

COMMUNITY ETHICS COMMITTEE REPORT to the
HARVARD ETHICS LEADERSHIP GROUP on
USE OF SOCIAL MEDIA

March 11, 2010

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INTRODUCTION

The Community Ethics Committee (CEC) is a group of sixteen members living in the general Boston area who are representative of the population served by the Harvard teaching hospitals. The need for such a consultative group has been evident for a long time since individuals currently serving as community members on hospital ethics committees are not able to be broadly representative of multiple communities. Solicitation for membership on the Committee has been cast widely through community, business, and church groups, with a specific application process to ensure selection of a diverse and effective working group.

The Community Ethics Committee is comprised of members within the geographic region of the Harvard hospitals who are diverse as to socio-economic status, religious affiliations, cultural and language groups, and educational backgrounds. Of the sixteen members, ten are women and six are men; we range in age from our teens to our seventies. Some of us have advanced degrees and some of us have high school diplomas. Among us are a high school student and a school administrator and two high school teachers; a rabbi and a minister of a large downtown Boston church; and parents with disabled or medically involved children. Two of us have disabilities and two of us are retired, one from a large Boston law firm. We are students and writers and small business owners and volunteers. We volunteer at a local rape crisis center, on an Institutional Review Board, and in health care facilities. We belong to eight different religious traditions, including atheism, and we speak seven different languages. Most of us were able to attend the Harvard Bioethics Course, where we first met and began our conversation as the Community Ethics Committee.

PROCESS

The Committee met throughout the winter, spring and autumn of 2009 to educate ourselves about the ethical issues which arise from the use by patients, their families and medical staff of social media including internet social networking sites, blogs and sites such as Facebook. As a Committee, we corresponded by e-mail and shared articles we had found and information we had gathered. Our meetings were at a location on the Harvard Medical School site and, although scheduled to run from 6PM to 9PM, our discussions often continued much longer than that. In January, we met with Dr. Steve O'Neil, with the Beth Israel Deaconess, and with Judi Friedson, with Children's Hospital, where they presented concerns raised within the local medical communities regarding particular instances of troubling encounters which occurred while using internet support

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communities. Dr. O'Neil had maintained a site on an internet support community during the period of his daughter's illness and Mrs. Friedson had participated on various ethics consults having to do with the use of social media sites.

Among the many different factual scenarios presented illustrating the use/misuse of social media were: outside-of-the-institution contact between an organ donor and recipient; an angry parent who disclosed the names of staff as well as patients who had died on the Unit; a parent who refused to talk with an ethics consult team so the team obtained background information through logging into an internet support community site; patient fundraising based on a particular diagnosis that was subsequently changed; and whether a professional obligation to report is triggered by reading a parent's posting of suicidal thoughts should their child die. In addition, there was concern raised about psychiatric doctors accessing information about patients through social media without those patients' prior express permission.

We focused much of our energies on trying to determine what were the actual benefits and burdens to medical staff when they became involved with patients and families through information obtained on internet support communities or other social media sites. Interestingly, we were not able to obtain consultative services from anyone in the professional internet world who would speak to questions of legal liability and staff obligations and those sorts of issues. We relied in large part on anecdotal accounts of our own experiences with these communities and our general knowledge of internet usage, recognizing our significant limitations in this area. We were very grateful to have a high school student among us. While a great deal of activity exists in the form of policy development to address the use or prohibition of use of social media, the terrain upon which we entered appears to be relatively uncharted.

Based on our group discussions and in order to obtain everyone's viewpoints, a survey was developed and distributed that solicited individual Committee members' thoughts on various topics that arose during our meetings. We met throughout the spring of 2009 to review the Committee members' survey responses and to focus our thoughts regarding this multi-faceted topic. Then, as a further outreach to the broader community and to buttress our conclusions, we distributed a modified survey to the general public through our own personal social networking contacts and through a student intern at Tufts, who polled students there. Now that we are in the spring of 2010, we have settled in our thoughts enough to finalize both this Report and our proposed Guidelines. Some of the comments from the various surveys are included in this Report.

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RESOURCES and SURVEY

A Bibliography of articles and resources distributed to the CEC is attached as Attachment 1; and the Survey that was distributed to the CEC members is attached as Attachment 2.

