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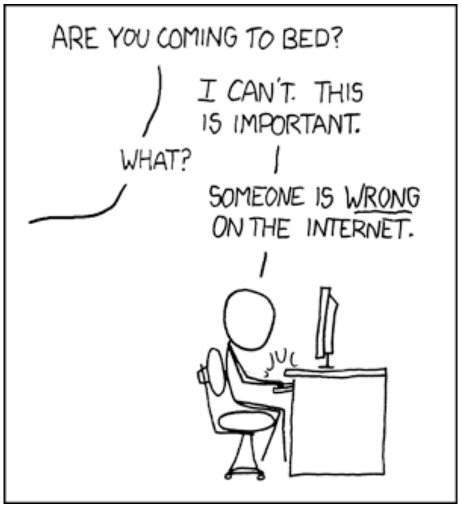
Apomediation and Ancillary Care: Researchers' Responsibilities in Health-Related Online Communities

ABSTRACT

This paper examines the responsibilities of researchers to provide ancillary care – care beyond that necessary to assure subject safety and scientific validity – to the subjects of their investigations into health-related online communities. The paper argues that many health-related online communities are online environments in which information is apomediated – that is, mediated in a social fashion by peers – rather than intermediated by authorities and experts for the benefit of lay persons. Researchers who investigate such online communities arguably have an ancillary care responsibility to those communities; namely, to become apomediaries themselves in order to help mitigate the dissemination and acceptance of incorrect or even dangerous medical (mis)information within those communities. This paper explores these arguments and proposes a simple, three-step sequence of questions to aid decision-making for researchers in these situations.

INTRODUCTION

Issue #386 of *XKCD*, the popular webcomic (Munroe, 2008), is called 'Duty Calls':



In this article, I explore the ways in which "duty calls" to academics who, in conducting research into health-related online communities (HROC), find that "someone is <u>wrong</u> on the Internet." Do academic researchers have an ethical obligation – a duty – to intervene and make the correction? When "someone is <u>wrong</u> on the Internet" in a HROC, it can be far more serious than disagreements in other online communities (best movie, worst sports team, etc.). The medical nature of the error has the potential to be deleterious to the health of other members of the community – a physical or mental harm that is absent in most instances of online "wrongness."[1]

Thus there is, arguably, an ethical obligation for the researcher to intervene and correct errors in HROCs. Such an intervention can usefully be framed as an instance of "ancillary care." Ancillary care has been defined within the field of bioethics as "that which goes beyond the requirements of scientific validity, safety, keeping promises, or rectifying injuries" (Richardson & Belsky, 2004, p. 26.) The "care" in question in this article is the correction of wrong and potentially dangerous health information that may be acted upon by members of the HROC. The vulnerability of such communities to the dissemination and acceptance of such information lies, I suggest, in the apomediated nature of information exchange within them. "Apomediation" refers to the social mediation of information, as opposed to the intermediation of that information by recognized experts and/or authorities (Eysenbach, 2008). It is the apomediation of medical and health information within HROCs that may provoke those instances in which "duty calls" to the researcher to provide ancillary care. By providing ancillary care, the researchers in effect transform themselves into apomediaries within the community, helping to mediate information socially. This article is an exploration of that transformation as an instance of ancillary care and the ways in which researchers can make decisions about *when* it is appropriate and *how* such an intervention might take place.

In this first section of this article, I explain briefly the theory of apomediation and the ways in which it is contrasted with traditional, intermediated, methods of information exchange and access. I then describe some cases in which the apomediation of information within HROC works well for members of those communities, and some cases in which apomediation could potentially lead to deleterious health outcomes. I then suggest that the provision of ancillary care – correcting the information – in such cases would effectively require the researcher to become an apomediary. In the second part of the essay, I explore arguments about ancillary care from the field of bioethics, notably the "Georgetown" positions developed out of the 2006 workshop on the obligations of medical researchers in developing countries. In this section, I go on to argue that the differences between off- and online community research renders some of the "Georgetown" arguments inappropriate, but that other arguments – notably the "duty of rescue" – do have direct application to online research ethics. In the third part of the article, I lay out more ways in which ancillary care provided to online communities differs from that given to offline communities and the ways in which these differences, which include questions of consent, authority, and authenticity, further impact upon the potential adoption by Internet researchers of the positions laid out in the bioethical literature. In the final section, I build upon the arguments for ancillary care – particularly the "duty of rescue" – and propose a fairly simple set of guidelines, cognisant of the differences between off- and online

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[1] Of course, other very serious harms can be done by being 'wrong on the Internet' – notably those emotional harms done by hate-speech (and the physical harms encouraged by them).

community research, to aid Internet researchers when making their decisions about providing ancillary care and becoming apomediaries within the online communities they are investigating.

