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Understanding and Facilitating Patient Expertise Sharing

Andrea L. Civan

A dissertation  
submitted in partial fulfillment of the  
requirements for the degree of

Doctor of Philosophy

University of Washington

2009

Program Authorized to Offer Degree:  
Department of Medical Education and Biomedical Informatics

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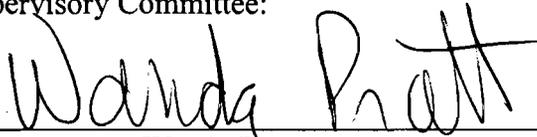
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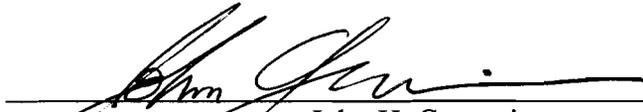
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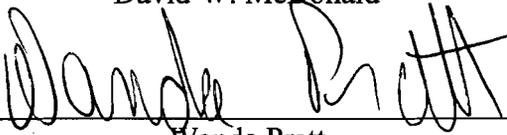
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**Abstract**

Understanding and Facilitating Patient Expertise Sharing

Andrea L. Civan

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A fundamental part of becoming an empowered patient is learning to engage in the day-to-day management of personal health. Yet learning to manage personal health can take substantial time and effort when patients do so through trial and error on their own. Although health informatics support has the potential to help patients overcome this challenge by facilitating patient expertise sharing, we lack the knowledge necessary to meet this potential. Prior work provides little clarity about the nature of patients' personal health expertise and has not explored the practices patients use to leverage this experiential knowledge offered by other patients in similar situations. This dissertation contributes foundational knowledge about *what* patient expertise is and *how* patients share this valuable resource. Within the context of breast cancer, I (1) describe the characteristics of patient expertise through a comparative content analysis that demonstrates how this unique form of knowledge significantly differs from the expertise obtained from health professionals in topic, form, and style, (2) describe practices patients use to share their expertise in their everyday lives during cancer treatment through a naturalistic field study, and (3)

employ a user-centered approach, informed by specific design recommendations I propose for enhancing health-related social software, to design a patient expertise locator to facilitate patient expertise sharing. This work provides substantial guidance on new ways to think about the design of supportive tools for patients. Patients need help from peers and this work provides the understanding and guidance necessary to empower patients by facilitating patient expertise sharing.

# TABLE OF CONTENTS

LIST OF FIGURES .....	vii
LIST OF TABLES.....	ix
Chapter 1. Learning to Manage Everyday Health through Patient Expertise Sharing.....	1
1.1 Research Aims .....	2
1.1.1 Aim 1: To Describe the Characteristics of Patient Expertise.....	3
1.1.2 Aim 2: To Describe the Practice of Patient Expertise Sharing .....	3
1.1.3 Aim 3: To Design a Patient Expertise Sharing Prototype.....	4
1.2 Patient Expertise Sharing in the Breast Cancer Context .....	4
1.3 Overview of Dissertation.....	7
Chapter 2. Why Understand and Facilitate Patient Expertise Sharing?.....	9
2.1 Understanding Patient Expertise: Three Contrasting Lenses .....	10
2.1.1 The Amateur Doctor .....	13
2.1.2 The Everyday Expert .....	14
2.1.3 The Experientialist .....	15
2.2 Facilitating Patient Expertise Sharing: Peer Scaffolding.....	17
2.2.1 Developing Patient Expertise: The Challenges of Trial and Error .....	18
2.2.2 Advantages of Patient Expertise Sharing.....	20
2.2.3 Potential Drawbacks of Patient Expertise Sharing .....	25
2.2.3.1 Medical Misinformation .....	25
2.2.3.2 Poor Fit of Information .....	26
2.2.3.3 Conflicting Information .....	27
2.2.3.4 Perceived Dangers to Professionals .....	28
2.3 Summary.....	30

Chapter 3. The Characteristics of Patient Expertise .....	31
3.1 Introduction.....	31
3.2 Methods.....	35
3.2.1 Content Sources.....	36
3.2.2 Coding Procedure.....	38
3.2.3 Ethical Considerations.....	43
3.3 Results.....	43
3.3.1 Topics Discussed.....	44
3.3.1.1 Medical Topics .....	45
3.3.1.2 Personal Topics.....	46
3.3.1.3 Topics that are Both Medical and Personal .....	47
3.3.2 Recommendations Offered.....	47
3.3.2.1 Action Strategies: Things to Do .....	48
3.3.2.2 Knowledge: Things to Know.....	49
3.3.2.3 Perspectives: Ways of Believing or Approaching Situations.....	49
3.3.2.4 Information Resources: Things to Obtain and Use .....	50
3.3.3 Differences in Topics Discussed between Sources of Expertise.....	51
3.3.4 Differences in Recommendations Offered by Sources of Expertise.....	53
3.4 Discussion.....	57
3.4.1 Empirical Contributions .....	58
3.4.2 Design Implications.....	58
3.4.2.1 Supporting Misinformation Safeguarding Strategies .....	59
3.4.2.2 Supporting Patient Expertise Location .....	60
3.4.2.3 Supporting Collaborative Management of Documents .....	62
3.5 Conclusion .....	64

Chapter 4. Facilitating Patient Expertise Sharing: Related Work .....	67
4.1 Conceptualizing Everyday Expertise Sharing .....	68
4.1.1 Key Features of Expertise Location.....	73
4.1.2 Key Features of Expertise Provision.....	76
4.1.3 Facilitating Expertise Sharing with Recommendation Systems .....	80
4.1.3.1 Collaborative Recommendation Systems.....	81
4.1.3.2 Social Matching Systems .....	84
4.2 Sharing Patient Expertise through Social Software.....	89
4.2.1 Interacting through Internet Forums .....	90
4.2.2 Capturing and Sharing Knowledge through Blogs .....	94
4.2.3 Building Collective Wisdom through Wikis.....	97
4.2.4 Connecting through Social Networking Tools.....	101
4.3 Gaps in our Understanding and Facilitation of Patient Expertise Sharing .....	105
4.3.1 Broadcasting Limits Diverse Means for Collaboration .....	105
4.3.2 Barren Representations of Users Limits Expertise Sharing.....	106
4.3.2 Fragmentation Limits Reuse of Patient Expertise.....	109
4.4 Conclusion .....	111
Chapter 5. The Practice of Patient Expertise Sharing.....	115
5.1 Conceptual Framework.....	116
5.2 Methods .....	117
5.2.1 Study Context.....	118
5.2.2 Data Collection and Analysis.....	119
5.3 Results.....	121
5.3.1 Value of Patient Expertise Sharing .....	121
5.3.2 Expertise Location .....	123
5.3.2.1 Initiating the Identification Process.....	124
5.3.2.2 Identifying Expertise .....	126

5.3.2.3	Selecting Expertise .....	135
5.3.2.4	Anticipating Breakdowns in Expertise Locating.....	143
5.3.3	Expertise Provision .....	147
5.3.4	Expertise Sharing Barriers .....	149
5.4	Discussion.....	154
5.4.1	Empirical Contributions .....	155
5.4.2	Design Recommendations.....	159
5.4.2.1	Supporting Expertise Location .....	163
5.4.2.2	Supporting Expertise Provision.....	167
5.4.2.3	Supporting Triangulation of Expertise .....	169
5.4.2.4	Supporting the Management of Unsolicited Advice .....	170
5.5	Conclusion .....	171
Chapter 6.	User-Centered Design of the Patient Expertise Locator.....	173
6.1	The Importance of Patient Expertise Location as a Design Focus .....	174
6.2	Initial Design of the Patient Expertise Locator.....	176
6.3	Use Case.....	180
6.4	Focus Group.....	188
6.4.1	Perceived Usefulness of the Patient Expertise Locator.....	191
6.4.2	Design Enhancements .....	193
6.4.2.1	Expanding Methods for Identifying Patient Expertise .....	193
6.4.2.2	Enriching User Profiles to Facilitate Patient Expertise Selection .....	197
6.4.2.3	Organizing Presentation of Results to Facilitate Expertise Selection ..	201
6.5	Conclusion .....	204

Chapter 7. Summary and Conclusion.....	207
7.1 Understanding & Facilitating Patient Expertise Sharing.....	207
7.2 Thesis Contributions.....	209
7.2.1 Consumer Health Informatics .....	209
7.2.2 Computer Supported Cooperative Work.....	210
7.2.3 Health Services .....	211
7.2.4 Community-based Support .....	213
7.3 Limitations.....	215
7.4 Future Work .....	216
7.4.1 Extending Our Understanding of Patient Expertise Sharing .....	217
7.4.2 Designing Tools to Meet Patients' Expertise Sharing Needs .....	218
7.4.2.1 Exploring a Range of Patient Expertise Sharing Designs .....	218
7.4.2.2 Designs that Improve Information Fit.....	220
7.4.2.3 Making Room for Patient Expertise Sharing in Clinical Systems .....	221
7.5 Concluding Remarks .....	222
Bibliography.....	223
Appendix A. Codebook for Content Analysis.....	247
Appendix B. Interview Guide for Field Study.....	259
Appendix C. Focus Group Protocol .....	263
Curriculum Vitae .....	265



## LIST OF FIGURES

Figure Number	Page
Figure 3.1 Comparison of Topics Discussed in Sources of Expertise.....	51
Figure 3.2 Comparison of Topics Discussed in Message Boards and Books .....	53
Figure 3.3 Comparison of Recommendations Offered by Sources of Expertise.....	54
Figure 3.4 Comparison of Recommendations Offered by Message Boards & Books.	55
Figure 3.5 Comparison of the Style of Recommendations in Sources of Expertise...	56
Figure 5.1 Nested Representation of Expertise Sharing.....	157
Figure 6.1 Example Knowledge Cloud .....	179
Figure 6.2 Q&A Threads .....	182
Figure 6.3 A Brief Synopsis for each of 12 Candidates. ....	183
Figure 6.4 Alysa’s Detailed Profile .....	184
Figure 6.5 Advanced Search Option to Filter Queries by Selection Criteria .....	190
Figure 6.6 Candidate Suggestions . ....	190
Figure A.1. Mapping between Content Units in Message boards and Books .....	257



## LIST OF TABLES

Table Number	Page
Table 2.1 Three Lenses for Conceptualizing Patient Expertise.....	12
Table 2.2 Three Common Forms of Social Support.....	20
Table 3.1 Content Sources.....	37
Table 3.2 Characteristics of Message Boards.....	37
Table 3.3 Codebook with Frequency Counts .....	41
Table 3.4 Inter-coder Agreement.....	42
Table 3.5 Distribution of Topics and Recommendations across Sources .....	44
Table 5.1 Coding Scheme for Field Study.....	120
Table 5.2 Examples of Problems for which Patient Expertise is Sought .....	123
Table 5.3 Design Recommendations to Support Patient Expertise Sharing.....	162
Table 6.1 Design Decisions for Representing Selection Criteria in User Profiles .	185



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*Chapter 1*

## **Learning to Manage Everyday Health through Patient Expertise Sharing**

---

A fundamental part of becoming an empowered patient is learning to engage in the day-to-day management of personal health. Patients have long been encouraged to play active roles in their health by taking responsibility for health decisions and behaviors, gathering and using resources to manage personal health, and collaborating with health professionals, family, friends, and other patients. However, most patients have scarce time with health professionals to assist them in this learning process. Left to their own devices, patients often acquire knowledge and skills required for everyday management of their health largely on their own. Although this *trial and error* approach to personal health management is one method patients use to adapt to illness, it requires considerable time and energy, and has the potential to result in costly errors. Developing expertise about the everyday management of one's health through trial and error alone is insufficient.