QUESTIONS PRESENTED

While recognizing there are myriad issues which arise upon the use of social media, the CEC focused on three questions which were most salient in connection with this topic. In brief, those questions were:

1. Should medical staff seek out and obtain personal information from patients and their families through the use of social media?
2. If medical staff do obtain personal information about patients and their families from social media sites, what are the particular concerns of the community in that regard?
3. If patients and their families post personal information on social media sites, what are the particular concerns of the community in that regard?

RESPONSES and COMMENTS

Even though the Committee acknowledges its stance may be too dogmatic for application in the “real world” and may be problematic in enforcement, we concluded that medical staff should NOT seek out and obtain personal information from patients and families through the use of social media. This conclusion was based upon our uniform bias that communication among medical staff, patients and families is best when it occurs face-to-face. Not only is it “best” but any, even minimal reliance on, communication on social media sites excludes significant parts of the population that already have difficulty obtaining the “ear” of the medical community – the elderly, the disadvantaged, and those who choose not to or are not able to communicate on social media sites.

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The CEC generated two proposed Guidelines in response to the other two questions raised by this consult request – Guidelines for Medical Staff and Guidelines for Patients and Families. Even while we are submitting proposed Guidelines, we are troubled by the “mixed message” that is being sent. The fact that Guidelines are perceived to be necessary assumes that our recommendation to abstain from obtaining information from social media sites will not be heeded. Such a reality is troubling to some on the Committee and merely an acknowledgement of our technology-driven society by others. It is a dilemma we have not solved.

We would also note that the discussion set forth below is necessarily condensed and cannot completely reflect the richness of the Committee’s discussions or the care with which we wrestled with these issues.

1. Recommendation that Medical Staff Abstain from Use of Social Media Sites

Most of the Committee felt comfortable saying medical staff should abstain from seeking out and obtaining information about patients and families through the use of social media. There was a general sense that relying on social media as a way to obtain information could lead to harming the underlying caregiving relationship with patients and families. The Committee attached a high value to the process of face-to-face communication because much more personal information is transferred in that way. The use of social media relies primarily on the written word and that alone separates out patient populations in a discriminating and disturbing manner. Racial and cultural disparities are noted in the ways different patient populations access and use social media. Most notably, the elderly, disabled and disadvantaged often do not have access to computers and may not be completely computer savvy or comfortable sharing personal information on a social media site. Medical staff who use social media sites to obtain information about patients, with the assumed goal of providing patients with the best possible care, are missing a large and especially vulnerable segment of their patient population. Perhaps it is stating the obvious, but medical staff using social media results in the “haves” having more access and a stronger voice in their care while the “have nots” are left with even less access and a significantly diminished voice in their care. In addition to the harm to good communication that is possibly done to patients who do not have access to social media sites, everyone loses to the extent face-to-face communication occurs less often and with less depth. Facial cues and body language, intonation and pauses and even volume – all convey necessary information that is lost in a social media encounter, no matter how many capital letters or exclamation points are used!

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In addition to creating an unrealistic expectation that medical staff will read and respond to all entries, medical staff participation on social media blurs professional boundaries, perhaps misleading a patient into concluding there is a level of intimacy and “friendship” which does not exist. Significant emotional burdens may then be placed on staff by patients and their families. One member of the Committee pointed out that, once a medical staff person has read a posting, they can’t “unread” it. That information, whether it is helpful or hurtful or just extraneous, still can affect a patient’s care and can alter staff’s interactions with both patients and their families. Lastly, a subtle but meaningful shift occurs when medical staff enter a patient’s or family’s social media site – their entry is ostensibly to help support the caregiving process but often they receive unrelated and highly personal information. In the Committee’s discussion it was noted that medical staff usually abstain from access to such personal information when discussions are happening in a patient’s room – staff leave the room, close the door, and allow families to have private conversations and personal interactions together. Our recommendation includes observation that medical staff should respect the private nature of some conversations on social media sites in the same way – by abstaining.