APOMEDIATION AND MEDICAL INFORMATION

Apomediation in Theory

Apomediation (from the Latin *apo* meaning “to stand by” or “next to”) is an academic term for “social mediation,” propounded most influentially by Gunther Eysenbach as one of the five defining characteristics of “medicine 2.0” (Eysenbach, 2008). Medicine 2.0, in Eysenbach’s formulation, refers to the practices of medicine at the intersection of personal digital health records with the social technologies of “web 2.0,” Central to those practices, he argues, is the apomediation of medical information. In the past, those seeking medical information (patients, their families and friends) were typically only able to access it through qualified intermediaries – nurses, doctors, and so on. A regulated system of education-based qualifications, which publicly recognized particular expertise in an area of medicine, enabled those seeking medical information to identify certain professionals as trustworthy intermediaries between themselves and the information sought. In medicine 2.0, this system is increasingly displaced by one in which medical information is not intermediated by professionals, but instead mediated via the social technologies of web 2.0: blogs, wikis, forums, and online social networks. In the place of one single recognizable intermediary between the information-seeker and the medical information he or she needs, there exists now an online network of apomediaries (bloggers, Facebook friends, forum members, and, of course, medical professionals) who can help guide the seeker to the information. No one particular apomediary is essential to the process. The seeker herself decides which apomediaries to use and to trust, basing her decisions upon her own experiences and the recommendations of other apomediaries within her network. On the plus side, such a system sees a radical centering of the patient (the information seeker) in the healthcare decision-making process. The patient in the apomediated world is empowered to take control of her own healthcare and a degree of the autonomy that was lost in becoming a patient in the intermediated system is regained. On the other hand, the apomediated system is quite clearly open to abuse by dishonest or ill-informed apomediaries, not to mention perhaps being unjustly weighted against those patients who lack the social capital (education, free time, Internet access) necessary to navigate the apomediated information presented to them (O’Connor, 2009).

Research into Health-Related Online Communities as Apomediated Environments

The apomediation of medical information is present in all health-related online communities that allow members to seek information from other members without imposition of a qualification-based system of moderation. In very many instances, apomediation works very well for members, enabling the sort of autonomous “patient power” stressed by advocates of medicine 2.0 (Bos, Carroll & Marah, 2008). In other cases, apomediation does not work, and can lead to the dissemination and acceptance of incorrect and dangerous medical information.

Although they do not explicitly claim to be investigations into apomediated information environments, much recent academic research into online communities can be described as such. For example, a 2009 study, by Case et al., of diabetes-based online bulletin boards was focused upon eliciting the racial disparities in content and frequency of posting to such boards, but it was also, implicitly, an investigation of an online community whose members served as apomediaries to one another (Case et al., 2009). Members of this diabetes-focused HROC sought and exchanged information about managing their symptoms, food and diet (a key factor in living with diabetes), their feelings about the condition and a variety of other topics, all without the traditional medical authority figure to mediate the flow of information or judge its accuracy. Similarly, a study by Takahashi et al., of an online social network for persons with depressive tendencies, focused explicitly upon potential benefits and harms, but, as such, it was also an investigation into an online community whose members acted as apomediaries helping one another access the health information necessary to living with their mental health problems (Takahashi et al., 2009). In both cases, the apomediation of medical information seems to have been of benefit to the community members.

It is easy to point to numerous further examples of health-related online communities in which the apomediation of information aids and benefits members. For example, there are hundreds of active members of the American Cancer Society's Cancer Survivor Network forums (http://csn.cancer.org/forum), all exchanging information on managing their disease experience, swapping strategies for pain management, and letting each other know about the latest clinical trials – all without benefit of medical authority beyond their own experiences. Consider also the proliferation of disease-specific Facebook pages, ranging from cancer and diabetes to scoliosis and fibromyalgia, and out-of-the-box health-related online communities, created for-profit by companies such as Patients Like Me (www.patientslikeme.com). The number of health related communities on the Internet speaks to their popularity and success in providing an online space in which patients can serve as apomediaries to each other.

Nevertheless, it is apparent that some caution is necessary. As the introduction to the Cancer Survivor Network forums reads, "Information posted on this site represents the experiences, opinions, and beliefs of the author; it may not be based on medical fact." The possibility that the information apomediated within health-related online communities "may not be based on medical fact" is, of course, the *XKCD* possibility that "someone is wrong on the Internet." Precisely how widespread untrustworthy or inaccurate apomediation within HROCs has become is, due to the sheer size of the Internet, impossible to say. Nevertheless, academic researchers have long been concerned with the in/accuracy of online health information (Berland et al., 2001; Eysenbach & Kohler, 2002; 2004. Slater & Zimmerman, 2003), and the widespread adoption of online social technologies (blogs, wikis, forums, recommendation systems) has only furthered this concern (Hoffman-Goetz & Friedman, 2007; Kortum, Edwards, & Richards-Kortum, 2008; Witteman, Chignell, & Krahn, 2008; Vance, Howe, & Dellavalle, 2009). HROCs, of course, rely upon those social technologies, and so it is unsurprising that researchers are increasingly encountering untrustworthy apomediation and potentially negative health outcomes within their subject communities. For example, several studies of sexual partner-meeting websites for MSM ("men who have sex with men"[2]) have noted the connection between such online communities/Websites and risky sexual behaviors and increased risk of HIV transmission (Rhodes et al., 2010, p. 30). In such communities, some members (but, of course, not all) serve as untrustworthy apomediaries, disseminating inaccurate information about HIV transmission, as well as encouraging and facilitating risky sexual behavior (i.e., unprotected sex). In a related study, Rosser et al. (2009) suggest that MSM sexual partner-meeting websites mean that "the Internet can be considered a unique risk 'environment'" in which inaccurate sexual health information circulates and risky offline behaviors are enabled (p. 747). Indeed, some participants in a study by Mimiaga et al. of MSM who contracted HIV in the context of crystal meth usage "felt strongly that MSM sexual partner-meeting websites represented a major starting point for crystal-influenced sexual 'hook-ups'" – sexual encounters which potentially lead to HIV transmission and/or drug addiction (Mimiaga et al., 2008, p. 30). Clearly, MSM sexual partner-meeting websites are a form of HROC due to the widespread discussion of sexual health information therein, and the potential health impacts of the sexual activities facilitated thereby. These studies show that, within HROCs, the apomediation of inaccurate information by ill-informed or dishonest community members can have seriously deleterious effects. What then, are the responsibilities of researchers when faced with dangerously inaccurate information in their subject communities?

