think it’s nicer to know you’ve been heard by people, who have the position or knowledge to act on what you said. [INQ16; female; mid-thirties; multiple health conditions; NHS England]

People posting online feedback do not want generic public relations style responses (Baines et al., 2018) – what one interviewee called the ‘Teflon technique’. They seek a meaningful exchange with relevant people. And yet, research conducted on Care Opinion found that only 6.5 % of the 475 responses analysed were categorised as ‘a transparent conversational response’ (Ramsey et al., 2019). Thus, with notable exceptions, feedback as ‘conversation’ was something interviewees aspired to rather than actually achieved.

By being able to view others’ feedback and relevant responses on sites such as NHS Choices and Care Opinion, interviewees were aware of variations in how different providers within the NHS engaged with online feedback. They evaluated not just the online feedback platform itself, but the relevant healthcare provider as actual recipient as well. Seeing a Trust or GP practice actively engaging with online feedback had

a positive influence on how interviewees perceived that provider:

I feel quite positive about it [Care Opinion] because I feel it does feed into improving services and I like my trust because it is obviously engaging with Patient Opinion. [INQ17; female; mid-thirties; mental health; NHS England]

Conversely, when a care provider was unresponsive, either directly to the interviewee or more generally, interviewees were disincentivised from providing feedback in the future, or looked for alternative feedback routes:

I’ve posted one or two on NHS Choices but my Trust is particularly bad at ignoring them, so it seems pretty pointless doing that.’ [INQ20; female; mid-sixties; mental health and chronic back pain; NHS England]

Inconsistencies and discrepancies between providers’ engagement with online feedback was deemed especially problematic in the context of the NHS, given the assumption it was meant to be equal, consistent and available to all, including in how feedback was managed. The relevance of online feedback for care improvement therefore goes beyond tangible changes made to care practices. The relationship sought through feedback communications is not simply the enhancement of existing care relations within the healthcare system. Rather, as feedback-related communication is itself understood as a vital form of care, it shapes care relations in new ways. Interviewees’ framing of feedback as, ideally, resembling a ‘conversation’ extended to the form the gathering of feedback took. Free text, narrative feedback were preferred to checkboxes, surveys and patient satisfaction style ratings. This was seen as enabling interviewees to ‘steer’ the ‘conversation’ and thus redress some of the power imbalances in relationships between healthcare service providers and users.

5. Conclusions

Although grounded in their own experiences and as such necessarily personal, the people we interviewed provided online feedback in the hope it would improve care for other patients, healthcare providers and the NHS more generally. However, the association between feedback and care improvement took two analytically different, if intertwined, forms. First, people provided online feedback in the hope it would inform healthcare services and result in tangible changes to them. Here, feedback served as a *medium* for care improvement (i.e. a form of advice, suggestion or recommendation directed at the service provider and aimed at changing care services for the better). For such feedback to be deemed effective, it needed to be picked-up and actioned by relevant healthcare professionals. Second, regardless of any actual changes made to services, providing online feedback was experienced by interviewees as *participation in care itself* – for example, by helping other patients and their families prepare, by making healthcare practitioners feel appreciated, by contributing to a wider transformation in the power dynamics between patients and healthcare service providers.

Building on an understanding of ‘good communication’ as both a crucial precondition for good care and ‘care in and of itself’ (Mol, 2008, p.76), online feedback can be understood as both contributing to care and as care in its own right. The ethics of care foregrounds ‘the compelling moral salience of attending to and meeting the needs of the particular others for whom we take responsibility’ (Held, 2006, p.10). Interviewees’ feedback practices were shaped by *both* their embodied experiences of care (good and bad) *and* a strong moral commitment to, indeed a sense of responsibility toward, other patients and service users, healthcare professionals and services, as well as ‘the NHS’ as a highly symbolic national resource. They were not providing feedback on *any* healthcare service, they were commenting on *their* healthcare services. Thus, in addition to online feedback being oriented toward improving care in the two ways mentioned above, these practices should be

understood as acts of care orientated toward care itself – what we refer to as *caring for care*.

Conceptualising online feedback as *caring for care*, invokes an understanding of care that is characterised as much by frustration, concern and vulnerability as by love, affection and nurture (Martin et al., 2015, p. 630). The dual weight interviewees placed on the anonymous and public nature of online feedback highlights how the personal (and private) and the political (and public) are closely coupled in online healthcare-related feedback – a point long argued in feminist care ethics more generally. People providing online feedback in the context of public healthcare services do so *both* as *patients* (or family members of patients) and as *public healthcare citizens*. Following Petrakaki and colleagues (Petrakaki et al., 2021), we suggest online feedback practices be understood as *productive* of particular forms of citizenship rather than representative of them. This productive dimension was particularly evident with prolific feedback providers, whose practices co-evolved over time alongside other roles and responsibilities.