An alternative approach that I explore is to scaffold patients' learning process through the facilitation of patient expertise sharing. I define **patient expertise** as knowledge about managing personal health gained from the day-to-day experience of illness. In contrast, clinician expertise is biomedical knowledge about the treatment and management of disease gained from professional training and practice. **Patient expertise sharing** is the process through which patients exchange their expertise with one another. We can view this collaborative process as a form of peer **scaffolding**, which is a learning approach that relies on developing knowledge through guidance provided by knowledgeable peers (Vygotsky, 1978, p. 86). Applied to patients, peer scaffolding can help patients to gain expertise in the everyday management of health by facilitating the exchange of tips and advice

among patients who share similar health situations. Rather than learning to manage through trial and error alone, patients can take advantage of the expertise available from other patients.

The Internet continues to provide opportunities for patients to connect with other patients who share similar health situations. The rapid increase in the health-related use of social software on the Internet (Elkin, 2008; Sarasohn-Kahn, 2008) demonstrates the need for and value of tools, such as forums, blogs, wikis, and social networking sites, which can facilitate peer exchange of health information and knowledge. However, very little research has examined users' needs for patient expertise sharing technologies. We lack a clear understanding of *what* it is these tools attempt to augment and *how* we can enhance these technologies to meet users' needs. Empirical work that enhances our understanding of both the characteristics of patient expertise and the natural practices that patients use to exchange this valuable resource with one another will deeply inform the design of tools that can facilitate patient expertise sharing.

## **1.1 Research Aims**

The purpose of this thesis is to develop a deep understanding of patient expertise sharing and to inform the design of informatics tools that can facilitate the exchange of expertise among patients. Through the following three Aims, I investigate the concept of patient expertise, the phenomenon of patient expertise sharing, and the design of a prototype to facilitate patient expertise sharing. The knowledge gained through these Aims provides important insights that fill gaps in our existing knowledge about consumer health informatics support needs.

### **1.1.1 Aim 1: To Describe the Characteristics of Patient Expertise**

The nature of patient expertise has long been the focus of turbulent discussions, but is an uncommon focus of detailed empirical investigations. For example, patient expertise can be confused with clinician expertise. Facilitating patient expertise sharing requires understanding the nature of patient expertise and exploring whether, and perhaps how, this form of expertise differs from clinician expertise. To describe the characteristics of patient expertise, I conducted a comparative content analysis of advice exchanged among patients and advice offered to patients by health professionals.

### **1.1.2 Aim 2: To Describe the Practice of Patient Expertise Sharing**

We know very little about the natural practices used by patients to exchange their expertise with one another. Although research has begun to explore strategies patients use to develop personal health expertise, such as trial and error (see for example, Paterson & Thorne, 2000), we lack clear descriptions of the strategies patients use to share that expertise with other patients. How might patient expertise sharing practices compare to the expertise sharing practices observed in professional work settings (see for example, McDonald & Ackerman, 1998)? Can we apply what we have learned more generally about expertise sharing in workplace settings to patients in personal health settings? Facilitating patient expertise sharing requires understanding patients' existing practices. I conducted a field study of patient expertise sharing practices to provide this necessary insight into the natural strategies used by patients to share their expertise in their everyday lives.

### **1.1.3 Aim 3: To Design a Patient Expertise Sharing Prototype**

Historically, design efforts for many consumer health tools have had very little involvement from target users, risking designs that neither reflect users' needs nor augment users' existing practices. Facilitating patient expertise sharing requires not only informing the design of tools with an understanding of the nature of patient expertise and the natural practices patients use for its exchange, but it is also enhanced by directly involving target users in design. I employed a user-centered approach, grounded by insights gained through the content analysis and field study, to collaborate with target users on the design of a prototype patient expertise locator.

## **1.2 Patient Expertise Sharing in the Breast Cancer Context**

Although understanding and facilitating patient expertise sharing can be of value for patients in general, I have selected breast cancer as an important focus for this research. In 2008, more than 250,000 new cases of breast cancer were estimated to emerge in the United States (American Cancer Society, 2008a). The pressures, uncertainties, and stress resulting from a cancer diagnosis can significantly disrupt the lives of these individuals, requiring them to quickly learn new jargon, navigate new environments, develop new schedules for work and home, and balance the stress of coping with the potential loss of life with the stress of ongoing work and family issues (McCarthy & Loren, 1997).

This 'patient work' of the breast cancer experience (Unruh, 2007) generates complex information needs that dynamically shift along a trajectory from diagnosis through survivorship (Rees & Bath, 2000; Lindop & Cannon, 2001). Although many people embark upon this trajectory with little or no prior experience, they acquire information throughout their experience from a diverse range of sources, including

clinicians, texts, the internet, and breast cancer survivors. This information arms them with knowledge and skills they can apply to the personal health responsibilities imparted upon them in their new role as cancer patient. It helps them form expectations about and gain control over aspects of their upcoming treatment (Lev & Owen, 2000; Bakker Fitch, Gray, Reed, & Bennett, 2001) and can influence their psychosocial health (Fallowfield, Baum, & Maquire, 1986) and quality of life (Rustoen & Begnum, 2000).

Our growing understanding of breast cancer patients' information work brings clarity to the information management challenges that result when patients seek information to gain these benefits. However, an important, yet under-acknowledged and under-investigated, part of this work involves the sharing of expertise among patients. Prior work has explored the development of patient expertise in the context of chronic illness. For example, patients develop expertise in the self-management of chronic conditions through their everyday experience with self-care over time (Benner & Wrubel, 1988; Paterson, Thorne, & Dewis, 1998; Paterson & Thorne, 2000). Some experienced patients can even come to know as much as their doctors about aspects of their health situations (Petersen, 2006). However, we know very little about the characteristics of patient expertise or the practices patients use to share that expertise, particularly in the prevalent context of breast cancer.

Insights from prior work point to breast cancer as a context that is ripe with potential for investigating patient expertise sharing. For example, Giese-Davis and colleagues (2006) argue that the intervention that newly diagnosed breast cancer patients want most is *“to speak with someone who has the same cancer, but who has lived through the crisis of treatment and is leading a ‘normal’ life”* (p.1014). Furthermore, experiential information derived directly from the cancer experience is an important information need expressed by breast cancer patients (Rozmovits & Ziebland, 2004).

When those needs for experimental information are met, breast cancer patients could experience enhanced health information competence (Shaw et al., 2007). Giese-Davis and colleagues (2006) further argue that *“In an era when patient advocacy is an increasingly powerful and important social force in medical care, and medical resources for provision of social support are scarce, developing and testing means of training patients to effectively assist one another would seem to be an important area of future research.”* (p. 1021).

This prior research suggests that breast cancer patients are well-suited for a peer-scaffolding approach to patient expertise sharing as a means for learning to manage everyday health. Might patients themselves actually *teach us* more about how to utilize informatics support to augment their natural social practices than what we can *train them* to do? Furthermore, the prevalence and significance of the breast cancer experience makes breast cancer patients an important population to support. They learn a great deal from their health experiences and many have a strong desire to ‘give back’ by sharing their expertise with other patients. As growth beyond the estimated 2.5 million breast cancer survivors is expected with earlier detection and improved treatments (American Cancer Society, 2008b), growth too can be expected in the amount and range of patient expertise those survivors can offer to newly diagnosed patients. Although breast cancer provides a valuable context for scoping this thesis, many contributions from this work could hold promise for extension and application beyond the context of breast cancer to the health consumer population more generally.

### 1.3 Overview of Dissertation

Chapter 2, *Why Understand and Facilitate Patient Expertise Sharing*, motivates this thesis by describing the importance of understanding the nature of patient expertise more deeply. I argue that patient expertise sharing offers advantages over learning to manage health through trial and error alone, but that we must also acknowledge potential disadvantages associated with this peer scaffolding approach.

Chapter 3, *The Characteristics of Patient Expertise*, presents the topics, forms, and styles of advice offered among patients who share similar health situations. These results from my comparative content analysis of online breast cancer message boards and books illustrate fundamental characteristics of patient expertise that differ significantly from the characteristics of expertise obtained from health professionals. I present both empirical implications and design implications these findings carry. The contributions of this content analysis fulfill Aim 1 of this thesis: To describe the characteristics of patient expertise.

Chapter 4, *Facilitating Expertise Sharing: Related Work*, reviews substantial guidance offered by related research that investigates expertise sharing more generally. I draw upon this work to consider informational support exchanged among patients as a type of *everyday expertise sharing*, survey key features of expertise sharing practices and supportive tools outside the health context, and evaluate health-related social software that could support expertise sharing, but lacks solid support in light of prior work. By summarizing those limitations, I illustrate gaps in our knowledge that must be filled to facilitate patient expertise sharing. I argue for the need to fill those gaps by establishing an understanding of the natural practices patients use to share their expertise in their everyday lives, which Aim 2 of this thesis addresses.

Chapter 5, *The Practice of Patient Expertise Sharing*, establishes a foundation of knowledge about the strategies that patients currently use to share their patient expertise with one another. I present results from my field study which describe how patients value expertise sharing, practices patients use to locate expertise from peers, practices patients use to provide expertise to peers, and barriers patients face in those practices. These findings expand on our empirical understanding of patients' needs and of expertise sharing more generally. Building upon the implications outlined in previous Chapters, I propose specific design recommendations for enhancing health-related social software to support patient expertise sharing. The contributions of the field study fulfill Aim 2 of this thesis: To describe the practice of patient expertise sharing.