Apomediation as Ancillary Care

If, faced with incorrect and harmful information in the study community, the researcher chooses to intervene and provide a correction, she, in effect, becomes an apomediary. In trying to understand the ethical issues surrounding this choice, it is my contention that the decision to become an apomediary in such a situation is best viewed as a problem of "ancillary care" in research. The pathbreaking definition of Ancillary care within the field of bioethics was made by Belsky and Richardson (2004): "that which is not required to make a study scientifically valid, to ensure a trial's safety, or to redress research injuries" (p. 1494). This definition remains the standard, with recent work by Merrit, Taylor, and Mullany (2010) referring to ancillary care as "care beyond what is necessary to ensure scientific validity and subjects' safety" (p. 211). That definition is based on work done regarding researchers' ancillary care duties within medical research protocols, i.e., investigations involving a physical intervention in the subjects' bodies. In terms of ensuring scientific validity, the same academic principles apply to Internet research as to medical research: methodological clarity, repeatability, justification of intervention,

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[2] The term "MSM" ("men who have sex with men") is used in order to include men who do not identify as gay or homosexual, but who nevertheless have sex with men.

etc. Subject safety is a slightly different matter. Judged solely by the impact of the research project, itself, whether the investigation is observational or interrogatory, the safety of the subjects of an investigation into a HROC (indeed, any online community) is far easier to ensure than that of subjects in an offline, physical medical research protocol. For example, the MSM who took part in an online survey by Rosser et al. (2010) into HIV risk behaviors, were at no risk of being harmed by the survey itself. This is in contrast to the direct physical risk that HIV+ MSM who enroll in a Phase I drug trial, say, are exposed to by drug researchers. Being observed or answering a survey are simply not as dangerous as taking an experimental drug. Both a medical research protocol and an Internet research project will take steps to ensure the privacy of their subjects, but, whereas a medical research protocol will seek to protect subjects from physical harms done by the protocol (screening for incompatible disease conditions, for example), an Internet research project has no such obligations, because no potential physical harms exist. Thus what within a medical research protocol would count as a part of the inherent ethical obligations of the researchers – protecting the subjects from physical harm – only ever becomes an issue for Internet researchers as a matter of ancillary care. To become an apomediary within an online community because of the physical harms posed by incorrect medical information is to provide care beyond that necessary to the scientific validity of the study and the safety of the subjects as impacted by the study itself. I want now to explore the arguments that bioethicists have given in favor of the provision of ancillary care, and examine the ways in which such arguments may or may not be appropriate to HROC research.

ANCILLARY CARE IN BIOETHICS

Almost all work on ancillary care has been done regarding medical research in the developing world, largely because in the developed world, those needs which would otherwise present as demands for ancillary care are already being met by the government or society at large. In this work, bioethical positions on ancillary care have been usefully divided into three camps, the expansive position, the narrow position, and the middle position (Georgetown, 2008, e90, 0710). The expansive position holds that researchers' obligations be assessed as a part of their duty to rectify global injustice more generally. Researchers have a duty to do everything they can to meet the ancillary care needs of those upon whom they are undertaking research. This position, propounded most successfully by Alex London (who referred to it as the "Human Development Approach"), works from the notion that the global structural inequalities that benefit researchers in the developed world are the same inequalities which trigger the need for ancillary care in the developed world. Thus, as beneficiaries of an unjust global system, developed-world researchers have a duty to rectify that system wherever they can, particularly if they are further benefitting from those inequalities by undertaking research in those global spaces worst impacted by them (London, 2005).

Participants in the influential "2006 Georgetown University Workshop on the Ancillary-Care Obligations of Medical Researchers Working in Developing Countries" came to a consensus that roundly dismissed the expansive view on the grounds that a) it is unclear why medical researchers are more responsible than anyone else from the developed world for rectifying global injustice, b) unlimited ancillary care demands would probably bring much medical research to a halt, thereby often worsening global injustices, c) an open-ended commitment to ancillary care could be construed as a *very* undue inducement to participation, and d) if researchers meet all ancillary care needs they are, in effect, displacing local authorities to whom those responsibilities belong (Georgetown, 2008, e90).

Equally, however, the Georgetown participants agreed that a narrow understanding of ancillary care, one which paints researchers as “pure” scientists with no obligations beyond the safe completion of their study, was also unacceptable. They point to a “broad consensus” regarding ancillary care duties: that some, if not all, demands for ancillary care within research settings, should be met. They based their reasoning for this “middle position” on four arguments: 1) That a due concern for the welfare of one’s fellow humans requires that one address their serious medical needs where possible, 2) That there is a “duty of rescue” incumbent upon all humans to help those in immediate and mortal danger, 3) That there is a duty to take *some* part in the rectification of global injustices where possible, and 4) That there is a certain element of trust given to the researcher by the subject regarding their health, for which the researcher then becomes at least partially responsible. The unifying theme of these four arguments is, I suggest, a commitment to practicality on the part of the Georgetown participants. It is a commitment to providing as much ancillary care as is practical without impinging upon medical research, without the practice of which there would be no researchers present to provide any ancillary care at all.