The literature on care has long recognised the mutuality – broadly understood as reciprocity, mutual influence, interdependency and a sense of common purpose (Brown, 2016) – of caring relations. However, analytical weight has usually been placed on interpersonal caring relations or on the practices of those more traditionally thought of as caregivers. We have drawn attention to how patients and other service users (typically seen as care recipients) use online feedback to enact care for healthcare professionals and services (typically seen as care providers). This prompts further questions about different ways patients and the public perform care for public services (for example, through campaigns, volunteering, bequests and donations, and so on), a topic that has to date received relatively little sociological attention.

It is widely acknowledged that digital technologies are changing how care is delivered, contributing to the emergence of new forms of distal care work (Pols, 2012; Roberts et al., 2012; Oudshoorn, 2011). A distinctive contribution of the paper is to include writing – alongside moderating (Ziewitz, 2017; Petrakaki and Kornelakis, 2021) – online feedback as a form of care work. This is based on the amount of practical and emotional labour that goes into people's online feedback practices, but also how these practices were motivated by a sense of care, commitment and responsibility toward other patients, healthcare professionals and a 'national' healthcare system. This contrasts with an understanding of feedback as done quickly or even flippantly.

Acknowledging the labour of providing online feedback highlights the importance of receiving an appropriate response. While interviewees did value the opportunity to give 'voice' to their experiences, this was not in itself sufficient. Ideally, they wanted feedback to be a 'conversation'. Open, publicly available 'conversation' was, in fact, a key mechanism through which they sought to enact care for care, though this, in practice, for the most part, remained an ideal rather than an actuality.

One side effect of publicly available online healthcare-related feedback in the UK is that people can see the responses and assess the relative responsiveness of different healthcare services. This has consequences for perceptions of and relationships with said service providers. Given the steady growth in online feedback, this is increasingly pertinent for NHS healthcare service providers. Currently, it is rare for healthcare service provider responses to be either conversational or transparent (Baines et al., 2018; Ramsey et al., 2019), and most healthcare improvement initiatives still rely primarily on solicited survey data (Gleeson et al., 2016). Nonetheless, when taken seriously, online feedback has the potential to tangibly improve care practices and relations (Munro, 2017).

Our analysis has emphasised that, as both citizens and patients, healthcare service users in the UK turn to online feedback to enact care for 'the NHS'. While our findings are distinctive to the UK and the NHS as a national institution, we hypothesize that elements of them will apply in other contexts where citizens feel both responsible for and dependent on public healthcare systems. Similarly, it is likely that aspects of 'caring for care' are present in systems where patients pay more

directly for their healthcare, given that here too people develop complex, emotionally charged, often long-standing, relationships with healthcare services, especially in contexts of chronic illness. However, given the importance of situating online feedback practices within *different* contexts and relationships, further in-depth qualitative studies are needed to ascertain what aspects of our findings are particularly pertinent for the wider international phenomena of online healthcare-related feedback. In particular, we would like to see research that interrogates the role different online platforms play in enabling online feedback to be understood as integral to care and, crucially on the perspective of healthcare professionals, institutions, and organisations on this.

Credit author statement

Fadhila Mazanderani: Conceptualization, Methodology, Formal Analysis, Writing (original draft), Writing (review and editing), **Susan Kirkpatrick:** Conceptualization, Methodology, Investigation, Formal Analysis, Writing (review and editing), Project Administration. **Sue Ziebland:** Conceptualization, Methodology, Writing (review and editing), Supervision, Funding Acquisition. **Louise Locock:** Conceptualization, Methodology, Writing (review and editing). **John Powell:** Conceptualization, Methodology, Writing (review and editing), Supervision, Funding Acquisition.

Acknowledgement

The authors would like to thank all the research participants, without whom this work would not have been possible. They would also like to thank James Munro for his support and insights, and the entire INQUIRE team. This paper summarises independent research funded by the National Institute for Health Research (NIHR) under its Health Services and Delivery Research Programme (Grant Reference Number 14/04/48). JP also receives funding from the NIHR Collaboration for Leadership in Applied Health Research and Care (CLAHRC) Oxford at Oxford Health NHS Foundation Trust. The views expressed are those of the authors, and not necessarily those of the NHS, the NIHR or the Department of Health.

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