The Committee discussed the fact that there are other professionals whose access to social media sites is expressly limited. As has been much reported in the local news and as is evident when searching for policies on the use of social media, many venues are now responding by limiting access to personal information found on social media. The Committee membership includes teachers and rape crisis center volunteers and they acknowledged that limits are placed on their social media activity and that emphasis is placed on maintaining clear boundaries to protect others. The presence of a “power disparity” in these relationships was recognized – it arises when anyone is given access to someone else’s private and sensitive information, even if that information is provided in a “public” setting. (We discussed the fact that, while everything published on social media sites is public to the extent filters are not placed on content, the general perception is writings on social media sites are still perceived to be private.) Because teachers and rape crisis volunteers expect, understand and respect limitations on their contact with students and clients, the Committee concluded that medical staff should be able to maintain similar boundaries and should be able to comply with the Recommendation not to enter patients’ and families’ social media sites.

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We were able to speak at length with the President of Carepages, currently one of the most used internet support community sites and one which is typically hospital-affiliated. Their “reason for being” is to provide a support tool for patients and families, allowing easy transfer of information to friends and family members and creating a forum to share their journey through the healthcare system. Carepages views its service as a “family tool, not a professional tool.” Even so, their client is technically the hospital and they report monthly to each institution how many Carepages sites are created, how long those sites stay active, and how many visitors enter, logged by zip code. A hospital-sponsored site contains a banner with an opportunity to link to the institution’s development office, as a way to facilitate financial donations. Interestingly, when Carepages works with an institution to establish the service, they recommend that medical staff not enter the patients’ and families’ Carepages site unless they are specifically invited to do so, and they should never post entries on the site.

Two other points should be made in connection with the complexity the Committee encountered in making this recommendation that medical staff should not seek out or obtain information from patients’ and families’ social media sites. First is the Committee’s understanding that there are varied levels of interactions on different sites. Some blogs are completely public and unscreened; a family’s Carepages site may be closely monitored and public access blocked; and other social media sites are viewed by many as private when, in fact, the information posted is completely open and public. In that context, it was the unanimous view of the Committee that sites such as Facebook should not be entered by medical staff. This strong recommendation of abstinence is based on our conclusion that there is an underlying implication of “friendship” being offered and accepted on Facebook and the disclosure of overtly personal information “crosses the line” in what would be expected in a therapeutic medical staff/patient interaction. Second is the Committee’s acknowledgement that this field is changing rapidly with new sites and technologies introduced all the time. We recognize that our recommendation may be outdated if and when medical staff can interact with patients and their families via social media sites in ways that closely aligns with our “gold standard” of face-to-face communication. In that event, our recommendation might change to reflect those technological changes. Nevertheless, the Committee’s bias toward face-to-face communication will remain until all population groups can be adequately accommodated. The medical community will need to take into account the absolute requirement to be inclusive, particularly with a group of patients and families who may be more vulnerable to misunderstanding and misinterpretation.

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In order to maintain the integrity of communication among patients, their families and medical staff and to maximize the incidence of face-to-face communication, the Committee recommends that medical staff abstain from seeking out and obtaining personal information from social media sites.

Comments from the Survey having to do with this recommendation to abstain from social media sites include the following:

- I think hospital policy should prevent staff from joining/reading entries – unless someone was joining as a family member or patient. In any case, I do not think staff should read the blogs written by his/her patients.
- Internet writings serve best as enhancements to but not as the primary vehicle of communication among all the interested members of the community. My hope is that other avenues for patients and families to communicate with medical staff will be found, developed, encouraged and used so that an open dialog can be maintained – all to accomplish the goal of providing the best healthcare for the benefit of everyone involved.
- Telling staff not to read patients' blogs and not to “google” patients probably won't work and shouldn't be expected. Better to focus on helping staff anticipate the problems that could come with learning information they might need to do something about – like suicidal thoughts.

2. Guidelines for Medical Staff

The Committee's views on the recommendation to limit medical staff's access to social media was varied and Guidelines were proposed to address the reality that medical staff would, in fact, seek out and obtain information on patient's and families' through social media sites. In response to the question “Should medical staff be able to read entries?” many on the Committee concluded that staff could read posts as long as it was done “mindfully”. All but one on the Committee felt strongly that medical staff should not post entries to social media sites. The one dissenting voice stated that medical staff should respond “in whatever way is appropriate”, recognizing that might include posting on a site. Guidelines for Medical Staff were reviewed and discussed and, while they are not exhaustive and are not intended to take the place of any institution-promulgated Guidelines, they do highlight what we, as a Committee, felt were the most important issues in this area.