Chapter 6, *User-Centered Design of the Patient Expertise Locator*, details the initial design of a patient expertise locator that draws upon my design recommendations to extend an online cancer community to facilitate patient expertise location. I demonstrate how a patient would use this prototype to locate expertise through a use case and describe feedback and design guidance obtained through a focus group with breast cancer survivors. The contributions of this user-centered design effort fulfill Aim 3 of this thesis: To Design a Patient Expertise Sharing Prototype.

Chapter 7, *Summary and Conclusions*, summarizes the contributions this thesis makes and presents possibilities for building upon this research in the future.

*Chapter 2*

## **Why Understand and Facilitate Patient Expertise Sharing?**

---

As patients deal with new health situations, they gain specialized knowledge about how to manage their health in the context of their daily life (i.e., **patient expertise**). This process can take substantial time and effort when patients learn it on their own. Experienced patients, who have dealt with similar health situations, can offer the expertise they have gained to other patients. Facilitating the exchange of expertise among patients could make the process of learning how to manage health much easier than learning how to do so through trial and error on one's own. **Patient expertise sharing**, the process through patients exchange their expertise, could hold benefits not only for those who seek patient expertise, but through mutual aid obtained by those who provide patient expertise as well. Yet, we know remarkably little about *what* patient expertise is or *how* patients exchange their expertise. This knowledge is necessary to design informatics support that can facilitate patient expertise sharing.

The overarching goal of this thesis is to understand and facilitate patient expertise sharing. Before describing the research I conducted to meet this goal, I motivate this work by discussing two fundamental issues. In this Chapter, I first I draw upon three contrasting conceptual lenses on the nature of patient expertise to describe the importance of enhancing our understanding of this specialized knowledge offered by patients (Section 2.1). Second, I describe challenges associated with developing patient expertise on one's own, through the process of trial and error, and argue that although patient expertise sharing is not without potential disadvantages, it does offer advantages that could help patients overcome those challenges (Section 2.2). Enhancing our understanding of patient expertise, and the practices patients use to

share that expertise, can inform the design of novel technologies that meet the breadth of patients' needs, including the important need for exchanging expertise with other patients who face similar health situations.

## **2.1 Understanding Patient Expertise: Three Contrasting Lenses**

The range of perspectives on the nature of patient expertise suggests that we are far from a clear consensus about the fundamental characteristics of the specialized knowledge offered by patients. Some suggest that we are far from even acknowledging the value of patient expertise (Thorne, Ternulf, & Paterson, 2000). Prior (2003) notes in her analysis of the concept of patient expertise that “*those who talk of lay expertise often fail to specify how exactly lay people might be expert*” (p. 45). Beyond talk of patient expertise, very little empirical research has actually investigated the characteristics of this knowledge, namely in the contexts of diabetes (Paterson & Sloan, 1994; Paterson, Thorne, & Dewis, 1998; Paterson & Thorne, 2000), alcoholism, stuttering, and ostomy (Borkman, 1984). Although some argue that the expertise of patients is an ‘untapped resource’ (Department of Health, 2001), others have documented strong resistance towards the notion of patient expertise (Thorne, Ternulf, & Paterson, 2000).

These varied perspectives could stem from lack of clarity about fundamental characteristics of patient expertise and about the practices used by patients to exchange their expertise. In turn, the shape of design implications for consumer health technologies that facilitate patient expertise sharing could depend distinctly on the orientating lens one chooses to conceptualize patient expertise. Tool designers could develop systems that begin to meet the breadth of patients' needs if we enhance our understanding of patient expertise sharing. However, before we can

develop such tools, we must first ask ourselves ‘What are the characteristics of patient expertise’? I ground my work by addressing this question through the first Aim of this thesis (see Chapter 3). Before describing my findings, I demonstrate our need to enhance our understanding of the nature of patient expertise by contrasting three distinct conceptual lenses on this important concept: The Amateur Doctor lens, The Everyday Expert lens, and the Experientialist lens. Only with clarity about the fundamental assumptions that shape one’s conceptualization about the nature of patient expertise can we investigate how patients develop this form of expertise and how informatics support for patient expertise sharing can facilitate that learning process. Differences among these conceptual lenses offer insights into how fundamental assumptions can shape both our understanding of and our efforts to support patient expertise sharing.

My differentiation of the Amateur Doctor lens, the Everyday Expert lens, and the Experientialist lens of patient expertise aligns closely with seminal work conducted by Borkman (1984, 1990). Borkman argues, from the context of self-help, that the experiential expertise of people who are knowledgeable about living with and coping with a health situation is qualitatively different from both the technical, scientific expertise of health professionals and from the folk information of the layperson who has not experienced, coped with, and reflected upon those situations. This threefold classification of professional, lay, and experiential frames of reference suggests that experiential knowledge developed by patients about specific health situations (i.e., patient expertise) cannot be duplicated by professionals or by lay social supports. Despite the growing emphasis placed on the importance of patient empowerment (Laine & Davidoff, 1996; Brennan & Safran, 2003), conventional wisdom in the medical informatics community, like that of the self-help community two decades ago (Borkman, 1984; Borkman, 1990), rarely makes this important distinction between knowledgeable patients and lay bystanders. Whereas many efforts aim to

empower patients by enhancing patients’ access to biomedical knowledge and patient-provider communication (Gibson, 1991), far fewer efforts facilitate complimentary avenues for empowering patients through peer support.

Following Borkman’s (1990) threefold classification of professional, lay, and experiential frames of reference, I categorize varied assumptions about the nature of patient expertise along three major conceptual lenses: the Amateur Doctor lens, the Everyday Expert lens, and the Experientialist lens (Table 2.1). We can differentiate these conceptual lenses by the type of knowledge they emphasize, the source from which that knowledge typically develops, and how the expertise reflected by that knowledge is valued. The distinction I make between professional and experiential forms of health knowledge is grounded in Radley’s (1994) distinction between **disease** (i.e., treated by doctors) and **illness** (i.e., experienced by patients). Thus, I assume that the professional knowledge of clinicians focuses on treating disease and experiential knowledge of patients focuses on managing with illness.

**Table 2.1 Three Lenses for Conceptualizing Patient Expertise**

	<b>Amateur Doctor</b> 	<b>Everyday Expert</b> 	<b>Experientialist</b> 
<b>Type of knowledge emphasized</b>	Biomedical knowledge about treating disease	Inherent knowledge about one’s own preferences, values, and beliefs	Experiential knowledge about managing personal illness
<b>Typical source of knowledge</b>	Professional training and practice	Integral part of one’s sense of self and life context	Experience with, practice of, and reflection on self-management of health
<b>Value of expertise</b>	Enhances the quality of professionals’ work	Enhances patient-provider relationship and quality of health-care	Enhances personal health management skills of self and others

### 2.1.1 The Amateur Doctor

The lens of the **Amateur Doctor** assumes that patient expertise reflects a high level of scientific and technical biomedical knowledge common to health professionals. This lens considers patients as experts on a particular health situation through their acquisition of knowledge and skills of the scientifically trained (Prior, 2003). In other words, having patient expertise means being well-versed in medicine, much like an “amateur doctor” (i.e., holding professional-like knowledge without having gone through professional training). Whereas health professionals typically acquire biomedical knowledge through professional training and practice, patients who typically lack such opportunities can pick up aspects of this knowledge through avenues, such as studying biomedical research or interacting with their clinicians.

Some argue that experiential knowledge derived from the experience of illness does not contribute toward an Amateur Doctor lens of patient expertise. Badcott (2005), for example, suggests that: *“Experience limited to an individual does not of itself give rise to the generalisations that underlie reliable clinical treatment. Neither do the vast majority of patients possess the physiological and pharmacological knowledge to fully appreciate the biological nature of their illness nor the basis, risks or limitations of therapeutic measures”* (p.1). Although the Amateur Doctor lens tends not to place value on the experiential knowledge acquired by patients, some have acknowledged the value that patients can bring to health-care by sharing biomedical knowledge they have developed about treating their health situation with their clinicians. For example, Peterson (2006), through interviews with patients about managing their genetic conditions, describes how *“a number of respondents recounted their efforts to keep up-to-date with developments in research and treatment by attending professional meetings and conferences, with some indicating that they had acquired knowledge not had by their doctors”* (p. 38).

### 2.1.2 The Everyday Expert

The lens of the **Everyday Expert** assumes that patient expertise reflects a patient's inherent knowledge about their own values, beliefs, and preferences within the context of their health situation (i.e., self-knowledge). This lens emphasizes the importance of knowledge offered by patients about their preferences, which can help to improve the patient-provider partnership and enhance the patient's active participation in quality health-care (Lorig, 2002). For example, Berry and colleagues (2003) highlight important personal factors reflecting '*who I am and what I do*', which prostate cancer patients incorporate into their treatment decision-making process.

Such self-expertise provided by patients about their lives (e.g., their medical history, experience of symptoms, and health concerns) is valued because it can inform the clinical diagnosis, treatment, and home management of health issues (Porter, 2000). Coulter (2002), for example, argues that "*only patients know about their experience of illness and their social circumstances, habits, behaviour, attitudes to risk, values, and preferences*" (p. 649). In contrast, she argues that clinicians hold professional expertise with respect to diagnostic techniques, causes of disease, prognosis, treatment options, and preventive strategies. Coulter suggests, "*The key to successful doctor-patient partnerships is to recognise that patients are also experts...Both types of knowledge are needed to manage illnesses successfully*" (p.649). In fact, Ruland (1999) demonstrates that providing patients with decision support tools to share their personal knowledge and experiences with health professionals can improve health-care and patient outcomes. The desire for a collaborative doctor-patient partnership that can support the goals of the health-care system is a strong motivator for the perspective of the Everyday Expert. Thus, we can consider this lens 'medico-centric'

because it “*retains a subordinate role for lay definitions of health and illness*” (Fox, Ward, and O’Rourke, 2005, p. 945-946).

### 2.1.3 The Experientialist

The lens of the **Experientialist** assumes that patient expertise reflects practical knowledge about personal health management that is derived from the experience with, practice of, and reflection on managing one’s own health situations over time (Diamond & Little, 1984; Benner & Wrubel, 1988; Patterson & Sloan, 1994; Paterson, Thorne, & Dewis, 1998; Paterson & Thorne, 2000; Cavanagh, Millar & McLafferty, 2007). In other words, patient expertise is about more than simply knowing and communicating one’s everyday values, beliefs, and health preferences. It is knowledge about the practice of managing one’s own illness (Edgar, 2005). Thus, we could consider patients as experts by virtue of having experiential knowledge about managing a health condition (Prior, 2003).

