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Information Behaviors in an Online Smoking Cessation Forum

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Smoking is a major contributor to morbidity and mortality today, and a focus of attention by primary care practitioners and public health. Few studies take into account the role of community-based information transactions, nor have they examined the information needs of quitting smokers beyond generic patient education pamphlets. A pilot study examines the function and value of information communicated in an online forum dedicated to smoking cessation. Firstly, a Web-based survey was sent to fourteen forum participants known by the author. Twenty questions about medications, decision support sources, the evaluation of those sources, and basic demographic information were asked and the resulting responses were analyzed. Secondly, 371 selected posts from the Web forum were collected to better understand the importance and frequency of specific types of cessation-related information. Several models are discussed in a preliminary attempt to characterize the forum's community-based information behaviors. Survey respondents view the existence of online community-based information resources (in the persons of their community peers) as a major factor in their cessation efforts. Although no attempt was made to generalize findings beyond this initial pilot, gaps were tentatively identified between the support provided by more traditional healthcare practitioners and the information needs experienced by this population. In their provision of a milieu for the exchange of information, online fora may enable support at a depth and quantity unavailable through more immediate channels. Further studies are needed to develop a better understanding of information-related behaviors of this large population.

> "I have learned compassion, patience, understanding, sympathy, endurance, what giraffe goo will do to your hair, 4,728 ways to have fun with whipped cream, […] what it feels like to have emphysema, how to fly a kite while naked, every Campbell's soup recipe ever invented, what it is like to watch a loved one die from a smoking related illness, and how to find the words to songs on the Internet. […] [T]hat I can live a full and happy life without cigarettes […] and how comforting it is to share time with people who are going through the same thing you are. And I have only been on this road for 9 months. I can hardly wait to see what I learn tomorrow!"
>
> – Quitnet participant

Smoking as a national issue

Addiction to nicotine still plays a major role in our society, despite more than four decades of effort by conventional medicine (Burns 2002). Even now, in the broadening wake of tobacco litigation, large-scale prohibition of smoking in public places, and the increasing direct costs of supporting the habit, some 25% of all adult Americans light up, resulting in more than 440,000 deaths per year – a stunning 40% of all preventable deaths. Smoking costs an estimated $50 billion in healthcare, with lost wages and productivity adding up to another estimated $47 billion per annum (Fiore 2000).

Tobacco addiction has now been characterized as far more than a 'habit'. Physiologically, it has been said to be addictive in much the same way as crack cocaine, due to nicotine's multi-system impact. In fact, nicotine has been found to activate the same dopamine-containing neural transmitters as crack and other addictive substances. Research is just beginning to consider the dopamine-enhancing role of substances as integral com-

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ponents of all addiction (Leshner 1998). Smokers attempting to quit often experience symptoms very similar to those experienced by other addicts in withdrawal, including sleep disturbances, depression, concentration difficulties, impatience, and anxiety (Hughes 1994).

> "Researchers found nicotine, just like cocaine, heroin and marijuana, activates dopamine containing neurons in the critical brain pathways that control reward and pleasure. This finding supports a convergence of data pointing toward at least one major commonality among all drugs of abuse: they all elevate levels of the neurotransmitter dopamine. It is this change in dopamine that is believed to be a fundamental root of all addictions." (Leshner 1998)

An estimated 35 million people, or nearly 70% of all smokers, try to quit each year, but very few actually succeed. Most who attempt to quit try to do so 'cold turkey' (without any sort of cessation aid). Only a slim 2.5% succeed in their initial attempt. More than 90% relapse within their first year, most within the first week. Long-term cessation often requires multiple efforts (Leshner 1998). Even though medicine has now discovered all of the fatal diseases caused by smoking, much remains to be discovered about the complexities of addiction overall and effective pharmacotherapeutic and psychosocial intervention. According to the U.S. Surgeon General's report, the most effective means of cessation involves a three-pronged prescription of bupropion (an antidepressant medication), nicotine replacement therapy, and support (U.S. Department of Health and Human Services 2000b).