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Comments from the Survey having to do with medical staff seeking out and obtaining personal information from a patient's or family members' social media sites include the following:

- I do think guidelines should be in place so that medical staff disclose the fact that they are reading a patient's or family's blog or internet support community site and there are disclaimers so that professional responsibilities aren't triggered by reading a patient's or family's entries.
- Provide guidelines, such as "only read them if invited explicitly by the patient."
- Should be accessible. Perhaps the best way to curb excess (entries) is to set parameter that designated or selected medical staff be included in readership. Medical team may learn important information about patient, family, etc. not otherwise communicated. Medical staff should NOT use this medium for communicating with family or patient except rarely, to be supportive.
- Unless there is a special and pressing need to do so in a given case (e.g. the patient is not communicating in any other way with the care team, and there is a worry about the patient's harming himself), I don't think staff are obligated to read patient blogs.
- There should be boundaries in any caregiver/patient relationship, and this should be one of them. If the hospital makes it a policy that caregivers not read patient blogs, I think it will alleviate concerns and anxieties for everyone.
- Medical staff should be aware of the ways blogging can compromise care and privacy, but this can't be a hard and fast policy or ban. Perhaps a hospital policy could strongly recommend that staff decline invitations to join support communities or read blogs and inform patients of this policy and reasons behind it. This would provide staff with a tactful way of declining and would also allow for discretionary exceptions. [In our case], caregivers in Boston found our Carepage helpful in following our progress while we were away and I think it positively impacted the care we received when we returned.
- If staff decides to read the blog, they must speak directly with the family in advance, informing them of their motivations and intentions as well as coming to agreement with the family on potential courses of action. If family does not agree, then the staff should not view the blog. If family agrees, and concerns later

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- arise regarding the blog content (patient suicide threats, family complaints about staff/treatment, personal references or identifying information), the staff and family will have already established a process, based upon honest and open communication to address these matters.
- It's ok to read it, but I don't think staff should be encouraged or expected to read a patient's blog. It's not the same as e-mail.
 - With the patient's permission, staff might gain information on patient emotions and struggles that could assist care.
 - Troubling motives [of staff] include: 1. Staff just has a morbid curiosity. 2. Staff wants to see if he/she is mentioned. 3. Staff wants to know more about a patient's personal life than is necessary/appropriate. 4. Staff is crossing the boundary in the caregiver/patient relationship.
 - One-to-one e-mail is appropriate, but direct communication by phone or in person is best.
 - You know something about a patient – you have to act on what you know.
 - It could be done face to face, i.e. "I read your blog and I wanted to give you my professional input on what you said."

Once again, the Committee concluded that institutions should be strongly encouraged to facilitate face-to-face communication by medical staff with patients and their families, recognizing that a healthcare environment that supports patients and families through direct and personal interactions is far superior to reliance on the relatively impersonal forum of social media sites.

3. Guidelines for Patients and Families

The Committee was primarily concerned about two aspects of patients' and families' use of social media – maintaining the privacy of others and limiting emotional "venting" that could harm others.

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One of the difficulties which the Committee wrestled with is the fact that social media sites often have the “feel” of private and protected communication, when they are, in fact, public and unprotected. Often what is posted remains available for public scrutiny forever. A momentary emotional outburst that might be understandable in the context of a difficult healthcare encounter may result in real and unintended professional and institutional harm. Care must be taken by patients and their families that postings be temperate and courteous.

Another difficulty is the fact that many of those who benefit from maintaining a presence within an internet support community such as Carepages are those who are “in the system” for long periods of time, those with a chronic illness. Those individuals often and understandably develop close friendships with others similarly situated. The benefits of the support gained by having others who “know” are inestimable. The problem arises when names of others become part of site entries and disclosures of private information include individuals’ diagnoses, courses of treatment, home locations, and even photographs. While medical staff have been sensitized to privacy issues through the HIPAA training process, patients and their families are often not as aware of the need to protect others’ privacy. Part of an institution’s sponsorship of an internet support community portal must be the institution’s responsibility to remind and encourage patients and their families to bear a heightened degree of sensitivity to protect the privacy interests of others.