The Georgetown arguments are, of course, based upon investigations into the experiences and responsibilities of medical researchers in the developing world. Thus, it is apparent that some of those arguments will not be directly applicable to research into health-related online communities. Most notably, the duty to take *some* part in the rectification of global injustice would seem to be misplaced in the context of providing ancillary care to a HROC, particularly if the community members are primarily based in the developed world. Additionally, the argument that researchers are trusted, at least in part, with their subjects’ health is hard to accept in online research situations wherein there is (invariably) no actual physical intervention and thus no potential physical harm that researchers are being trusted to avoid. For example in the study of vaccine-critical websites by Betsch et al., there is no physical intervention, merely observation of attitudes and potential behaviors of people who are exposed to such online communities, thus the researchers are not responsible, directly, for their subjects’ health (Betsch et al., 2010). Nevertheless, it is clear that the two other arguments – concern for fellow humans and the “duty of ‘rescue’” – do hold for those occasions during which research into HROCs uncovers the exchange or promotion of incorrect and dangerous medical information. Taken very broadly, concern for the welfare of fellow humans would seem to argue for the provision of ancillary care in almost any situation in which researchers encounter any incorrect information. The slightest correction of the smallest error (for example, the publication date of a particular cancer survivor autobiography, or the precise business hours of a particular physician’s office) could, arguably, improve the welfare of the subject community. So wide a reading of the argument from concern for welfare would be unfeasible, however, requiring the researcher to correct any and all errors on the off chance that the community's welfare is marginally improved. A more practical approach would dictate that it is only in instances of extreme errors, those likely to result in real physical harm, that ancillary care should be provided. Such an instance would certainly, for example, include the dissemination of inaccurate information about HIV transmission, as outlined in some of the MSM studies detailed above. This chimes with the argument from the duty of rescue, the obligation to help those in serious need, particularly when no other aid is forthcoming – a duty which has been described as a "general obligation... (which) requires researchers to offer ancillary care... simply because they are in the right place and the right time with access to the needed resources" (Merritt, Taylor, & Mullany, 2010, p. 212). Thus, I argue that when "someone is wrong on the Internet" and a "Duty Calls', it is the duty of rescue which does the calling. As I want now to suggest, there are important differences in the potential discharging of that duty in off- and online community research, differences which must be taken account of when proposing guidelines to help researchers decide *when* they should become apomediaries and *how* they should provide ancillary care.

"PATIENTS LIKE ME" IS NOT A DEVELOPING NATION

As I have already indicated, offline physical medical research is qualitatively different from Internet research in that it implicitly involves the potential for physical harm to subjects. There are two further important differences between off- and online research which must be taken into account when contemplating the ancillary care duties of Internet researchers to their subject communities. Both impact upon the likelihood of success of any online ancillary care intervention. Firstly, there is the question of consent: is it possible for online researchers to ensure that their interventions are consented to by their subject communities in the same manner that offline populations consent to ancillary care? Secondly, the nature of apomediation itself may limit the success of any online ancillary care intervention, changing the nature of Internet researchers' responsibilities.

Consent and Success

In offline medical research, there is a reasonable expectation that ancillary care interventions will enjoy some level of success. This expectation does not always exist in online research situations – a disparity which may, in part, be traced to the question of the subject community's consent to ancillary care. Offline ancillary care consists primarily of physical interventions, such as basic nutritional supplements, inexpensive medications (anti-malarial tablets, for example), and sanitary medical supplies. These interventions have often been demanded of the researchers by the subject community, meaning that they have consented to the ancillary care intervention in advance. Such practical interventions are highly likely to succeed in their stated aim of providing care for research subjects – a success grounded in the engaged, informed consent of the recipients. Online ancillary care – the apomediation of accurate medical information – has no such likelihood of success, nor necessarily the consent of the recipients, precisely because of the nature of apomediation. In online research situations, the researcher attempting to provide ancillary care becomes *just another apomediary* to whose intervention there is no reason to believe that the community has consented. There is no guarantee that the HROC members will trust the researcher anymore than they will the apomediary providing incorrect and dangerous information. This is in direct contrast to the practical interventions offline, wherein the ancillary care offered is typically done so because no alternatives are offered and the community has demanded and/or consented to the intervention.

One step which Internet researchers can take to overcome this disparity is to ensure that the ancillary care they offer is done so in a manner sensitive to the cultural norms of the study community, thereby building trust in themselves as apomediaries. This does not guarantee consent to the intervention, but it may mitigate potentially adverse reactions. Online researchers' lack of "embeddedness" in their subject communities can lead to mistrust and misunderstandings. For example, one of the respondents in the Miagama et al. (2008) study into MSM sexual partner-meeting websites and crystal meth usage advised against interventions by the researchers, saying, "I don't know whether the gay community wants intervention" – a reference to that community's understandable mistrust of well-meaning but culturally atonal (moralistic, judgmental) interventions by straight researchers (p. 35). Heidi McKee and James Porter have outlined the importance of community participation (or "time in world") as key to establishing trust between online researchers and their subject communities (McKee & Porter 2009, p. 21). Online researchers, particularly those whose research is primarily observational rather than interactive, may find it difficult to act as trusted apomediaries to their subject communities simply because they have not (or do not appear to have) spent any time in world. Offline researchers, present in world, on the ground, with their subject communities, are less likely to experience such problems. This is not to say that offline community research is not fraught with issues of cultural sensitivity, merely that such questions are more easily answered by researchers who understand those issues. Thus when Rhodes et al. (2010) designed their intervention into MSM online chatrooms (with the aim of reducing HIV risk behaviors), they "took time and effort to build trust, appeal to chatters, and tailor focused messages to individuals and groups" with the aim of creating interventions which were "culturally appropriate" to the MSM community being studied (p. 35, 36). This meant that the information provided by the researchers was apomediated in language sensitive to the needs and interests of MSM. It is only when Internet researchers provide their interventions in a similarly culturally sensitive fashion that they will begin to be greeted as trusted apomediaries by their subject communities. (On the importance of tailoring web-based public health interventions to specific audiences, see Bennett & Glasgow, 2009, p. 279).