Encouraging patients to stop smoking has become a priority in public health initiatives, given its cost to society. Indeed, it has been identified as a goal for the Healthy People 2010 initiative (US Department of Health and Human Services, 2000). Multiple support modalities and pharmacotherapeutic means are being explored in attempting to address the issue, and stepped-up anti-tobacco advertising, support in the form of in-person cessation clinics, individual counseling, and online self-help and mediated forums have all attracted increasing numbers of participants. However, scant attention has been given to the role of information in cessation. Some research has shown a limited benefit in the use of individually-tailored self-help materials with regard to their effect on successful cessation, but even so recent and well-regarded a review as the Cochrane Collaborative's 'Self-Help Interventions for Smoking Cessation' measured the effectiveness of 'self-help materials' only in the broadest sense, preferring to discuss format over content (Lancaster 2000), although the author did speculate that

> "Information is an important part of individual participation in all forms of health care, and the provision of written and other forms of information to smokers has important face validity. However, the effects of providing standardised self-help materials are modest at best. Smokers who seek help are likely to benefit more from brief advice or counseling, or from tailored materials. Large evaluations of Internet based systems offering tailored support have not yet been reported; this may be a powerful way to give smokers individualized resources" (Lancaster 2000).

The support known to be a crucial component of a successful quit has been defined in a number of different ways. For traditional medicine, it means inquiring about the patient's smoking status at every visit and the provision of standardized materials, supplemented in some practices with periodic telephone consultation (U.S. Department of Health and Human Services 2000b, Burns 2002, Lancaster 2000). For some allied health professionals, however, support has meant ongoing interaction, 'social support' by means of peer community building, incorporating the practice of 'information therapy' [1] – or at least information is considered a component of patient support.

Online communities, in the form of e-mail partnerships, bulletin-board systems, lists and fora have evolved to enable the sharing of experience and information in addiction recovery, disease-focused conditions such as breast cancer or AIDs, Alzheimer's disease, and social conditions such as parenting or post-divorce coping. The concept of 'community' in the specific population chosen for this pilot study is similar to what has been defined in the literature of health studies as a group of individuals whose social interaction is loosely structured around an uniting principle or goal (Finn 1999).

Nicotine addiction has now been characterized as a chronic illness (Leshner 1998). Research has shown that several factors contribute to the need for self-help groups in populations dealing with chronic illness, including the lack of access to for-

mal healthcare, insufficient resources, the rising cost of healthcare, lack of support within the medical system, and a growing distrust of medical professionals (Finn 1999). Although participation in this type of community has been found to enhance the psychological well-being of people dealing with disease by providing support to those who might otherwise be isolated from more immediate sources of support in the amounts and intensity desired, there is little evidence to date that such social supports provided by those defined as 'weak ties' in the self-help literature (Cline 1999) [2] have any substantial impact on the cessation rates of group participants.

QuitNet: A community of quitters

For this study, the author chose to investigate a population of smokers who form a large community (an estimated 200,000 users) called QuitNet.com. Originally the brainchild of Nathan Cobb, a smoking cessation counselor (and now a practicing physician) at a Boston health clinic, QuitNet grew as a project of the Boston University School of Public Health, funded by grants from the Robert Woods Johnson Foundation. Year round, smokers at some stage of their quit (and many long past their initial throes of withdrawal) are active participants in QuitNet's bulletin boards, chat rooms, its 'premium membership' expert bulletin board, where certified cessation counselors provide tailored support and intervention, its access to decision-support information for medications and methods, and its news feed of tobacco industry and addiction research. One hundred and sixty (160) countries have been represented on the boards, although for the most part (some 85%) members log in from the U.S. More recently, QuitNet has gone public, and although it continues to be associated with Boston University, it is a separate entity. As such, the company has contracted with the states of both New Jersey and Colorado to provide premium support services for citizens, subsidized by tobacco settlement funds, and are seeking further opportunities for growth in the provision of tailored support to corporate employees (QuitNet 2003).

The author has been an active participant in the QuitNet forum for more than two years, and found research and information to be her own 'best method' for staying quit. Prior to becoming a full-time library student, she worked as a medical and consumer-health librarian, and has been increasingly intrigued by consumer health information as an important component of the patient- (or consumer-) practitioner collaborative relationship. It seemed a natural fit that she would examine how people in this online 'place' function with regard to information.

Rather than attempting to examine broader health information-seeking behaviors, [3] the focus for this pilot has been the information behaviors of quitting smokers among themselves and in their personal environments. For the purposes of this pilot study, this is broadly defined as information transactions related to medications (prescribed and over-the-counter, includ-ing herbs and supplements), methods (including 'cold turkey', massage and other therapies), their effects, and the physiological, emotional, and behavioral/cognitive aspects of cessation. By focusing on these more intimate aspects of cessation, the author hopes to add to the overall understanding of the quitting smoker's information needs, and thus enhance the abilities of healthcare and information professionals to provide assistance.