Comments from the Survey about issues surrounding patient and family use of social media include the following:

- Talk to the patient’s family and ask them to remove it [the posting] or have the internet service remove it.
- Families are free to post their experiences. They must be warned that anything written down is likely to be read by many individuals. They should not use names and that the hospital administration may use postings in a manner that they had not intended.
- If possible, patients/families should refrain from identifying specific staff by name. If a patient would like to report something about a physician, s/he should do so through the appropriate medical board. I believe it would violate free speech to try to prevent someone from discussing their frustrations and negative experiences on their internet postings.

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- I think there is great value to the quick communication to family and friends that is available via these internet sites. I am more careful of the privacy issues – meaning I am not sure I would want myself or my family members exposed to the public by sharing overly personal medical information or photos. I would also be concerned about finding myself reliant upon internet sites to communicate with healthcare professionals when that indirect way may create a sense of intimacy or transparency that is not, in fact, there.
- I'd rather communicate face to face. Plus, I'd write differently if I knew providers were reading.
- Yes [I would want health care providers to respond to a posting], but respond to me directly and face-to-face, not through the blog or internet posting. It would be an encouragement to know they were interested enough to follow-up with me to read a blog or posting, but it would be important to me to know they cared enough to follow-up in person.
- I would feel that guidelines are appropriate and may be protecting me as well as the health care facility.
- If guidelines pertained to privacy of staff and patients, that is understandable. However they cannot tell me what kind of content to write.
- An important issue to deal with. Won't go away. Policy and guidelines? Very necessary. Mandates? Not sure what this would look like.

4. Public Survey Results.

Results of the public surveys – those distributed to the broader community through Committee members' social networking (89 responses) and through a student intern's polling of their Tufts community (93 responses) – were striking in their confirmation of the Committee's recommendation to encourage face-to-face interactions between health care providers and patients.

For instance, when both the public and Tufts surveyed individuals blogged about an illness, 90.9% : 88.9% said they did NOT blog “to communicate with nurses, doctors and other health care staff”; and 93.3% : 100% did NOT invite hospital staff to read their blog. In response to the statement “I don't think it is a good idea for nurses and doctors to be Facebook friends with their patients (or their patients' family members),

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73.2% : 80% agreed or agreed strongly; while 62.1% : 66.7% disagreed or strongly disagreed with the statement “I think connecting with nurses, physicians and other health care providers on social internet sites might help them understand me better.” And perhaps most telling, 72.7% : 79.5% agreed or strongly agreed that “In more cases, I would rather have my health care provider respond in person to medical concerns posted on a weblog.”

Concerns about privacy and maintaining professional boundaries were paramount and many of the comments reflected a longing for better connection with their health care providers, posting comments such as:

- Why not [communicate with your doctor through an internet site]? Especially since they are often too busy to stop and talk.
- I would welcome more participation by health care providers online. My doctor and her office seem so remote and inaccessible, you can only get to them by phone during office hours, and then contact is limited.
- As long as privacy is maintained, electronic contact is a good supplement to face-to-face care. N.B. It is not a substitute for it.
- Not appropriate. Doctors should have professional relationships with their patients, and social networking sites represent something in the personal sphere. Professional and personal shouldn't mix.
- One would have to be wary of crossing the line of professionalism and veering into being over-familiar or less authoritative in performing one's healthcare role. It might make the process more impersonal for some who need the human touch.
- I believe this can blur the boundary between patient and practitioner. A healthcare professional is not your friend. Communicating via the internet is fine at face value, but not when it involves “friending” someone and gaining access to non-healthcare related personal information.
- As a nurse practitioner, I would not feel comfortable interacting with my patients in this manner. I rely heavily on face-to-face and phone conversations I have with my patients. I would be afraid I would miss a crucial aspect of my assessment over a social networking site.

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- No, it is not the place for private business. Although it may increase communication between the two groups, it more likely adds distance to the relationship.
- This would seem to impersonalize a relationship that should already be more personal.
- I don't think interaction between patients and their providers on a social networking site constitutes a professional relationship. Both patients and doctors deserve their own separate lives.
- The doctors' time is too valuable. Face to face contact is a better way of dealing with medical issues.