The Experientialist lens assumes primacy of the practical knowledge and wisdom embedded in the patient’s experience of illness. This experience occurs largely outside of the clinical context, such as when diabetics perceive patterns in their day-to-day responses to health influences and situations, and then modify their self-care routine as they learn to manage their health over time and in their day-to-day lives (Price, 1993; Hernandez 1995; Paterson, Thorne & Dewis 1998; Paterson & Thorne, 2000). From the experientialist perspective, patient expertise is a largely untapped resource that can offer great value to the holder of the expertise as well as to other patients with whom they share their expertise. Specifically, patients’ experiential knowledge can enhance their own personal health management. Furthermore, patients can enhance the personal health management of other patients by sharing those skills.

Overlooking these varied conceptual lenses on patient expertise (i.e. Amateur Doctor, Everyday Expert, and Experientialist lenses) can present a primary barrier to designing appropriate support for patient expertise sharing. Each interpretation carries different assumptions about the fundamental nature of patient expertise, and thus, can arrive at different implications for the design of tools that can facilitate patient expertise sharing. For example, those operating from the perspective of the Amateur Doctor lens might design tools that encourage patients to share scientific and technical biomedical resources with one another, whereas those operating from the lens of the Everyday Expert might focus on tools that help patients share their health-care preferences with clinicians. On the other hand, those operating from the Experientialist lens might design tools that encourage patients to exchange their experiences and practical health management tips with one another. Clarity about the conceptual lens one uses to view patient expertise is critical because that lens carries assumptions that shape how we come to understand and appreciate patient expertise, as well as how we go about designing informatics support to facilitate its exchange.

Although all three diverse conceptual lenses offer value, it is unclear which lens aligns most closely with the expertise that patients offer to one another in practice. If patient expertise is unique from the biomedical expertise of an amateur doctor, yet inherently carries value by offering insight into a different sphere of health problem solving (Powell, 1990), then we should focus effort on supporting patients by facilitating their exchange of experiential expertise with one another. Unfortunately, we lack a solid body of empirical research that clearly details the characteristics of that expertise. Although the characteristics of patient expertise could align with any one of these conceptual lenses, prior research that has directly engaged patients to learn about their personal health knowledge suggests that patients' experiential knowledge is a critical aspect of that expertise (Borkman 1984; Diamond & Little, 1984; Patterson & Sloan, 1994; Paterson, Thorne, & Dewis, 1998; Paterson &

Thorne, 2000; Petersen, 2006; Cavanagh, Millar, & McLafferty 2007). The first Aim of this thesis is to enhance our understanding about the fundamental nature of this specialized knowledge of patients by describing the characteristics of patient expertise in the context of breast cancer through a comparison to the characteristics of expertise offered by health professionals (see Chapter 3).

## **2.2 Facilitating Patient Expertise Sharing: Peer Scaffolding**

With a deeper understanding about the nature of patient expertise, we become better equipped to design informatics tools that can facilitate patient expertise sharing. However, such tools must also take into consideration the expertise sharing practices patients already use in their current practice. The second Aim of this thesis is to initiate discourse on this unexplored topic by investigating the expertise sharing practices used by breast cancer patients as they undergo treatment (see Chapter 5). To meet the third and final Aim of this thesis, I use knowledge gained through Aim 1 about the characteristics of patient expertise (see Chapter 3) and knowledge gained through Aim 2 about patient expertise sharing practices (see Chapter 5) to develop a tool that facilitates patient expertise sharing (see Chapter 6). Related work on expertise sharing practices and supportive tools provides significant guidance for meeting the second and third Aims of this thesis (see Chapter 4).

In this section, I motivate the research I conducted to meet the second and third Aims of this thesis by demonstrating our need to help patients overcome challenges associated with learning to manage health through trial and error. I argue for the promise of an alternative peer scaffolding approach to develop patient expertise. Grounded in educational and social learning theories, **scaffolding** occurs when a more experienced individual helps a less experienced individual acquire skills that

are beyond what they can currently acquire on their own. In the context of personal health, individuals who have experience dealing with a health situation (i.e., peers) can scaffold the learning of less experienced individuals by sharing the knowledge they have gained by actively managing their health. I use the term **patient expertise sharing** to refer to this peer scaffolding approach to learning. After describing challenges associated with learning to manage health through trial and error alone, I describe some of the advantages, as well as potential drawbacks, of patient expertise sharing.

### **2.2.1 Developing Patient Expertise: The Challenges of Trial and Error**

Active engagement in the management of one's health, by taking responsibility for health decisions and behaviors, gathering and using resources to manage personal health, and collaborating with health professionals, family, friends, and other patients, can be empowering for patients (Laine & Davidoff, 1996; Brennan & Safran, 2003). We can view this range of personal health management activities as part of the work it takes to be a patient (Unruh, 2007). As patients gain experience with this work over time, they can develop expertise that helps them manage their health. Thus, we can conceive of the development of patient expertise as a learning process.

Unfortunately, most patients have scarce time with health professionals to assist them through this learning process. However, many patients do gain a wealth of the background and skills required to manage personal health through trial and error effort on their own. For example, people commonly develop patient expertise about managing chronic illness, such as diabetes, through trial and error experimentation with strategies for managing their everyday self-care (Benner and Wrubel, 1988; Hernandez 1995; Patterson, Thorne, & Dewis, 1998; Paterson & Thorne, 2000). This

**bricolage learning approach**, in which learners piece together the bits of accumulated and on-hand knowledge to solve problems in a trial and error fashion (Levi-Strauss, 1966; Turkle & Papert, 1992), is common for learners who lack significant domain knowledge. Bricolage learning enables learners to develop practical expertise that is embedded in the ‘do-it yourself’ strategies that they create. This is a natural learning path for many patients who initially lack background and skills to manage the new health situations they face.

Although bricolage learning can result in the development of patient expertise, this trial and error experimentation requires time and self-reflection to arrive at working strategies. It could even require an accelerated pace for a patient who is diagnosed with a serious illness, such as cancer, where there is little room for practice or mistakes. Although the trial and error process of piecing together a working solution to a personal health problem might be the status quo for patients who are learning to adapt to illness, this effortful and time-consuming approach fails to take advantage of expertise available from other patients who have developed useful strategies for solving similar personal health problems. Unlike other contexts in which peer competition can be salient (e.g., some professional work and educational settings), the health context offers a rich source of underutilized patient expertise, which is embedded in the experiences of altruistic patients who have ‘been there before’. Such patients are often eager to share their knowledge with other patients (Petersen, 2006).

Thus, managing personal health through trial and error alone presents patients with significant challenges, which perhaps intensify when patients must quickly learn about and quickly respond to acute health issues. Trial and error bricolage, however, is not necessarily the only path that patients can take as they learn to manage new health situations. Alternatively, we could facilitate patient expertise sharing. By

helping patients share the expertise embedded in their personal health management strategies, we can scaffold the learning process to overcome challenges of trial and error experimentation.

### 2.2.2 Advantages of Patient Expertise Sharing

Patient expertise sharing reflects the strategies that patients use to seek, provide, and exchange health-related knowledge with one another. These strategies provide a means for informational support, which is a form of social support observed among patients and their formal (i.e., organized and process-driven) and natural (i.e., family and friends) social networks. **Informational support** involves the provision information and advice used to guide one's personal health management and can enhance perceptions of control by providing patients with knowledge and coping strategies to manage illness in new ways (Helgeson & Cohen, 1996). Informational support can be distinguished from **emotional support** (i.e., communication of caring and concern) and from **instrumental support** (i.e., provision of material goods) (House & Kahn, 1985; Helgeson & Cohen, 1996). Table 2.2 contrasts these three functional forms of social support adapted from Helgeson and Cohen (1996).

**Table 2.2 Three Common Forms of Social Support**

<b>Form</b>	<b>Definition</b>	<b>Examples</b>
Informational support	Provision of information used to guide or advise, enhance perception of control over managing illness, and ameliorate confusion	Explanations, opinions, personal experiences, advice, information resources
Emotional support	Communicating caring and concern to bolster self esteem and permit the expression of distress	listening, empathizing, reassuring, comforting, encouraging
Instrumental support	Provision of material goods or practical assistance to offset loss of control experienced during illness	Transportation, money, or assistance with household chores

Personal health guidance afforded by informational support is a patient need that is thought to be strongest during transitions after emotional support needs associated with a crisis have been met (Jacobson, 1986) and is a need that is commonly met by experts (Weiss, 1974). In the context of patient expertise sharing, experienced patients, through offers of experiential guidance, serve as experts. Peer support programs for cancer patients that provide opportunities to exchange such guidance are associated with positive benefits for patients (Campbell, Phaneuf, & Deane, 2004; Hoey, Ieropoli, White, & Jefford, 2008). I argue that patient expertise sharing offers an alternative approach to learning to manage illness on one's own through trial and error, which could hold mutual benefits for seekers and providers of patient expertise.

Perhaps the strongest line of evidence suggesting advantages offered by patient expertise sharing over trial and error learning comes from constructivist thought, which is rooted in educational and social learning theories. Unlike the transmission orientation of the learner as a sponge who absorbs and reacts to a body of objective, quantifiable knowledge that is transmitted by an expert (Skinner, 1974), constructivist perspectives (Bruner, 1973; Vygotsky, 1978; Piaget, 1980) conceive of the learner as an active constructor of knowledge. Learners actively assimilate and accommodate new information in relation to what they already know from experience (Piaget, 1980). Knowledge is expressed within the cognitive structures an individual develops and then adjusts as they acquire new knowledge (Bruner, 1973). The learner may be a member of a knowledge community who actively co-constructs knowledge through collaborative interpretation (Vygotsky, 1978; Wenger, 1998).

Constructivist thought is consistent with modern views of health consumers as active, rather than passive, participants. Enhanced effectiveness of active over passive forms of learning (Held & Hein, 1963; Craik & Lockart, 1972; Schwartz &

Bransford, 1998), correspond to the enhancements in quality of life and psychological adjustment found in cancer patients who use active, rather than passive, coping strategies (Fawzy, Secher, Evans, & Giuliano, 1995). However, active learning relies on experience: one acquires new knowledge by expanding upon what they already know (Bruner, 1973; Piaget, 1980). For example, research demonstrates the value of helping diabetic patients learn from their past behavior through technology that facilitates reflective sense-making (Mamykina, Mynatt, Davidson, & Greenblatt, 2008). However, a newly diagnosed cancer patient, for example, might not necessarily have adequate prior knowledge about the cancer experience to build upon, nor the time for personal reflection. Patients facing health situations that incorporate acute features often need to get things right the first time.