An important concept in cessation theory known as the 'Stages of Change' model was initially adapted from broader behavior change models to fit the smoker's progress toward and beyond cessation (Prochaska 1991). It is the framework used by the QuitNet cessation experts in their provision of forum-based cessation readiness testing and other pertinent information. In this construct, the smoker is viewed as progressing through five distinct stages identified as precontemplation, contemplation, preparation, action and maintenance. Criticism of this model (Miller 1999) centers upon the lack of any provision for relapse, which has been recognized as an integral part of quitting (Leshner 1998).

Although articles about the 'stages of change' address helping the patient realize the benefits of quitting and the need to explore alternative coping mechanisms, there is little or no mention of the smoker's need for information as an entity in the process of decision support. In trying to comprehend this lack, Dervin's discussion of what she labels as 'emerging themes' concerning the nature (and failure) of public health campaigns lends perspective (Dervin 1999). Though her study

Table 1: Stages of Change Model adapted to smoking cessation (Prochaska, 1991)

Pre-contemplation	Contemplation	Preparation	Action	Maintenance
No thoughts of smoking, or seeking of interventions	Seriously thinking of quitting within 6 months; aware of ill effects, but also still perceives positive aspects of smoking	Serious about quitting, has set a quit date within next month	Has quit within the previous 6 month period	Has remained smoke-free for at least 6 months

examines the information behavior of pregnant addicts, there are elements pertinent to the addicted smoker and their failure to not only quit (aside from the addiction itself) but to find the abjurations of healthcare professionals of much use in terms of psychosocial support. What Dervin identifies as themes includes the issue of 'gaps' between expert information and the intended audience, as well as a faulty assumption on the part of healthcare entities that simply translating such technical, expert jargon to lay terms couched in the appropriate literacy-leveled terminology suffices to change minds and thus, to remedy negative behaviors. Even beyond that, she speaks of the deficit-correction approach taken by many health campaigns, explaining that such an approach – intended to strengthen with fact-based information – might instead assign blame and reinforce the very same negative coping behaviors intended to be extinguished.

It was beyond the reasonable reach of the pilot study to directly approach participants, due to their geographic distribution. While it might have been valuable to conduct the type of deep, open-ended interview Dervin used to uncover her population's real needs as separate from what had been perceived by the institutional entity of healthcare, doing so would have taken considerably more time than was feasible. As well, the study population, although obviously made up of individuals, is also an interdependent community whose effectiveness appears to stem from its size and online availability. For this reason, the author chose to focus on both the individual, by means of a survey, and on the community, by observation and data gathering.

Participant survey

The survey instrument was a 20-question Web-based form designed to elicit responses about basic demographic information (including smoking history), cessation strategies past and present with regard to medications and therapies, and a number of questions designed to have participants report and assign value-weight to the information they have received from various channels for the period of time from their pre-contemplative stage to the present day. In addition, respondents were asked to characterize the cessation-related content of their participation on the web forum. The author used free survey templates and Web hosting, [4] even though doing so meant the survey 'launch' time was then limited to ten days, and the survey itself could not exceed twenty questions.

The people selected for this part of the research pilot are all adults who have already attempted to quit smoking at least one time while participating at the Quitnet forum, of which they are all members. They all speak English, and demonstrate at least a basic level of ability with regard to Web page navigation, e-mail, and reading and posting on a bulletin board. Assumptions made include the relative financial well being of these participants, since they all are able to access the Internet from home or work – although there is nothing preventing anyone from logging on via a computer in a public library.

Initially, the author contacted the Web forum's administration by e-mail, and then talked with them by phone. The study's purpose and goal were discussed, and the author received their acknowledgment and some unpublished data gathered during their own, unpublished survey. It was completely understandable that the QuitNet administration felt it important to avoid any assumption that this research was being supported or subsidized by their organization, and so 'public' announcements (posts placed on the forum itself) were careful to explain that the study was for a library school class.