ASSUMPTIONS leading to the Committee's decision to limit medical staff entry into internet support communities and to provide guidance to patients and families regarding their postings.

This area of patient/medical team communication is ever-evolving and the Committee felt strongly we were entering uncharted territory. As has been stated, our "gold standard" of patient and medical team communication is direct dialogue, with an assumption that sufficient time can be allocated to ensure an airing of patient and family questions, hopes and fears; a reading of body language and other nuanced modalities of communication; and, of course, expressions of respect and concern, accommodating the many differences presented by the "community" at large. The Committee made the recommendation it did based in large part on the assumption that by advocating as strongly as possible for that "gold standard" of direct dialogue, it might actually occur.

Another assumption the Committee held was that the varied forms of social media lie on a spectrum. Some forms of communication on social media require less "protection", being more public and carrying fewer expectations of a direct personal encounter - such as postings on public blogs. While other forms of social media communication would seem to require more "protection", being more private and carrying expectations of "friendship" and personal connection - such as Facebook and MySpace. The form of social media that many on the Committee felt might enhance patient and medical staff interactions is direct e-mail - a forum where questions can be posed and answered in a well-constructed, private and secure manner. That form of

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social media seemed to present the possibility of enhancing that “gold standard” of direct dialogue. Another facet of social media which the Committee acknowledged was developing at great speed was video conferencing and we recognized that, once again, that form of social media interaction might come close to approximating the direct dialogue we so want to foster and protect.

Lastly, the Committee did not want to assume that medical personnel would ignore its recommendation and enter these more personal social media sites ill-advisedly. As was mentioned above, we hesitated in presenting Guidelines for Medical Staff because we did not want to send a “mixed message.” But we also recognized that for every rule there is an exception and we could conceive of situations where direct interaction with a patient’s medical team might not be possible and the use of social media as a secondary (or even primary) form of communication might be better than no communication at all. We hope that would be a rare occasion but it is for those occasions that our Guidelines are provided.

Guidelines for Medical Staff *vis a vis* Communication with Patients and their Families through Internet Support Communities

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Purpose:

The institution encourages the use of the internet to provide patients and families with community support (through internet support communities) and with a way to process their healthcare and life experiences (through blogs). These Guidelines address individual patient/family blogs and formal internet support communities (such as CarePages and Caring Bridge), as well as popular networking sites such as Facebook, MySpace and Twitter.

The terms used in these Guidelines such as “blogs” and “internet support communities” are not intended to be exhaustive of the myriad ways in which patients and families may communicate about their healthcare experiences. The extraordinary growth of different venues for connecting with others will necessarily make any specific reference to electronic communication time-bound. As a result, these Guidelines will use the term “social networking sites” in a generic way.

These Guidelines are based upon the underlying premise that the use of social networking sites is essentially a private function with the primary goal of benefiting patients and their families. While expectations of privacy may or may not be realistic or protected, the essential act of a patient or family member writing about his or her encounters within the healthcare system are considered private – much like the unspoken expectation that exists when family members enter a patient’s room for a visit, the healthcare staff leave to facilitate private interactions and support.

Of particular import, these Guidelines reflect an institutional bias toward face-to-face interactions between patients and their families with medical staff. Much is lost in the interpersonal exchange of information when it is confined to an electronic medium alone. Tone of voice, facial movements, body language, eye contact all convey in powerful ways additional information and emotional content. Such “face-to-face” forms of communication must be protected and these Guidelines are predicated upon a desire to preserve the primacy of direct communication within the healthcare setting. The goal of excellent communication with medical staff is to provide not only relevant clinical information but crucial emotional support as well. That goal is met most effectively in direct interactions with patient, family members and medical staff.

In sum, these Guidelines are provided both to enhance the benefits which are available to patients and families through their use of the internet and to protect the medical staff from the burdens inherent in communicating on these social networking sites.

**Guidelines for Medical Staff
vis a vis Communication with Patients and their Families
through Internet Support Communities**

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Recommendation:

The institution recommends that medical staff refrain from participating in social networking sites by entering, reading, posting, commenting or in any way communicating on sites which provide an individual entry to a patient's or family's posting.