A remedy for this challenging situation advocated by constructivist paradigms is the process of scaffolding (Wood, Bruner, & Ross, 1976; Vygotsky, 1978), whereby a more experienced individual helps a less experienced individual to acquire skills that are beyond what they can currently acquire on their own. Acting as coaches or mentors, experts provide learners with just enough guidance to become increasingly accomplished problem solvers (Quintana et al., 2004). They can also model effective skills and behaviors (Bandura, 1989), and through collaboration in communities of practice, develop and spread knowledge (Wenger, 1998). In much the same way that mentors can scaffold student learning (Wood, Bruner, & Ross, 1976; Vygotsky, 1978), knowledgeable peers can assist patients in acquiring the knowledge and skills they need to manage their health effectively.

Peer scaffolding within the health context relies on the exchange of personal health management knowledge. For example, some describe knowledgeable patients as critical 'allies' to diabetic patients because they serve as a source of personal health management strategies (Paterson & Sloan, 1994; Hernandez 1995; Paterson, Thorne,

& Dewis 2000). Peer scaffolding is also likely to occur through the prevalent exchange of experiential knowledge observed in online support groups (Schubert & Borkman, 1994) surrounding health conditions, such as depression (Salem, Bogat, & Reid, 1997) and cancer (Shaw et al., 2007). Other types of technologies, such as capturing and sharing health-related activities through computer visualizations and photography (Smith, Frost, Albayrak, & Sudhakar, 2006) or cell phones (Grimes, Bednar, Bolter, & Grinter, 2008) can facilitate knowledge sharing among people in similar health situations. Such resources could provide particularly rich sources of patient expertise because they help patients establish weak social ties, through which they are likely to obtain useful information that differs from the information available through the strong social ties of their existing personal networks (Granovetter, 1973).

Thus, we could mitigate challenges associated with the trial and error approach to personal health management by helping patients learn from other patients who have experience with similar health situations. This peer scaffolding approach could aid the development of patient expertise by facilitating expertise sharing among patients. By taking advantage of what other patients have already learned, patients could save themselves valuable time, energy, and potential risks associated with trial and error experimentation. Patient expertise sharing could also provide opportunities for chance discovery of working solutions that a patient might never have arrived at through their own devices. A natural implication of the patient empowerment model of health-care, which encourages patients to seek out information about their health, is that patients will explore multiple avenues of expertise, including professional sources (Gibson, 1991) as well as other patients.

I have argued that patient expertise sharing could offer advantages to learners. However, the mutual aid that results from offering one's own knowledge to other

patients in need can also be empowering in its own right. The helper-therapy principle (Reissman, 1965) suggests that experienced patients who provide expertise to others might gain as much benefit as recipients. For example, patients could experience physical and emotional health benefits from the help they provide, which is described by Luks (1988) as the 'helper's high'. A phenomenon called 'response-shift' (Howard & Dailey, 1979), in which helpers (e.g., peer counselors) experience a shift in their self-evaluations could underlie these empowering benefits (Schwartz & Sendor, 1999). For example, talking through a traumatic experience can be therapeutic by bringing clarity to its meaning. Patients who help other patients manage problems they have dealt with before can certainly benefit from internal growth and development (Mowbray, Moxley, Thrasher, Bybee, & Harris, 1996).

Although peer counselors, such as cancer survivors who provide emotional support, information, or cancer recovery stories to newly diagnosed patients, might not necessarily enhance their self-efficacy or quality of life through their provision of expertise, research demonstrates that the support they provide has no adverse affects (Giese-Davis et al., 2006). Some caution against potential risks of utilizing experienced patients (i.e., 'veterans') in peer support roles for newly diagnosed patients (i.e., 'newcomers'), such as role strain, boundary issues, and feelings of failure when their efforts are unsuccessful (Mowbray et al., 1996). However, others suggest that facilitating exchange between newcomers and veterans, who have gained an experiential base of knowledge about specific problems and their resolution, is the most critical element in the newcomer's learning process (Powell, 1990). Thus, facilitating patient expertise sharing could offer the potential for mutual benefit to the patient who seeks expertise, and reciprocally to the patient who offers that expertise as well. Despite these advantages, it is important to address potential drawbacks that could be associated with facilitating patient expertise sharing.

### 2.2.3 Potential Drawbacks of Patient Expertise Sharing

The literature on peer support in the health context often articulates cautions and potential dangers associated with peer interaction due to its autonomy from professional guidance (Chesler, 1990). For example, Helgeson, Cohen, Schultz, & Yasko (2000) reported that negative interactions among breast cancer patients in emotional support-based peer discussion groups were associated with reduced physical functioning in patients with low levels of social support outside of the group. In contrast, the vast majority of studies on social support interventions have found peer support beneficial (Hogan, Linden, & Najarian, 2002). However, the paucity of empirical research makes it unclear to what extent dangers actually exist (Chesler, 1990). Thus, it is important to consider potential drawbacks that could be associated with efforts to facilitate patient expertise sharing. The literature suggests four potential drawbacks to facilitating patient expertise sharing: (1) potential spread of medical misinformation, (2) potential for exchange of information with poor fit, (3) potential for exchange of conflicting information, and (4) potential dangers to professionals.

#### 2.2.3.1 Medical Misinformation

One of the most commonly expressed concerns about patient interaction is the potential spread of **medical misinformation** (i.e., inaccurate medical information). Patients frequently show misunderstandings about their illness, its prognosis, and its treatment (Jefford & Tattersall, 2002). Thus, patients can be a source of inaccurate information (Prior, 2003) and could pass along those misunderstandings to other patients, particularly in online environments that lack quality control and professional moderation (Culver, Gerr, & Frumkin, 1997; Winzelberg, 1997; Dickerson, Flaig, Kennedy, 2000; White & Dorman, 2001; Levy & Strombeck,

2002). Examples include uncontrolled risks of ‘snake oil’ (i.e., claims that are unproven or unsafe) or other scams, such as promises of medical cures on internet-based support groups (Culver et al., 1997; Preece, 1998). With the rise in use of social software for health purposes, some have raised important concerns about the quality of user-generated content (Tsai, Tsai, Zeng-Treitler, & Liang, 2007).

Although the potential for these forms of medical misinformation certainly exists, particularly through democratization enabled by the internet, studies that have examined peer interactions in online health communities have found low levels of inaccurate medical information (Kelly et al., 2002; Eysenbach, Powell, Englesakis, Rizo, & Stern 2004; Esquivel, Meric-Bernstam, & Bernstam, 2006; van Uden-Kraan et al., 2008). It appears that self-correction (Winzelberg, 1997; Esquivel et al., 2006) and warnings from watchful members (i.e., self-policing) (Preece, 1998) are strategies that are already in use by health consumers to halt the spread of medical misinformation within social software (Sarasohn-Kahn, 2008). Although the ability of health consumers to collectively correct mistakes on the internet remains an open question (Adams, 2008), we could design patient expertise sharing tools to facilitate and extend those misinformation strategies that patients already put to use.

### **2.2.3.2 Poor fit of Information**

Even when information is accurate, potential dangers to patients can still result from the problem of information having poor fit. **Poor fit of information** occurs when the health situation of the patient receiving the expertise aligns poorly with the context from which that expertise is drawn. This problem can result in the misapplication of sound advice that simply does not transfer well from one health situation to another, whether by mismatch in temporality, geography, health management trajectory, personal constraints (e.g., finances, family, or work), or other contextual factors. For

example, cancer patients have compared themselves to other patients who have similar cancer experiences, but who may have been treated several years prior, when making treatment decisions (O'Rourke, 1999). Furthermore, some cancer patients are influenced by the treatment experiences of acquaintances and relatives, even if they had a different clinical situation or disease (Berry, Ellis, Woods, Schwien, Mullen, & Yang, 2003). Such differences between health contexts can make the transfer of relevant health information and advice challenging. For example, we might expect that managing a genetic condition is similar to managing other chronic illnesses. However, people with genetic conditions tend to encounter unique challenges in managing their condition due to its heritable nature (Petersen, 2006).

Although maximizing similarity of a focal problem and personal characteristics among members of self-help groups can enhance group cohesion and effective problem solving (Medvene, 1990), these benefits must be balanced with benefits offered by group diversity, which can stem from learning through modeling between 'newcomers' and 'veterans' (Borkman, 1990). Because patients from a range of contexts can shape other patients' health behaviors through the expertise they offer, patient expertise sharing tools could be designed to help patients make solid matches between their own needs and the contextual factors that surround the expertise available from other patients.

### **2.2.3.3 Conflicting Information**

In other cases, information can be both accurate and have good fit with the recipient's situation, but some consider it dangerous because it operates from a conflicting value system or model of health. The perspective of western medicine can deem such **conflicting information** as unconventional. For example, O'Rourke and Germino (1998) note that cancer patients who relied on friends, family, and the

lay literature for advice to help them make treatment decisions, found that this advice could sometimes be contradictory to medical opinion and thus confusing. Fox, Ward, and O'Rourke (2005) describe how the pro-anorexia movement in online communities “*creates a distinct ‘expertise’ that runs counter to the medical explanatory model of anorexia*” (p. 946). Although such expertise has the potential to result in dangerous outcomes, it is not necessarily inaccurate. Similarly, some describe complementary and alternative therapies for Autism as ‘controversial’ because those therapies lack the empirical evidence base desired by western medical models (Schechtman, 2007). Awareness of how ideological assumptions can shape the tools we build to support patients is critical. For example, Johannsen and Kensing (2005), reporting on fieldwork observations of a patient portal, note that systems designed to meet patients’ information needs (e.g., personal health records) often privilege the provision of clinically-oriented information (e.g., health status or treatment options). They found that other forms of information desired by patients, including experiences of other patients, were “*not encompassed by what medical authorities find relevant*” (Johannsen & Kensing, 2005, p. 204). Although we cannot expect patient expertise sharing tools to smooth underlying ideological conflicts, they could make strides by making those ideologies more explicit for the user.

#### **2.2.3.4 Perceived Dangers to Professionals**

Perceptions of **dangers to professionals** associated with patient expertise sharing have focused largely on challenges to professional authority. For example, professionals could feel threatened, rather than welcomed to collaborate, by the assertiveness of patients who claim to be expert in self-management (Paterson & Sloan, 1994). Some describe concerns over the promotion of resistant attitudes towards health professionals, which could result in viewing those patients who resist professional direction as ‘noncompliant’ or in fears about the loss of professional

service to patients (Mantell, 1983; Chesler, 1990). Other concerns relate patient expertise sharing to the creation of ‘amateur doctors’, whom encourage unconventional therapies, recommend alternative professionals and services, or offer therapeutic-like advice that can endanger themselves and others because it is beyond their skills and training (Chesler, 1990). Although facilitating patient expertise sharing could encourage patients to actively participate in their health-care by asking their doctors many more questions, it is worthwhile to mitigate forms of professional resistance to patient interaction that can actually interfere with the expertise sharing process, such as counter-transference or an overprotective organizational culture (Ringler, Whitman, Gustafson, & Coleman, 1981).