Participation was solicited by means of the forum's proprietary e-mail system, known as 'Q-Mail'. The author approached people she knew, although once it appeared that all the respondents were older, several younger people were deliberately selected in order to gather a greater range of responses. All but one person completed the survey very quickly. This last person demonstrated extraordinary patience, finally completing a text-based version of the survey questions sent in the body of an e-mail when they encountered inexplicable and frustrating difficulties with the submission of the online survey post-completion. Many more individuals offered enthusiastic support and information following forum announcements than could be included in this pilot.

Response was complete, with all 14 of the 14 people filling out and submitting their surveys. Ten of the 14 were female; most (78%) were 36 years of age or older. The author did not ask about race or education, but due to personal knowledge, is fairly comfortable in asserting that 11 of 14 were U.S. residents, or 78%. Comparing the survey responses to those provided by the QuitNet administration, it appeared that the small sample, at least in this way, was representative. Their own respondents from a 3-month e-mail survey were mostly female (71.7% to this pilot's 71%) and non-Hispanic white (92.4%) with an average age of 38 years. Although the survey form divided this category into age groups rather than simply asking for age, by far the largest number of responses fell into the age-range from 36–45, or 46%. All respondents agreed to re-contact.

Cessation aids

> "I am going to try to quit smoking in the near future (again)! My doctor told me to take Wellbutrin for just one week before I quit, however, several pharmacists told me that I should be on the medication a minimum of two weeks before it will really be in my system enough to help. Is there anyone out there who really knows how long I should be on Wellbutrin before trying to quit smoking?"
>
> – post from new Quitnet participant

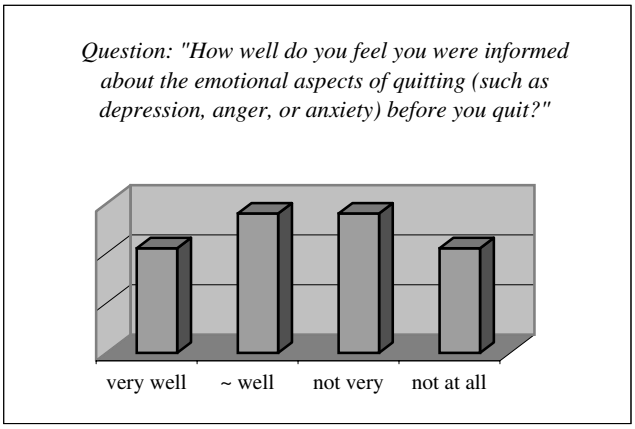
Only two questions about medications and therapies were asked, but these were fairly detailed. For the first, respondents were asked to indicate their current or past use of any of the listed medication categories, which included prescribed (29%), non-prescribed (OTC) (43%), herbs (36%), supplements (7%), or none (CT) (21%). A last item in this category asked whether the respondent thought they might have used any of these substances had they been aware of them (14%). Categories were described carefully to forestall confusion ("supplements, either single supplements such as Vitamin E, or multi-vitamins specifically sold as cessation aids') but in examining the responses, it appears that a little more explanation would have been beneficial. There is realistic concern that the statistic for 'none', for example, is faulty because respondents could have thought the question meant 'nothing ever, in any of their attempts to quit' rather than what had been intended by the question, which was if they had ever attempted to quit 'cold turkey'.

Questions were asked about a number of therapeutic interventions, including acupuncture (7%), acupressure (0%), aromatherapy (36%), counseling with a cessation support counselor (14%), counseling with a healthcare professional (defined as a doctor, nurse, or nurse practitioner, 21%), group sessions associated with a cessation clinic (43%), hypnosis (7%), massage therapy (21%), none (36%), and 'other' (7% – this was a traditional Chinese practitioner.) Perhaps the most surprising response to this question was the use of 'aromatherapy', since the author had never seen it mentioned anywhere on the forum as an alternative therapy in cessation. Second, it seems clear that the people answering this survey have been open to a number of therapies. In considering the relatively low number of people who had therapeutic support from their healthcare practitioners (21%), it appears that the question might have been defined with more care, to include brief discussions. Lastly, it seems of some interest that of the four males responding to this survey, only one used any type of counseling or medication.

Information sources and interactions

It is clear that quitting smokers are gathering their information from a number of sources. By far the most-cited source was fellow quitters at the QuitNet forum (93%), followed by the World Wide Web (86%; the survey did not ask for URL's, or any further information on this issue); doctors

Figure 1: Respondents levels of how well informed they were about emotional aspects of quitting



(50%); organizations such as the American Lung Association (43%); cessation counse-lors (43%); friends or family member (21%) and 'other' (14%). One respondent mentioned a traditional Chinese doctor, while another cited an article in a health magazine, *Self*.