Guidelines:

Recognizing that not all medical staff will be able to draw a bright line between professional/public and personal/private roles with certain patients and their families, these Guidelines are provided to help limit participation on internet support communities when that happens. The fact that some social networking sites are sponsored by the institution implies that medical staff employed by the institution accept the following Guidelines.

1. Be transparent – state who you are and in what capacity you are participating on the site;
2. Be judicious – use words carefully and purposefully – do not write things you would not say to the individual directly;
3. Write what you know – do not rely on someone else's description of events or interactions;
4. Perception is reality – even if what a patient or family member perceives as something that happened or how an interaction occurred is “mis-remembered”, respond with an understanding that people process encounters differently;
5. Are you adding value – make sure that what you post is helpful, true and supportive;
6. Moderation – choose your words and your moments of interaction carefully;
7. Focus on the individuals – communication with patients and their families should be focused on them and their needs and should not be a forum for conveying professional expertise or insights.
8. Be protective of the patient – recognize there is a “power disparity” and that, even though you may have become a personal “friend”, you also represent the institution caring for a family's loved one; we recommend you do not post, but if you do, post carefully. Thank you.

Guidelines for Patients and Families Communication through Internet Support Communities

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The terms used in these Guidelines such as “blogs” and “internet support communities” are not intended to be exhaustive of the myriad ways in which patients and families may communicate about their healthcare experiences. The extraordinary growth of different venues for connecting with others will necessarily make any specific reference to electronic communication time-bound. As a result, these Guidelines will use the term “social networking sites” in a generic way.

These Guidelines are based upon the underlying premise that the use of social networking sites is essentially a private function with the primary goal of benefiting patients and their families. While expectations of privacy may or may not be realistic or protected, the essential act of a patient or family member writing about his or her encounters within the healthcare system are considered private.

We want to encourage face-to-face interactions with the medical staff and hope that the use of internet support communities will not be used to replace that direct communication. Much is lost in the interpersonal exchange of information when it is confined to an electronic medium alone. Tone of voice, facial movements, body language, eye contact all convey in powerful ways additional information and emotional content. Such “face-to-face” forms of communication must be protected and these Guidelines are predicated upon a desire to preserve the primacy of direct communication within the healthcare setting. We do not want you to rely on communicating concerns and information that may have clinical significance on an internet support community site. The institution has established Guidelines that recommend that medical staff NOT participate in any way in those internet support community sites.

In sum, these Guidelines are provided both to enhance the benefits which are available to patients and families through their use of the internet and to protect the medical staff from the burdens inherent in communicating on these social networking sites.

Guidelines for Patients and Families Communication through Internet Support Communities

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Recommendation:

Even though close ties may be developed with the medical staff caring for you or your loved one, the institution recommends that you refrain from asking medical staff to participate in social networking sites by entering, reading, posting, commenting or in any way communicating on internet support community sites.

Guidelines:

We encourage you to show general courtesy and thoughtfulness when using internet support communities. These Guidelines are provided to help facilitate participation on those internet sites. The fact that some social networking sites are sponsored by the institution implies that patients and families who enter those sponsored sites accept the following Guidelines.

1. Be judicious – use words carefully and purposefully – do not write things you would not say to any individual directly;
2. Write what you know – do not rely on someone else’s description of events or interactions;
3. Protecting others’ privacy – many of you develop close ties with other patients and families who share your experiences within the healthcare community. Their personal information (their names, where they live, what the patient’s medical diagnosis is, their internet support community site name) should be protected and not included in your posting (you can always use initials if you want to identify someone);
4. Photographs – some medical staff are shy and do not feel comfortable having their photograph posted in a public setting such as the internet – be sensitive to those feelings and always ask before posting;
5. Be careful of professional reputations – recognize that what you post in an emotionally charged moment stays on the internet forever. Professional reputations can be harmed by “letting off steam” and we would ask that you use care in posting anything that could harm someone else.
6. Always discuss medical information face-to-face - we have recommended that medical staff not participate on internet support communities. We want to be sure that medical information is conveyed to staff in a way that will be processed promptly and professionally. We want to encourage face-to-face dialog between the patient, the family and medical staff.