The next step that online researchers can take in ensuring the success of their ancillary care interventions is to seek forms of community consent. Offline community-based health-related research is typically undertaken with the agreement and/or cooperation of authorities that are able to provide consent on behalf of their community. Such cooperation and consent is vital to the success of any offline ancillary care interventions. Nevertheless, there is concern about the potential for such interventions either to displace provisions made by community authorities or, worse yet, to enable said authorities to abdicate responsibility for such provisions. Internet researchers, too, must be careful to negotiate these lines of authority and responsibility in order both to ensure the success of their protocol and their ability to be welcomed as trusted apomediaries. Once again, Rhodes et al. (2010) provide a successful example of such negotiations, grounding their HIV-risk-reduction chatroom-based intervention in Community Based Participatory Research (CBPR), which “ensures equitable and true participation by communities affected by the issue being studied” (p. 30). CBPR, done in this fashion, engenders the same sort of community consent available to offline researchers – consent which increases the likelihood that the interventionists will be met as trusted apomediaries: representatives from the gay community, members of gay, lesbian and transgender health organizations, as well as local public health officials were involved in the design of the Rhodes et al. (2010) intervention, resulting in a transparent and non-judgmental form of intervention in which trained researchers entered MSM chatrooms not to criticize behaviors, but simply to offer accurate, reliable HIV information, announcing themselves with chatlines such as “In the room to answer questions about HIV/AIDs” or “Want to get tested for HIV? IM me, I can help” (p. 31). This intervention was not actually ancillary care, but rather a public health campaign. Nevertheless, it demonstrates the importance of community consent to successful interventions with HROCs. It is through such well-planned programs of community engagement and consent that online researchers can become trusted apomediaries and thus begin to emulate the likely success of their offline colleagues when it comes to offering interventions and/or ancillary care to their subject communities.

The final consent-related difference between off- and online research is that of transparency. Does the subject community know who is providing the ancillary care and why? Offline researchers who provide ancillary care are already known to the subject community; their competency to provide the ancillary care intervention consented to by the community will have been established in advance. This may not always be the case with online research, especially that which is more observational than participatory. For example, a sociologist investigating the impact of gender within a cancer-focused HROC may not have the relevant expertise or knowledge to confidently correct what he or she suspects to be incorrect information about, say, cancer treatment. In some cases, it may be appropriate for training to be provided in advance of the research, such as that given to the interventionists in the Rhodes et al. (2010) HIV risk reduction intervention, who were “trained to serve as health advisors, opinion leaders, community advocates, and data collectors” (p. 31). It is paramount that researchers who become apomediaries are open and honest about the limits of their expertise and that the subject community is informed about those limits when (or even before) the intervention is made. Indeed, researchers who become apomediaries must identify themselves as such to the subject community, both to ensure that the community is fully informed about the nature and background of the intervention and (concomitantly) that the resultant apomediation is justly viewed as trustworthy by the community.[3]

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[3] I am grateful to an anonymous reviewer of this article for this important point.

Intermediation versus Apomediation

At root, the differing expectations of success between off- and online ancillary care are a function of the difference between the offline researcher's role as an intermediary (between the subject community members and, say, nutritional supplements only the researchers have access to) and the online researcher's role as an apomediary (to subject community members who can look elsewhere for the medical information being offered). It is entirely possible that the provision of ancillary care within a HROC will not only be refused (as the MSM respondent to Mimiaga et al. [2008] feared), but, as the community reacts negatively to the unsought outside intervention, will lead to the further acceptance of the incorrect medical information within the community. The nature of apomediation (the lack of an intermediating authority who decides correct from incorrect) means that online researchers, when discharging the duty of rescue, may have the right – indeed the responsibility – at some point to step back and realise that they cannot force subject communities to accept ancillary care. For example, the interventionists in the chatrooms in the Rhodes et al. (2010) study cannot reasonably be expected to ensure that other chatters accept what they say about sexual health; they can only present the information to them as sensitively as possible. Where there is no ability to discharge a duty, there cannot really be any duty to begin with. Apomediation thus means that, in contrast to the offline researcher who must ensure that the anti-malarial tablets are not just provided but taken properly, there is no concomitant duty upon the online researcher to ensure that the correct medical information becomes accepted by the community.

Bearing in mind these important differences regarding the application of the duty of rescue to off- and online community research situations, I want, in the following, final section, to propose a simple set of guidelines to assist Internet researchers in making decisions about whether or not to become an apomediary and offer ancillary care to their subject communities.