When asked about perceptions of how well participants felt themselves to have been informed prior to their quit, responses clearly showed where gaps might be in the area of cessation information available to at least this pilot group of quitters. While most felt they were 'very well' (21%) or 'somewhat well' (50%) informed about cessation medications, herbs, and therapies, the remaining 28% felt 'not very' (21%) or 'not at all' (7%) well prepared. Far greater discrepancies were demonstrated in the area of emotional issues related to quitting, with equal numbers expressing that they were 'very well' or somewhat well' prepared, and 'not very well' or 'not at all' prepared. 64% and 35%, respectively, felt more or less well informed about the physical aspects of cessation.

Two questions designed to discover aspects of the participant's forum-based provision and requests for information followed. The question asked was 'have you ever provided information about the following *to* fellow quitters on the QuitStop forum, or any other cessation support forum? Please check all that apply." An overwhelming number of respondents said they had provided 'information about [their] *own experiences* with quitting' first, at 93%, then behavioral aspects of quitting (86%; this included coping mechanisms for filling in the time formerly taken up by smoking), then emotional aspects (71%) and physical aspects (also 71%). Seventy-one percent (71%) claimed to have provided information about both quit-related medications, while 64% gave 'other' information.

All 14 respondents said they'd obtained information about others' experiences from the forum, followed by information about the emotional aspects of quitting (79%), physical aspects (71%) and all three categories – behavioral aspects of quitting (64%), medication information (57%), and 'other' rated a 64% response.

Participants were asked to evaluate the information they found most helpful in their quits. Most found information about the emotional aspects of quitting most valuable (93%) followed by the experiential narrative (86%), then information about the physical effects of cessation (71%), and then information about cessation medications (29%; this question did not differentiate between prescription or non-prescription medications.)

With regard to people's perceptions of the support they received – perhaps unsurprisingly, given the population, most very strongly credited the online forum's support and interaction (100%) – then, second and somewhat less strongly, friends and family (54%), followed by their own physicians (38%). However, in retrospect the author recognizes this as a potentially biased response (at least with regard to their rating of the forum, because most were and had been participants for at least a year).

Survey participants were queried about their perceptions of the support they'd received from various places. Despite the fact that they tended not to have received information from their doctors, most found their doctors to be a source of 'strong' or 'somewhat strong' support (58%), although 21% found their physician 'not very' or 'not at all' a source of support, and a further 21% who marked this question 'n/a'. None of the participants had used a homeopathic healthcare counselor.

Of the 5 persons who had used a cessation counselor, they found this interaction to be either 'strongly' supportive (60%) or 'somewhat' (40%) supportive. Friends and family were helpful, with this undifferentiated category rated strongly or somewhat strongly supportive (78%), followed by 21% who felt that their environment provided inadequate cessation support. Overwhelmingly, the participants found the Quitnet forum itself to

be a central component of their quit, rating it as strongly (93%) or somewhat strongly (7%) supportive.

Data-gathering on the forum itself

The initial intent was to capture posts from the forum over a 3–5 day period, but due to time constraints and the task's complexity, only two full days of data were gathered. Even with that, 53 unique 'threads' (complete sequences of messages, including an initial posting and any subsequent responses) were gathered by copying their URLs into a table. After this step, each separate thread was printed and then coded. Counting and coding each response, 371 individual messages were collected for analysis. Rather than gathering every single post and response within that time period only those clearly focused on cessation itself were selected. For example, messages celebrating quit 'anniversaries' [5] were ignored, based upon the reasoning that these posts (although certainly informational) were often not really about the quit effort itself. This was a difficult call to make, as every post made in the Quitnet forum could fairly be said to be 'about' quitting, if only in the most peripheral way; people post and respond to jokes, share day-to-day incidents, argue and discuss issues of the day, and so forth, passing time – and by doing so, keep their hands busy (and away from cigarettes). These activities help to build what is a very clearly identified community.

The initial postings were separated from the responses for reasons of analysis, because it was initially thought that an examination of the ask-answer patterns, and their apparent congruence might be instructive. Initial posts were separated into 26 categories, while responses had 32 subjects identified. There was no limit set on the number of codes assigned to messages, although this would have made the identification of prevalent topics of discussion a far simpler task.