These potential drawbacks associated with patient expertise sharing can certainly exist. However, arguments suggesting that these drawbacks are commonplace and pervasive, particularly on the internet, remain unsupported. As such, fears that underlie those arguments do not warrant abandonment of a patient expertise sharing approach. However, it is important to maintain awareness about these potential dangers in efforts to facilitate patient expertise sharing. What might informatics offer to maximize the benefits, while minimizing the potential dangers, of patient expertise sharing? Clearly, we need to enhance our understanding of the breadth of strategies employed by patients to safeguard against misinformation before we can fully facilitate patient expertise sharing in ways that balance associated risks and benefits. In addition, professional moderation is a commonly expressed solution. However, this expensive solution assumes a medical model when it is not clear that this is the only model upon which potential dangers can be judged. Chesler (1990) suggests that collaboration among professionals and patients might help professionals gain a deeper understanding of patient expertise sharing mechanisms, such as self-help groups: *“To a certain extent, professionals’ exaggerated anticipation of specific dangers can be demythologized and disaggregated. Then the patients/parents and*

*other self-help group members can educate the professionals about the real needs and perceptions of members and about the actual activities of self-help groups” (p. 321).*

## **2.3 Summary**

This Chapter motivates the research Aims that make up this thesis by arguing for our need to enhance our understanding of the nature of patient expertise and to overcome the challenges of developing that expertise through trial and error by facilitating patient expertise sharing. Informatics could play a role in facilitating benefits and mitigating potential drawbacks of patient expertise sharing, but we need significant insight to guide the design of supportive tools. Enhancing our understanding about the nature of patient expertise and about the strategies that patients use to exchange this valuable resource will make us better equipped to design informatics tools that can facilitate patient expertise sharing. To take hold of the advantages of patient expertise sharing through innovative informatics designs, we must first fill three important gaps in our existing research base. First, we must investigate and describe the characteristics of patient expertise. Second, we must investigate and describe the practices patients currently use to share their expertise. Third, we must incorporate these insights, with the direct involvement of patients, to explore the design of tools that can facilitate patient expertise sharing. The three Aims of this thesis on understanding and facilitating patient expertise sharing provide a first step toward filling these gaps.

## **The Characteristics of Patient Expertise**

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When patients need health information, they turn to both health professionals and other patients. Yet, we know little about how the information exchanged among patients (i.e., patient expertise) contrasts with the information offered by health professionals (i.e., clinician expertise). To enhance our understanding of the nature of patient expertise, I compared the characteristics of patient expertise to that of clinician expertise for breast cancer. In this Chapter, I present a comparative content analysis of topics discussed and forms of recommendations offered in sources of patient expertise and sources of clinician expertise. This work meets Aim 1 of this thesis by describing the characteristics of patient expertise. Next, I introduce important background that grounds this work (Section 3.1) and present the methodology that underlies my analysis (Section 3.2). Findings from this analysis offer a characterization of patient expertise in terms of topic, form, and style (Section 3.3) and carry both empirical and design implications (Section 3.4).

### **3.1 Introduction**

In addition to the indispensable information received from health professionals, patients use information and advice offered by other patients to help them actively participate in their own health-care and make informed personal health decisions (O'Rourke, 1999; Berry et al., 2003). Although patients are best known for providing emotional support, they also offer guidance through informational support provided to other patients based on the expertise they have gained from managing similar health situations. **Patient expertise** is knowledge gained from personally managing the day-to-day experience of illness. For example, patients develop expertise in the

self-management of chronic conditions through their everyday experience with self-care over time (Benner & Wrubel, 1988; Paterson, Thorne, & Dewis, 1998; Paterson & Thorne, 2000). Some experienced patients can even come to know as much as their doctors about their health situations (Peterson, 2006). In the context of breast cancer, patient expertise reflects practical know-how and coping strategies exchanged among breast cancer patients, cancer survivors, and their caregivers, family members, and friends (i.e., peers). In contrast, **clinician expertise** is biomedical knowledge gained from professional training and practice. Clinician expertise is exchanged between breast cancer patients and health professionals (e.g., physicians, nurses, therapists, and support staff).

Patient expertise has been valued in varied and growing contexts. For example, personal knowledge, such as lifestyle, priorities, and experiences, is an important contribution patients make to shared decision making with health professionals (Berry et al., 2003). Providing patients with decision support tools to share their personal knowledge and preferences with health professionals can improve nursing care and patient outcomes (Ruland, 1999). Other research has demonstrated the value of involving patients as teachers who share their illness experiences through medical education (Wykurz & Kelly, 2002). In this work, I focus on patients sharing their expertise with one another. Breast cancer patients, for example, have expressed a strong need for experiential health information provided by peers (Rozmovits & Ziebland, 2004). When those needs for patient expertise are met, patients might be better able to receive and appropriately use health information than when patients interact with an ‘ask the expert’ service that offers clinically-oriented resources (e.g., Shaw et al., 2007). However, we lack a deep understanding of the characteristics of patient expertise, which hinders clear guidance on how to design informatics tools that facilitate patient expertise sharing.

Historically, patients who share similar health situations have helped one another cope with illness by sharing their expertise through participation in patient-led support groups (Diamond & Little, 1984), as mentors in pioneering programs such as ‘Reach to Recovery’ (Burdick, 1975), and as instructors for chronic disease self-management programs (Lorig et al., 1999). Although the Internet has facilitated expertise sharing among patients in online health communities, many content analyses of interactions among correspondents of online breast cancer communities (Weinberg, Schmale, Uken, & Wessel, 1996; Sharf, 1997; Klemm, Hurst, Dearholt, & Trone, 1999; Hoybye, Johansen, & Tjornhoj-Thomsen, 2005; Winefield, 2006) highlight the broad recognition of these personal health environments as premiere resources for obtaining emotional support (Preece, 1998). Yet growing evidence illustrates the high prevalence of patient expertise exchanged through informational support in online health communities (Meier, Lyons, Frydman, Forlenza, & Rimer, 2007; Shaw et al, 2007).

Patient expertise has continued to gain visibility as Internet-based social software (e.g., social networking tools, blogs, wikis) helps patients readily exchange information and advice with others who face similar health situations (Adams, 2008; Elkin, 2008; Sarasohn-Kahn 2008). For example, personal profiles and commenting features of PatientsLikeMe (<http://www.patientslikeme.com>) allow users to ask one another about specific health experiences and to offer advice and recommendations that stem from those experiences (Frost & Massagli, 2008). Many patients now use social software more often to obtain expertise from other patients than to obtain their emotional support (Sarasohn-Kahn, 2008).

Despite the growing prevalence of patient expertise sharing, we still lack a fundamental understanding of what the characteristics of patient expertise are, and how it differs from clinician expertise. For example, Meier and colleagues (2007),

through a content analysis of cancer-related internet mailing lists, found that patient exchanges of information and advice clustered around medically-oriented topics (e.g., treatments and communication with health-care providers). Other work notes that nearly half of interactions between cancer patients and survivors through a telephone-based peer support system revolved around psychosocial and day-to-day issues, such as the impact of cancer on family and friends, compared to interactions revolving around cancer treatments and side effects (Dasch & Kendall, 2007).

What remains to be investigated is how the expertise exchanged among patients contrasts with the expertise offered by clinicians. Facilitating patient expertise sharing will depend on this knowledge to form a solid understanding of the fundamental characteristics of the expertise that patients exchange. For example, could we meet patients' needs for information solely by enhancing communication between patients and health professionals? Alternatively, do patients need help finding other patients who have had similar health experiences because clinicians have neither the time nor personal expertise to meet all their needs? An important first step to answering these questions is to understand the role that patient expertise plays in meeting patients' needs.

Thus, the purpose of this study is to enhance our understanding of patient expertise and to assess how it differs from clinician expertise. In the context of breast cancer, I conducted an in-depth and comparative content analysis (Krippendorff, 2004) to investigate how patient expertise and clinician expertise compare with respect to topic, form, and style. Through a multi-phased approach, I (1) characterize patient expertise through the analysis of content from peer-oriented message boards and books that serve as sources of patient expertise, (2) characterize clinician expertise through the analysis of content from a leading breast cancer resource book written by a health professional and an 'ask the doctor' message board for breast cancer, and (3)

contrast the characteristics of patient expertise and clinician expertise. I conclude with suggestions for how results from this analysis can be used to inform the design of consumer-health tools to facilitate patient expertise sharing.

## **3.2 Methods**

Using an evolving coding scheme that was grounded in the data (Crabtree & Miller, 1999), I conducted the content analysis of patient expertise and clinician expertise in four phases. First, I analyzed content from sources of patient expertise to identify both emergent topics discussed and advice (i.e., ‘recommendations’) offered. Next, I expanded the coding scheme by repeating this procedure using content from sources of clinician expertise. I then solidified the coding scheme into a codebook and tested the reliability of the coding procedure. Finally, I contrasted the kinds of topics discussed and forms of recommendations offered in sources of patient expertise and sources of clinician expertise. This multi-phased analysis answered two research questions:

1. How do topics discussed in sources of patient expertise compare to topics discussed in sources of clinician expertise?
2. How do forms of recommendations offered by sources of patient expertise compare to forms of recommendations offered by sources of clinician expertise?

### 3.2.1 Content Sources

Sources of patient expertise included three online message boards that support correspondence among breast cancer patients and two books written by cancer survivors (Table 3.1). Although books offer the provision of extensive expertise, message boards bring insights into the kinds of expertise actively sought. I included both messages boards and books to capture the breadth of expertise available to patients through these different kinds of sources. Selection of message boards was based on public accessibility, high volume of use, longevity, and variation in formality (i.e., varied levels of moderation and affiliation with health-related organizations). I selected these books because they are autobiographical, yet differ in style (i.e., highly narrative vs. handbook-like).

Sources of clinician expertise included an ‘ask the doctor’ message board that supports correspondence between breast cancer patients and health professionals, and *Dr. Susan Love’s Breast Book*, which is a popular book written by specialists for breast cancer patients (Table 3.1). I selected this message board over clinical advice summaries or health professionals’ blogs to enable analysis of questions from patients and answers from health professionals. I selected this book because users in the message boards I analyzed often recommend this popular resource to one another.

Table 3.1 shows the content sources, including the number of text pages analyzed and the number of content units (see 3.2.2 Coding Procedure) each source contributed to the analysis. Table 3.2 shows characteristics of the four message boards.