DECIDING TO BECOME AN APOMEDIARY

In seeking to provide guidelines on ancillary care for Internet researchers, it is helpful to explore existing offline guidelines on the subject to see if they can be adapted and applied to research into HROCs. It is clear that advance planning is essential. Participants in the influential 2006 Georgetown workshop on ancillary care, for example, promulgated a three-part set of questions that Research Ethics Committees (RECs) should ask when considering the possible ancillary care duties in a research study: 1) What ancillary care needs are likely to be encountered? 2) Can those needs be met by the local health system? and 3) How strong is the obligation to provide ancillary care? (Georgetown, 2008, e90, 0711). The Georgetown guidelines are, of course, intended for offline research and thus necessarily conceive of any putative ancillary care services as intermediated by researchers. Ancillary care in HROC research is, as I have argued above, only ever apomediated by researchers. Internet researchers are, by the apomediated nature of their subject communities, never the only potential source of information. Thus the second question in the Georgetown guidelines – "Can identified ancillary care needs be met by the existing local health system?" – cannot apply to HROC research because, by definition, the ancillary care needs (accurate medical information) arise precisely because the "local health system" (the HROC itself) is meeting those needs, albeit incorrectly. The Georgetown guidelines rest on the assumption that ancillary care is only provided when the researchers are the only possible source of that care. In an apomediated information environment, such as a HROC, ancillary care is only ever provided in the face of one or more competing sources of care. Anyone can provide an alternative "fact" in an online debate, essentially placing apomediating researchers into a marketplace of ideas in which they are in competition with other apomediaries. Therefore, online researchers should seek to ensure that the manner of their interventions will be acceptable to the subject community (recalling here what I argued above regarding the importance of cultural sensitivity, community consent, and transparency in the provision of online ancillary care). This is why the "+CLICK" web-based sexual risk reduction intervention discussed by Markham et al. (2009) seeks to provide 'consistent, confidential and motivational' information to online MSM communities regarding HIV transmission (p. 625) and that the similar, "Sexpulse" intervention discussed by Rosser et al. (2010), was developed on the understanding that "online HIV prevention must be comprehensive, highly visual and more sexually explicit than conventional prevention programs" (p. 2100). Both +CLICK and Sexpulse are public health interventions, rather than instances of ancillary care, but both understand their roles as apomediaries, competing *with*, rather than *replacing* or augmenting, the local health system. It is this understanding which ancillary care interventions in HROC must be capable of emulating if they are to be successful.

It is clear that to succeed within the apomediated "marketplace," online ancillary care interventions may have to be planned in advance, which brings us to Questions 1 and 3 of the Georgetown guidelines – "What ancillary care needs... are likely to be encountered?" and "How strong is the responsibility of researchers... to address the ancillary care needs they identify?". Although the ancillary care needs in HROC research are, I would argue, *always* the correction of incorrect and dangerous medical information, the nature of that information is likely to relate directly to the theme or interest of the HROC. Investigators researching the American Cancer Society's Cancer Survivor Network can expect to encounter information relating to cancer. Rhodes et al. (2010) and Rosser et al., 2010 expected (and did) encounter information relating to HIV and AIDS when investigating online MSM communities. Online researchers and their RECs should consider in advance what sort of misinformation may be encountered within the "theme" of the subject HROC and plan potential ancillary care interventions accordingly. This reinforces my suggestions above that a) researchers should be clear about the limits of their expertise within the 'theme' area, and that b) it may be appropriate to provide training in the theme area, as Rhodes et al. (2010) did.

The strength of HROC researchers' responsibility to correct incorrect medical information is typically defined by the level of danger presented to the HROC members by the erroneous information. The greater the danger, the greater the responsibility. The criteria for deciding the trigger point at which this level is reached will, naturally, differ from subject community to subject community, and it will be the responsibility of researchers and their RECs to delimit those criteria relative to each research project. However, underpinning any such delimitation, I would argue, must be the duty of rescue as defined by Merritt, Taylor and Mullany (2010): “the obligation to help those in serious need, particularly when no other aid is forthcoming” (p. 212).

A focus upon “serious need” precludes the sort of frustration expressed in the *XKCD* comic which opens this article: correcting every error would be unfeasible – the apomediary role could become overblown, detracting from the quality and timeliness of the research itself (remembering here the Georgetown concerns about unlimited ancillary care needs bringing medical research to a halt). It is useful, one last time, to turn to the MSM online community studies I have used throughout this article to illustrate this point. In all the MSM studies mentioned above, the potentially dangerous information being apomediated within the communities has been regarding HIV transmission and risky sexual behavior. Clearly, the potential for acquiring HIV is a serious need, which would trigger the duty of rescue. However, as both Rhodes et al. (2010) and Rosser et al. (2009, 2010) make clear, it is the continued *pervasion* of the information that has triggered their interventions. Thus, in these cases, both studies worked with the community to provide alternative sources of accurate information, rather than interrupting every community interaction featuring erroneous medical information. This is not to say that there will not be instances in which it is appropriate for a researcher to apomediate directly with individual community members, merely that, considering what I argued above regarding the necessity of cultural sensitivity and community consent to the success of any apomediated intervention, in cases of pervasively incorrect, dangerous, information, it may be best to work with community representatives to provide alternative, accurate information. Similarly, when researchers encounter dangerously incorrect information, pervasive or otherwise, within a HROC, they and their REC should plan to leave a waiting period in order to see if other aid is forthcoming and the community self-corrects the error; this both shows respect for the community members as autonomous apomediaries and allows the researcher to focus upon their primary responsibility: accurate and timely research. In all cases, it is apparent that the *style* or manner of the apomediated ancillary intervention is absolutely crucial.[4] Researchers and their RECs should be clear in advance about *how* any potential interventions will take place, grounding their decision in an assessment of the likelihood that the researcher will be accepted as a trusted apomediary (culturally literate, has the consent of the community to intervene, etc.) without losing sight of her responsibilities as a researcher.