For initial postings, by far the most frequent category was the request for general support or advice, non-specific ('I'm planning on quitting next Monday – help!') 51% of all initial posts fell into this category. Other frequent topics were either a sharing of, or a request for, information with regard to the emotional aspects of cessation ('I feel like I've lost my best friend, I can't stop crying'; 22 of 53 posts, or 42%); and the disclosure of a narrative cessation or smoking history came next, followed by comments or questions about the behavioral or cognitive aspects. Questions or comments related to cessation medications or therapies were mentioned in 28% of initial postings.

Responses to posts did not always address the specific questions asked, and several times, there were questions posted which never did garner any type of response, whether accurate or not. No extensive analysis of the 'fit' between the initial posting and the responses was performed, due to time constraints.

By far the largest number of responses offered either general or spiritual support ("I know you can do it!") (59%). Other frequent content was a narrative account or display of cessation statistics ('I've been quit 39 days, 2 hours, 2 days of my life saved!) (44%), then "me too" responses, which empathized with the initial poster's comments by mirroring back their own, similar circumstances or history (26.7%).

Models and theories

In attempting to characterize the information behaviors of forum participants, the author found Dervin's work on information gaps to be an important component. Dervin (1999) also cites others who had found that there was a "great deal of distrust of expert medical information, particularly among the poor and marginalized of society, but also among the generalized populace." The findings of this pilot did not directly echo this conclusion, but as a participant-observer, the author would have to agree. Whether this is true overall of forum participants could perhaps be addressed in a far broader survey. It is not known, due to the construction of the survey, whether respondents had actually requested information or had it made available to them. What was found instead was that people seem to actively prefer the information provided by those with whom they share common traits over the more generic cessation literature and counseling of health professionals. What was seen appears to be a fair amount of confusion and distrust expressed on the forum by people attempting to clarify medication or other questions in the case of incomplete, absent, or conflicting information found elsewhere. What was measured with this pilot survey and

by way of observations was their satisfaction with answers provided by their quitting peers.

These findings appear to confirm a few similarities between the information-related behaviors of smokers and those with chronic conditions, at least with regard to the categories. References to nicotine addiction as a chronic illness led to the exploration of literature addressing the information behaviors of people in an online community centered on disease. A listing of categories for postings in an online group (Finn 1999) led to a preliminary examination of the similarities and differences between this listing and findings in this pilot study. Finn's study analyzed a total of 718 posts from an online forum for those dealing with a disability. For purposes of this pilot, the classification of 'chit chat' was not used, and 'friendship' posts were grouped under either 'general support provision' or offers of follow-up assistance. There was no category for 'taboo topics' in the pilot, but a larger-scale study might contain such a category. Damaging statements and poetry and art, again, were categories not included in this pilot study. Finn groups all 'asks information' or 'provides information' together, failing to differentiate between the subjects of that information except in the broadest sense. At the same time, Finn's categories shown here are only part of his listing, and are comprised only of those defined by the coding process as 'helping mechanisms'. They do not include the topical area coding that was also done, using health issues, political issues, social relationship issues, legal issues, and 'other'. Importantly, because his project measured all postings, and not just selected ones as this pilot had done, and also because his study assigned only one code per message, it was not possible to compare frequencies between the studies, even if this pilot had been larger. Nonetheless, his category listing proved useful in helping to determine those areas where more detail was needed, and those of little interest for this pilot.

The initial results appear to confirm that conventional medicine does not usually provide the level or intensity of support needed by this population, but it is doubtful that this can ever be done. Today's pressurized environment of care means professionals and systems must provide the best, most economically conservative care they can that results in the greatest good, and the struggle is ongoing. However, the forum participants who responded to this survey expressed universal satisfaction with the community-based support they encountered as a result of their participation. Statements about the actual impact of social support on cessation success are not an outcome of the pilot, but the QuitNet's own survey found that time spent engaged online correlated to the rate of abstinence from smoking (Graham, Cobb, & Bock 2002).

During the course of the study, and particularly in coding the forum postings, the author realized that part of what she was seeing was some interesting narrative of QuitNet participants in some ways functioning as gatekeepers as they become more experienced in both their quit and in providing information to others. Gatekeeping activity has been defined as information-provision behavior by those who function as 'intermediaries between the subculture and the information resources of the larger society' (Agada 1999, and his discussion of the research of Chatman and others.) The author points here to the seeming discrepancy demonstrated by participants as they expressed their faith in their physician's informational support – even as they acknowledged the overwhelming importance of support and information provided within the QuitNet community.