**Table 3.1 Content Sources**

	Source	Text pages	Content units
Patient expertise	Message board A	174	50
	Message board B	316	50
	Message board C	276	50
	Book 1: McCarthy & Loren, 1997 <sup>a</sup>	230	79
	Book 2: Willis, 2001 <sup>b</sup>	220	131
Clinician expertise	'Ask the Doctor' message board	277	150
	Book: Love & Lindsey, 2000 <sup>c</sup>	552	225

- (a) McCarthy, P., & Loren J.A. (1997). *Breast cancer? Let me check my schedule!* Vancouver, WA: Innovative Medical Education Consortium.
- (b) Willis, J. (2001). *The cancer patient's workbook: Everything you need to stay organized and informed.* New York, NY: Dorling Kindersley.
- (c) Love, S.M., & Lindsey, K. (2000). *Dr. Susan Love's breast book.* Cambridge, MA: Perseus.

**Table 3.2 Characteristics of Message Boards**

Message board	A	B	C	Ask the Doctor
Year of inception	1998	1994	1998	2000
Moderation	YES	NO	NO	YES
Affiliation with a health-related organization	YES	YES	NO	YES
Total threads included/total threads collected	50/66	50/130	50/81	150/150
Total messages (i.e., individual posts)	379	152	316	300
Messages/thread (mean & range)	8 (1,31)	3 (1,10)	8 (1,27)	2 (1,2)
Days worth of threads	5	24	55	85

### 3.2.2 Coding Procedure

In **phase 1**, I analyzed content from the sources of patient expertise. The unit of analysis for message boards was the **thread** (i.e., one or more related messages) and for books was the **subsection** (i.e., a titled section within a chapter). Inclusion criteria for the analysis were **content units** (i.e., message board thread or book subsection) that solicited or offered informational support (i.e., ‘information used to guide or advise’; Helgeson & Cohen, 1996) related to the diagnosis, treatment, or long-term management of breast cancer. I collected archived threads from the patient message boards with posting dates starting in February 2006 until 50 content units were obtained from each board that met inclusion criteria. Obtaining an equal number of content units from each patient message board required the collection and filtering of more threads from message board B (i.e., 130 threads) than from message board A (i.e., 66 threads) or message board C (i.e., 81 threads) (see Table 3.2). Common kinds of threads excluded from the analysis reflected exchanges of pure emotional support, technical support issues, threads labeled by users as “*off topic*”, and spam-like advertisements. For the corresponding examination of expertise in books, I divided both patient books into subsections. All subsections from both patient books met inclusion criteria. Sources of patient expertise contributed 360 content units in total. The patient message boards contributed 150 content units and patient books contributed 210 content units (see Table 3.1).

Based on themes that emerged from a preliminary analysis of informational support exchanged in the patient message boards (Civan & Pratt, 2007a), I coded content units from the sources of patient expertise while expanding the coding scheme. For each content unit, this evolving coding scheme was used to identify emergent topics discussed and forms of recommendations offered:

- **Topics** reflect a spectrum of personal health issues discussed, such as specific situations or problems. Topics represent the predominate theme of a content unit, which was typically most clearly identified within the introductory paragraph of a book subsection or within the initiating message and subject line of a message board thread. One topic was assigned to each content unit.
- **Recommendations** reflect a range in functional form taken by the advice offered for dealing with the personal health issues. Unlike the breadth captured by topics, recommendations were fine-grained statements of advice, such as potential problem solutions, that were often sprinkled throughout content units. One or more recommendation was assigned to each content unit.

In **phase 2**, I expanded the coding scheme by repeating the coding procedure on content from sources of clinician expertise. I collected threads from the ‘ask the doctor’ message board until 150 content units were obtained that met inclusion criteria. Unlike the threads from the patient message boards, the threads from the ‘ask the doctor’ message board were generally short, consisting of a question posted by a user and a response posted by a health professional, and each met inclusion criteria. I divided the clinician book into subsections and excluded subsections that did not meet inclusion criteria. I excluded subsections from Chapters 1 through 9 of the clinician book because content from those Chapters describes the development of healthy breasts and common breast problems rather than relating directly to the diagnosis, treatment, or long-term management of breast cancer. Sources of clinician expertise contributed 375 content units in total. The ‘ask the doctor’ message boards contributed 150 content units and the clinician book contributed 225 content units (see Table 3.1).

In **phase 3**, I collaborated with Wanda Pratt, Ph.D., through card sorting (Lincoln & Guba, 1985) and discussion, to solidify the evolving coding scheme into a code book made up of two main overlapping topics (i.e., medical and personal) and four forms of recommendations (i.e., action strategy, knowledge, perspective, and information resource). The codebook (see Appendix A), which reflects the endpoint of the evolving coding scheme, includes clusters of subtopics discussed, as well as different styles through which recommendations were expressed across all content units. Table 3.3 overviews the codebook and provides frequency counts for the kinds of topics and forms of recommendations assigned to content units from patient and clinician sources. Part I of Table 3.3 shows coding categories for topics and part II shows coding categories for recommendations.

Table 3.3 Codebook with Frequency Counts

<b>I. Topics</b>	<b>Content units from Patient Sources</b>	<b>Content units from Clinician Sources</b>
<b>Medical</b>	<b>102</b>	<b>309</b>
• Deciding on health-care teams, treatments & procedures, and research trial enrollment	• 24	• 35
• Understanding biomedical/clinical concepts & processes	• 41	• 246
• Managing interactions with health professionals	• 6	• 17
• Managing information to collaborate with clinicians and understand biomedical issues	• 31	• 11
<b>Personal</b>	<b>200</b>	<b>31</b>
• Managing life at home	• 24	• 0
• Managing work life	• 17	• 2
• Managing one's emotional response to illness	• 23	• 4
• Managing interactions with one's social network	• 26	• 4
• Managing personal tasks and projects	• 102	• 21
• Managing advocacy and volunteer work	• 8	• 0
<b>Both Medical and Personal</b>	<b>58</b>	<b>35</b>
<b>II. Recommendations</b>	<b>Number from Patient Sources</b>	<b>Number from Clinician Sources</b>
<b>Action strategies</b>	<b>966</b>	<b>623</b>
• Prescriptive	• 551	• 596
• Personal story	• 415	• 27
<b>Knowledge</b>	<b>1046</b>	<b>1978</b>
• Prescriptive	• 578	• 1845
• Personal story	• 468	• 133
<b>Perspectives</b>	<b>311</b>	<b>79</b>
• Prescriptive	• 166	• 76
• Personal story	• 145	• 3
<b>Information resources</b>	<b>964</b>	<b>1242</b>
• Books	• 24	• 195
• Contact information	• 40	• 314
• Magazines & magazine articles	• 5	• 15
• Multimedia	• 4	• 140
• News articles	• 30	• 2
• Poems & quotes	• 29	• 0
• Academic journals & research articles	• 75	• 350
• Templates	• 115	• 4
• Web pages	• 552	• 119
• Miscellaneous publications	• 90	• 103

The codebook was used to test the reliability of the coding procedure using a 10% reliability sample of content units (see Appendix A). Based on the number of contributing units, I randomly selected a set of content units from each content source for the reliability sample. An independent coder (Ching-Ping Lin (“CL”), Ph.D. Candidate) applied the codebook to the reliability sample. Kappa scores were calculated to determine the level of inter-coder agreement between codes applied to the reliability sample by CL and I (Table 3.4). I applied linear weighting to the Kappa calculations (Lowry, 2008) for recommendations to account for the level of agreement between coders for both types and numbers of recommendations (i.e., coders could assign multiple types and numbers of recommendations to each content unit). Reliability test results show good agreement overall and excellent agreement for recommendations in the form of information resources (see Table 3.4).

**Table 3.4 Inter-coder Agreement**

Code	Kappa
Topic	0.71
Action strategy	0.69*
Knowledge	0.72*
Perspective	0.54*
Information resource	0.94*

\*weighted Kappa

In **phase 4**, I compared the kinds of topics discussed and the forms of recommendations offered in sources of patient expertise and sources of clinician expertise. The distribution of topics and recommendations was determined by calculating weighted averages for patient sources and for clinician sources based on

the number of content units that individual message board and book sources contributed to the analysis. I then compared the distribution of topics and recommendations between sources of patient expertise and sources of clinician expertise.

### **3.2.3 Ethical Considerations**

I thought deeply about ethical considerations and evolving guidelines for conducting internet-based research (Eysenbach & Till, 2001; Brownlow & O'Dell, 2002; Kraut, Olson, Banaji, Bruckman, Cohen, & Couper, 2004; Bruckman, 2006; Moreno, Fost, & Christakis, 2008) while obtaining, analyzing, and reporting findings from online message board content. Thus, I selected public message boards for which membership was not required to access content, collected archived threads, removed identifiers from collected threads, and took care in reporting results to balance the anonymity of correspondents with research trustworthiness. This approach aligns closely with the approach taken in other content analyses of online health message boards, such as Finn (1999). IRB approval was obtained through the University of Washington prior to data collection from the message boards.

## **3.3 Results**

I analyzed 735 content units across all sources. Each content unit is associated with one topic. Content units contained 7209 recommendations in total. Table 3.5 shows the contribution of content units, topics, and recommendations from each content source. The contribution of content units from sources of patient expertise and from sources of clinician expertise was well-balanced.

**Table 3.5 Distribution of Topics and Recommendations across Sources of Expertise**

	Content units	Medical topics	Personal topics	Medical & Personal	Recom-mendations	Action strategies	Knowledge	Perspectives	Information resources
<b>Patient sources</b>									
Message board A	50	25	18	7	556	215	200	86	55
Message board B	50	12	22	16	252	119	52	33	48
Message board C	50	32	13	5	279	106	111	25	37
Book 1	79	12	58	9	837	300	368	121	48
Book 2	131	21	89	21	1363	226	315	46	776
<b>Total</b>	<b>360</b>	<b>102</b>	<b>200</b>	<b>58</b>	<b>3287</b>	<b>966</b>	<b>1046</b>	<b>311</b>	<b>964</b>
<b>Clinician sources</b>									
‘Ask the Doctor’	150	144	3	3	348	122	225	0	1
Book	225	165	28	32	3574	501	1753	79	1241
<b>Total</b>	<b>375</b>	<b>309</b>	<b>31</b>	<b>35</b>	<b>3922</b>	<b>623</b>	<b>1978</b>	<b>79</b>	<b>1242</b>

Next, I detail the kinds of topics and forms of recommendations that emerged from the analysis across content units from all sources. I then describe how sources of patient expertise and sources of clinician expertise compare with respect to those characteristics.