A 3-Question Sequence

With these critiques of existing guidelines in mind, I propose three questions to aid Internet researchers in making decisions about providing ancillary care in HROCs. The questions are based upon the contention that ancillary care in health-related online communities always manifests as the correction of incorrect or dangerous medical information and that, in making such a correction, the researcher becomes an apomediary. The

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[4] I am grateful to (another) anonymous reviewer of this article for this important point.

questions are also grounded in the assumption that researchers and their RECs have a) identified the dangerous or incorrect information they are likely to encounter and b) planned *how* their apomediated intervention will take place. The questions run sequentially:

1) Is the incorrect medical information likely to lead to serious harm to members of the subject community?
If the answer is "no," then there is no duty of rescue, and the researcher does not have an obligation to become an apomediary. If the answer is "yes," then there is a duty of rescue, and the researcher should consider the next two questions:

2) *Are other apomediaries within the community available and/or likely to correct the information?*
If the answer is "yes," then the researcher's obligation to become an apomediary is lessened. If the answer is "no," then the researcher's obligation to become an apomediary is strengthened. In both cases, the researcher should consider the next question:

3) *Does the researcher have the necessary community experience ("'time in world") and community consent to function as a trusted apomediary within the community?*
If the answer is "yes," then the researcher has a clear obligation to provide ancillary care (correct the harmful information), especially if the answer to question 2 is "no" and there are no alternative apomediaries. If the answer to question 2 is "yes," and there *are* other apomediaries, a researcher who then answers "yes" to question 3 only has an obligation to become an apomediary if judging that apomediation will aid the other apomediaries in correcting the dangerous information. If, in the apomediary's assessment, the intervention will either make no difference to, or potentially prejudice, the alternative efforts at correction, then he or she does not have an obligation to become an apomediary. Indeed, in the case of prejudicing alternative apomediation efforts, the researcher may have a strong obligation *not* to become an apomediary. If the answer to question 3 is "no," then the researcher's obligation to provide ancillary care is lessened, especially if the answer to question 2 is "yes," and other, trusted, apomediaries are available and likely to make the correction; a maladroit attempt at apomediation by someone seen as a "noob" may well damage other attempts at correcting the information. If the answer to both questions 2 and 3 is "no," then the researcher finds him or herself in the worst of all worlds: unable to convincingly act as an apomediary and without the comfort of knowing that others are likely to make the correction. In such a situation, the researcher arguably has a strong obligation to spend more "time in world" and develop the cultural literacy necessary to becoming a trusted apomediary.

These questions are not intended comprehensively to cover every possible issue in ancillary care decision making likely to face Internet researchers investigating HROCs. Rather, the questions are intended as guidelines which enable researchers to take due consideration of the apomediated nature of the communities they are investigating and they ways in which that nature necessarily impacts upon the need for, and provision of, ancillary care.

CONCLUSION

My aim in this article was to consider how researchers should respond when "Duty Calls" and "someone is *wrong* on the Internet." I focused particularly on investigations into health-related online communities (HROCs), because, when someone is *wrong* in such spaces, the consequences can be very harmful. I suggested that researchers correcting harmful medical information in HROC could usefully be considered an instance of ancillary care within research, and that such ancillary care when provided in HROC effectively involves researchers becoming apomediaries. Having outlined the nature of apomediation in HROC, I then explored the bioethical arguments for the provision of ancillary care in community settings. Of all these arguments, I suggested that it is the duty of rescue that applies most clearly to the provision of ancillary care in HROC research. In then exploring how ancillary care provision off- and online differs, I sought to make clear that it is the apomediated nature of HROCs that researchers must seriously consider when making decisions about their obligations to provide ancillary care. With that consideration in mind, I made use of existing offline guidelines regarding ancillary care to propose a three-question sequence to aid researchers in their ancillary care making decisions, that is to say, in their decision to become apomediaries and correct harmful information in the HROCs they are investigating.

As the *XKCD* comic indicates, there is an element of painful futility in attempts to deal with any and all instances of someone being "*wrong* on the Internet." Much of that futility is a function of the apomediated nature of information in online communities: almost anyone can say almost anything and claim that they are correct. The three-question sequence that I propose aims to remove some of the futility from making corrections in online communities by accepting that those communities are apomediated environments and that, as such, it is simply not always necessary or practical to make the correction. Either the error is minor and harmless, or there are other apomediaries standing by to make the correction. The duty of rescue permits researchers to focus on those instances in which "someone is *wrong"* in such a way as to be actively harmful to other members of the community. Accepting that there may be other, more trusted apomediaries available still to make the correction, further diminishes that sense of futility.

Ancillary care, though obviously an important field of inquiry, is a relatively small one within the larger academic enterprise of bioethics. Much of the foundational work in bioethics focused upon the ethics of human subjects research and, as such, there exist a wealth of offline bioethical guidelines to aid researchers in their investigations. In adapting and applying some of the bioethical ideas and theories about ancillary care for use in Internet research, I hope I have shown that there are opportunities for Internet researchers and bioethicists to borrow and learn from each other. My application of ancillary care to HROC research is but a small part of a much larger project which should see us asking whether or not traditional bioethical concerns such as autonomy, authority, accuracy and privacy can simply be migrated online. Much more work needs to be done to integrate the heavy philosophical artillery of offline bioethics with the dynamic and emergent field of Internet research studies.

ABOUT THE AUTHOR

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REFERENCES

Bennet G. G., Glasgow R. E. (2009). The delivery of public health interventions via the Internet: Actualizing their potential. *Annual Review of Public Health,* 2009. 30, 73–92.

Berland G. K., Elliot M. C., Morales L. S., et al. (2001). Quality of health information on the Internet: accessibility, quality, and readability in English and Spanish. *Journal of the American Medical Association,* 285, 2612–2621.

Belsky L. & Richardson H. (2004). Medical researchers' ancillary clinical care responsibilities. *British Medical Journal* 328;1494 doi: 10.1136/bmj.328.7454.1494.