In addition, while continuing to read and research in the areas of psychology, public health, and medicine, discussion of a concept known as the 'helper principle' was found which appears central to some aspects of this community. This idea characterizes how individuals help themselves both by accepting and offering help, and even illustrates the "shift in roles from helpee to helper […] The principle encompasses a complex process of cognitive reframing during which rookie helpers become veterans" (Cline 1999, 524). This model illustrates the role of 'veterans' as they use observation and the retelling of personal narratives to validate the experiences of newcomers, reinforce motivation, and highlight progress. Because of the author's direct observation and participation, this model in some ways appears to provide a far better 'fit' than other models examined, in describing some of the behaviors of this community. Data from both the pilot survey and the 'post-gathering' exercise seem to confirm this, but a larger study refocused upon this aspect might provide further clarification.

Earlier in this paper, an illustration of the 'stages of change' model that serves as a foundational theory in smoking cessation was provided (Prochaska 1991). Later reassessment shows that this author may have attempted to attribute more to this model than should perhaps be done, by expecting it to also address the provision of information. It is in the area between and around stages – infused throughout the whole – where this author believes information, information therapy, and the recognition of community as a source of valuable support belongs. It is this 'in between' area that appears to have been slighted in the medical literature. Prochaska's model is the framework, while QuitNet and other cessation modalities currently in use are part of a pioneering process to flesh out the framework, enhancing the growing efforts of healthcare to stem the epidemic of smoking in this and other countries.

What might be missing is what this web forum attempts to provide: a caring counselor immersed within the community, available to provide so many things. An imaginary position description might encompass all those needs measured by this pilot study, and more: cognitive, behavioral, and physiological advice; crisis and bereavement counseling, skill-coaching, medical consultation, holistic, simultaneously empathetical and tough-minded support – and do it, twenty-four hours a day. No one individual could possibly provide all that, seven days a week – but a community such as the QuitNet forum may begin to approach that ideal.

However, the community, as entity, cannot provide universal care to all. It misses those who never go there, who cannot. It may fail to address the needs or to reflect the concerns of specific populations, as Dervin posits, such as men, the very young, and minorities. Much more needs to be done in understanding the needs of these individuals who are so underrepresented within online support communities such as QuitNet.

Conducting the pilot: Reflections

Having been a forum participant for more than two years at the time this pilot was initiated, the author feels that being known enhanced the level of interest and trust. She had additionally become known as a 'gatekeeper' due to her former job as a medical librarian, and very often had been approached for information about cessation medications and their effects, cessation-related physiological and emotional issues, and even questions about health issues unrelated to cessation. One intriguing observation that might be worthy of further study is the issue of being a medical librarian immersed within a community. It seems to this author that such placement provides an incredible benefit for both research and for questions that are generated on a daily basis by quitting smokers.

In retrospect, more focused questions might have been asked on the survey. As well, it seems important to recognize the bias caused by the selected population, most of whom had quit numerous times, had smoked for longer, and in fact were mostly longer-term forum participants. The author could have asked (but never did) whether the choice of quit aid was based upon information, how they had decided what to use, and what their criteria had been. A follow-up interview would have helped with this. One reason this question might be important is that it might serve to highlight the role of misinformation in this decision process, an issue not addressed at all in this study. Another valuable follow-up would be to ask about how the level of preparation affected success in this and past attempts.

A full-scale study would be both broader and deeper, using more focused questions on the initial survey, covering a longer period of time for observations – and rather than counting only select messages, all postings would be gathered to examine overall content and proportions. In-depth follow-up interviews or focus groups might assist in determining information needs over time, and the influence of the number of quit attempts on the information-seeking behaviors of quitters could be examined.

Aside from issues of access (which can hardly be set aside) it seems clear there need to be additional access points for various populations based upon models of support communities (Cline, 1999). Although much has been done with regard to using the cost of cigarettes as a public health intervention/pressure to force a correlating drop in the number of smokers, there is still work to be done, and understanding to be achieved.

With all that is now being discovered with regard to addiction, it may be time for a new model of support. Elements from health behavior psy-

chology (Prochaska 1991), 'gap theories' (and the failure of public health initiatives in effecting change) (Dervin 1999), online community-based communication (Finn 1999), gate-keeper theory (Agada 1999), and the concepts of 'helper-helpee' evolutionary processes (Cline 1999) all appear to work in concert to define this extraordinarily rich environment and population, with no one model sufficiently comprehensive.

And there are other, more specific issues, related to individuals and their health questions. This pilot study found that most respondents felt less well prepared than they might have been for their quit, in the important affective realms of emotional and behavioral issues related to cessation. Men are very underrepresented, and it may be worthy of notice that only one of the four men in the survey had sought any kind of therapeutic assistance from their physicians or cessation counselors. And yet, men smoke more than women (27% of the U.S. population compared to women's 22.6%); they die more often from complications of smoking (roughly 279,000 deaths per year compared to women's 150,000) (Centers for Disease Control and Prevention 2000). If men are poorly served, women are equally so, particularly with regard to cessation in pregnancy and the interactive effects of heightened emotional liability during the perimenstrual period, making it more difficult to quit. Yet another underserved group is comprised of younger people. The Quitnet forum actually has a members-only forum specifically for people under 25, but no participant numbers were provided. Based upon simple observation in the main forum, which is by far the most heavily used, the author believes it to be fairly small – but that is not necessarily an indicator.

After all the data gathering, after counting and coding, analysis and speculation, the author finds what may be sizeable gaps between the perceived and expressed information needs of participants, and their provision by more traditional channels. The findings cannot be generalized beyond this single forum, but the demographic data provided by the forum administration agrees with this study's finding that participants largely conform to a rather exclusive and homogenous range. They are Caucasian, middle-aged, better educated, and female. Where, one wonders, are the needs of others being met? The young pregnant woman reaching out for support will need to keep looking. It seems as clear a proof as any that the 'digital divide' still exists. But so many questions are unanswered. Do non-participants (assuming their readiness to change) simply not know about this resource, and do the format, communication style, and ethnic, gender, and educational level within the forum alienate or fail to mirror other populations? These may be unanswerable questions, but it may be important to seek answers. A clearer comprehension of the information needs (defined as reaching beyond the scope of the available patient education literature provided by conventional medicine) might help save lives.

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Notes

1. "Information therapy" is not a new concept, although it has only recently been discussed in any detail in the medical literature using that specific term. Searching Medline, the author found earlier mention of this concept [Mitchell D.J. 1994. Toward a definition of Information Therapy. *Proceedings – the Annual Symposium on Computer Applications in Medical Care: 71–5.]* More recently, it has been written about by Donald Kemper, chairman and CEO of Healthwise who has presented himself and his wife Molly as having both coined the term and developed the idea that information can and should be part of the provision of healthcare service, and that its inclusion ultimately is a beneficial component of patient empowerment. [Kemper, D.W. and M. Mettler. 2002. Information therapy: prescribed information as a reimbursable medical service. Boise, Idaho: Healthwise, Inc.]
2. Concepts of societal ties as a function in the conveyance of information and their characterization as 'strong' or 'weak' was first discussed in Granovetter, M. 1973. The strength of weak ties. *American Journal of Sociology* 78: 1360–80. Later research, including that published by the same author, explores this model with regard to the dissemination of information (Granovetter, M. 1982. The strength of weak ties: A network theory revisited. In P. Marsden & N. Lin (Eds.), *Social structure and network analysis:* 105–129. Beverly Hills, CA: Sage.) and others.

3. Enormous and ongoing studies of consumer health information seeking have already been performed by such organizations as the Pew Internet and American Life Project (Fox, S., Rainie, L. et al., (2000, November 26). Pew Internet & American Life: the online health care revolution: how the web helps Americans take better care of themselves. Available online at http://www.pewinternet.org/reports/pdfs/PIP_Health_Report.pdf [viewed 15 September 2003]
4. This is available at http://www.zoomerang.com [viewed 15 September 2003]
5. These are-community-conceived cessation milestones that are celebrated by means of culturally entrenched ceremonies. Explanation of the traditions created and passed along between participants over time would itself constitute an interesting study. For example, week one of cessation is known as Hell Week, followed by Weak Week. Conventional wisdom about withdrawal experiences during these crucial periods is shared, thus providing the new participant with an immediate sense of community, and validating their experiences.

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