Betsch C., Renkewitz F., Betsch T. & Ulshöfer C. (2010). The influence of vaccine-critical websites on perceiving vaccination risks. *Journal of Health Psychology*, 15, 446-455.

Bos, L., Carroll, D. & Marsh, A. (2008) The Impatient Patient. In Bos, L. (ed.), *Medical Care and Compunetics* 5. Amsterdam. IOS Press. 1-13.

Case S., Jernigan V., Gardner A., Ritter P., Heaney C. A., & Lorig K. R. (2009). Content and frequency of writing on diabetes bulletin boards: does race make a difference? *Journal of Medical Internet Research*. 11(2), e22.

Eysenbach, G. (2008). Medicine 2.0: social networking, collaboration, participation, apomediation, and openness. *Journal of Medical Internet Research*, 10(3), e22.

Eysenbach G. & Köhler C. (2002). How do consumers search for and appraise health information on the World Wide Web? Qualitative study using focus groups, usability tests, and in-depth interviews. *British Medical Journal*, 324, 573–577.

Eysenbach G. & Köhler C. (2004). Health-related searches on the Internet.*Journal of the American Medical Association*, 23;291(24), 2946-9.

Griffiths K. M., Crisp D., Christensen H., Mackinnon A. J. & Bennett K. (2010). The ANU WellBeing study: a protocol for a quasi-factorial randomised controlled trial of the effectiveness of an Internet support group and an automated Internet intervention for depression. *BMC Psychiatry*, 10;20. doi:10.1186/1471-244X-10-20.

Hoffman-Goetz L. & Friedman D. (2007). A qualitative study of Canadian Aboriginal women's beliefs about "credible" cancer information on the Internet. *Journal of Cancer Education*. 22(2), 124-8.

Kortum P., Edwards C., Richards-Kortum R.. (2008). The impact of inaccurate Internet health information in a secondary school learning environment. *Journal of Medical Internet Research*, 10(2), e17.

London A. J. (2005). Justice and the human development approach to international research. *Hastings Center Report*, 35(1), 24-37.

McKee H. A. & Porter J.E. (2009). Playing a good game: ethical issues in researching MMOGS and virtual worlds*. International Journal of Internet Research Ethics*, 2(1), 5-37.

Markham, C. M., Shegog R., Leonard A. D., Bui T. C. & Paul M. E . (2009). '+CLICK: harnessing web-based training to reduce secondary transmission among HIV-positive youth*. AIDS Care*, 21: 5, 622-631.

Merritt M., Taylor H. & Mullany L. (2010). Ancillary care in community-based public health intervention research. *American Journal of Public Health*, 100(2), 211-216.

Mimiaga M. J., Fair A. D., Mayer K. H., Koenen K., Gortmaker S., Tetu A. M., Hobson J. & Safren S. A. (2008). Experiences and sexual behaviors of HIV-infected MSM who acquired HIV in the context of crystal meth use. *AIDS Education & Prevention*, 20(1), 30-41.

Monroe R. (2008). 'Duty Calls.' http://xkcd.com/386/

O'Connor D. (2009). Apomediation and the significance of online social networking. *American Journal of Bioethics*, 9(6-7), 25-27.

Participants in the 2006 Georgetown University Workshop on the Ancillary (2008) Care obligations of medical researchers working in developing countries. *PLoS Medicine*, 5(5), e90. (Identified as 'Georgetown' in text)

Rhodes S. D., Hergenrather K. C., Duncan J., Vissman A. T., Miller C., Wilkin A. M, Stowers J., Eng E., (2010). A pilot intervention utilizing Internet chat rooms to prevent HIV risk behaviors among men who have sex with men. *Public Health Reports*, 125(Supp 1), 29-37.

Richardson H. & Belsky L. (2004) The ancillary-care responsibilities of medical researchers: an ethical framework for thinking about the clinical care that researchers owe their subjects. *Hastings Center Report* 34(1), 25-33.

Rosser B. R. S., Miner M. H., Bockting W. O., Ross m. W., Konstan J., Gurak L., Stanton J., Weston E., Jacoby S., Carballo-Diéguez A., Mazin R. & Coleman E. (2009). HIV Risk and the Internet: results of the Men's INTernet Sex (MINTS) Study. *AIDS Behavior*, 13(4): 746–756. doi:10.1007/s10461-008-9399-8.

Rosser B. R. S. Oakes J. M, Konstan J., Hooper S., Horvath K. J., Danilenko G.P., Nygaard K.E.,& Smolenski D. J. (2010). Reducing HIV risk behavior of men who have sex with men through persuasive computing: results of the Men's INTernet Study-II. *AIDS*, 2010, 24, 2099–2107.

Slater M., & Zimmerman D. (2003). Descriptions of websites in search listings: a potential obstacle to informed choice of health information. Am J Pub Health, 93(8),1281-1282.

Takahashi Y., Uchida C., Miyaki K., Sakai M., Shimbo T. & Nakayama T. (2009). Potential benefits and harms of a peer support social network service on the Internet for people With depressive tendencies: qualitative content analysis and social network analysis. *Journal of Medica; Internet Research*., 11(3), e29.

Vance K., Howe W. & Dellavalle R. (2009). Social Internet sites as a source of public health information. *Dermatologic Clinics*. 27(2), 133-6, vi.

Witteman H., Chignell M., & Krahn M. (2008). A recommender system for prostate cancer websites. *American Medical Informatics Association Annual Symposium Procedings*. 6, 1177.