### 3.3.1 Topics Discussed

Most content units fell into two broad topic categories: discussion that was mostly **medical** in nature (i.e., 56% of all content units) or discussion that was mostly **personal** in nature (i.e., 31% of all content units). A smaller proportion of content units contained discussion that shared aspects that were **both medical and personal** in nature (i.e., 13% of all content units). Next, I provide representative quotes to

describe the types of personal health issues that emerged as subtopics in each topic category.

### 3.3.1.1 Medical Topics

Topics that were medical in nature involved problems or concerns about constructs or processes that are tied closely to the health-care delivery system, biomedical research, and health professionals' work. Medical topics often reflected discussion that could stimulate an improved understanding of the medical domain or strategies to better fit one's life to the health-care delivery system. Common clusters of subtopics that fell in this category included discussion about:

- Deciding on health-care teams, treatments and procedures, and research trial enrollment (e.g., being in a "*dilemma about reconstruction*")
- Understanding biomedical concepts and processes, medical treatment processes and procedures, manifestation of side effects, medical tests, and biomedical research (e.g., "*pathology report question*")
- Managing interactions with health-care professionals (e.g., "*I was supposed to take the [diagnostic] reports to a General Surgeon, but I wonder if this is necessary, since nothing was found*")
- Managing medical information to collaborate with clinicians or to understand biomedical issues, such as tracking medication or pain to share with your health-care provider, preparing questions to ask during appointments, or reviewing biomedical research articles (e.g., "*questions to ask your oncologist*")

### 3.3.1.2 Personal Topics

Topics that were personal in nature involved problems or concerns around constructs or processes that are tied closely to one's personal life, including ongoing responsibilities and activities associated with family, friends, the home, work, and health-related activities that occur outside of the health-care delivery system. Personal topics often reflected discussion that could stimulate the development of strategies to fit health management into one's ongoing life. Common clusters of subtopics that fell in this category included discussion about:

- Managing life at home, including recovery from medical treatments and procedures, keeping up with family and household responsibilities, and oversight of legal, financial, and insurance issues (e.g., *“Our diagnoses of breast cancer caused us to reevaluate our sense of responsibility and, when it was appropriate, to let go”*)
- Managing work life, such as shifting one's work load during treatment, considering the potential impact on work prospects and insurance, interacting with coworkers, colleagues, or clients during treatment, and deciding whether to work during treatment (e.g., *“Have any of you gone back to work during part of your chemo?”*)
- Managing one's emotional response to cancer, such as coping with anxiety, anger, depression, and fear (e.g., *“Finding ways to cope with the emotional roller coaster”*)
- Managing interactions with one's social network (e.g., *“What to tell your children”*)
- Managing personal tasks and projects, such as lifestyle (e.g., diet, exercise, and meditation), self-care, spirituality, hobbies, and managing personal health information (e.g., keeping track of *“the kind acts of others”*)

- Managing advocacy and volunteer work (e.g., “*Breast cancer has helped us discover our mission and taught us that we can make a difference*”)

### 3.3.1.3 Topics that are Both Medical and Personal

I placed content units that shared medical and personal topics fairly equally into the overlapping category *Both Medical and Personal*. Examples that fell in this category included:

- Understanding biological concepts and processes AND managing interactions with family (e.g., “*The risk of developing breast cancer is higher for women who have family history of cancer...Telling our mothers about our diagnosis and anticipating their responses was a source of major concern and anxiety for all of us.*”)
- Managing interactions with health-care professionals AND managing personal tasks and projects (e.g., “*After all of your treatments are completed...write down how you feel in general terms about once a month. Not only will it assist you in communicating with your doctor but it will also give you a barometer by which to measure your progress.*”)
- Managing treatments and appointments AND managing life at work (e.g., “*schedule your chemotherapy right before the weekend so that it interferes with work as little as possible*”)

### 3.3.2 Recommendations Offered

Recommendations offered across all content units fell into four major functional forms: action strategies (i.e., 22%), knowledge (i.e., 42%), perspectives (i.e., 5%),

and information resources (i.e., 31%). Some recommended action strategies, knowledge, and perspectives were direct, or **prescriptive**, in nature (i.e., *you should...*), while others were carried implicitly through **personal stories** (i.e., *when I was in your situation, I...*). I considered recommended knowledge that was descriptive or explanatory (i.e., *the process works this way...or the definition of that term is...*) as prescriptive. Content units contained recommendations for a full range of information resources. During analysis, my collaborators (WP & CL) and I recognized overlap among action strategies, recommended knowledge, perspectives, and information resources. For example, an action strategy can rely on acquiring knowledge and we can acquire knowledge through our actions. Although chunks of text in a content unit could contain combinations of related recommendations in these different forms, I broke the text down (e.g., sentence-level) to code each recommendation with the form it best fit rather than allow overlap among recommendation forms.

### 3.3.2.1 Action Strategies: Things to Do

Action strategies refer to recommended actions (e.g., low-level tasks) that one can take to help deal with a personal health situation. I considered recommendations that offered low-level, specific, and actionable tasks as ‘action strategies’ that can contribute towards solving a problem (e.g., “*It may be helpful for her to meet with a radiation oncologist before the surgery to discuss the pros and cons [of different treatments]*”). Action strategies were either prescriptive, reflecting a direct instruction for a prescribed action (i.e., *You should do this...*), or were implicitly carried through a personal story (i.e., *When I was in your situation, I did this...*). For example, action strategies offered through discussion about ways to prepare yourself for a mastectomy included: “*One piece of advice is to use a pillow or some sort of padding for your over the shoulder seatbelt*” (i.e., prescriptive) and “*What helped me*

*was searching the internet for photos and having various women who had been through it send me their photos” (i.e., personal story).*

### **3.3.2.2 Knowledge: Things to Know**

Recommended knowledge refers to informative facts and opinions that one can learn about to help them deal with a personal health situation, such as working through questions about one’s pathology report. Unlike action strategies, I considered recommendations that described concepts or ideas that one can come to learn and understand as ‘recommended knowledge’ (e.g., “*Both lumpectomy and mastectomy require anesthesia*”). Recommended knowledge that was prescriptive included subjective perceptions, opinions, or prescribed facts (e.g., “*the pathology report [describes] the...tumor and...nearby lymph nodes*”) and descriptive or explanatory knowledge, such as term definitions or descriptions of concepts or processes (e.g., “*Staging breast cancer is the process of...*”). Other recommended knowledge was carried implicitly through personal stories (e.g., “*do you have to wait very long [to meet with your oncologist]? I hope not, because waiting is the worst part*”).

### **3.3.2.3 Perspectives: Ways of Believing or Approaching Situations**

Perspectives refer to recommended belief systems, attitudes, or philosophies that drive an overarching approach for dealing with a personal health situation, such as coping with emotions. In contrast to action strategies, I considered recommendations that reflected high-level and generalized beliefs or attitudes towards an overarching experience as ‘perspectives’ (e.g., “*I made this decision [mastectomy vs. lumpectomy] to be comfortable with my body*”). Recommended perspectives were either prescriptive in style (e.g., “*I know it’s hard but I think you are actually mourning your old life...you need to give yourself time to do that*”), or were carried

implicitly through personal stories (e.g., “*One of my big moments came when I really understood that everything will always be different from the ‘before’ and that I must adjust to that*”).

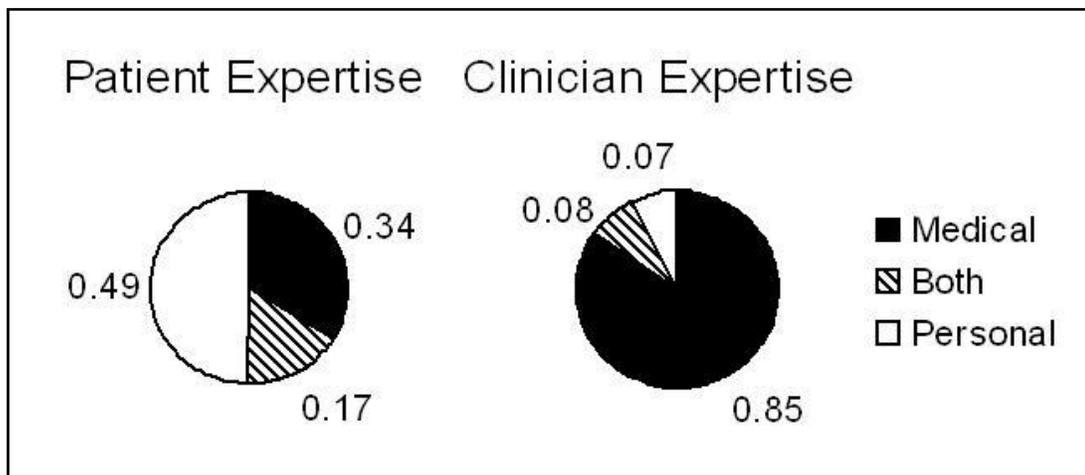
#### **3.3.2.4 Information Resources: Things to Obtain and Use**

Information resources refer to recommendations for obtaining and using specific tools and tangible artifacts to deal with a personal health situation. A diverse range of information resources were recommended, including books, contact information (e.g., for health professionals, health organizations, and local services), magazines and magazine articles, multimedia (e.g., videos, pictures, graphs, figures, audiotapes, calculators), news articles, poems and quotes, academic journals and research articles, templates, web pages, and miscellaneous types of publications (e.g., conference papers, pamphlets, brochures, white papers, and recipes).

The diversity of recommended web pages (i.e., ranging from cancer-related organizations to personal websites) and multimedia (i.e., ranging from static figures and graphs to audio, video, and interactive programs) is striking. Templates, which included structured lists, tables, and forms for users to personalize by filling them in, were an unexpected type of information resource. Templates reflect an embodiment of expertise that offer scaffolding to organize thoughts or actions surrounding personal health issues, such as tracking one’s health status, side effects and day-to-day events, recording research evidence that supports one’s treatment decisions, preparing for medical procedures, or assessing personal level of resilience, pain, and nutrition.

### 3.3.3 Differences in Topics Discussed between Sources of Expertise

Although sources of patient expertise and sources of clinician expertise contained content units that spanned both medical and personal topics, the proportions of content units falling under each topic differed significantly between those sources (Pearson's  $X^2 = 233$ ,  $df = 2$ ,  $p < 0.0001$ ). On average, sources of patient expertise discussed topics that were significantly more personal in nature and significantly less medical in nature than clinician sources (Figure 3.1). Patient sources discussed topics that spanned both medical and personal issues twice as frequently as clinician sources did.



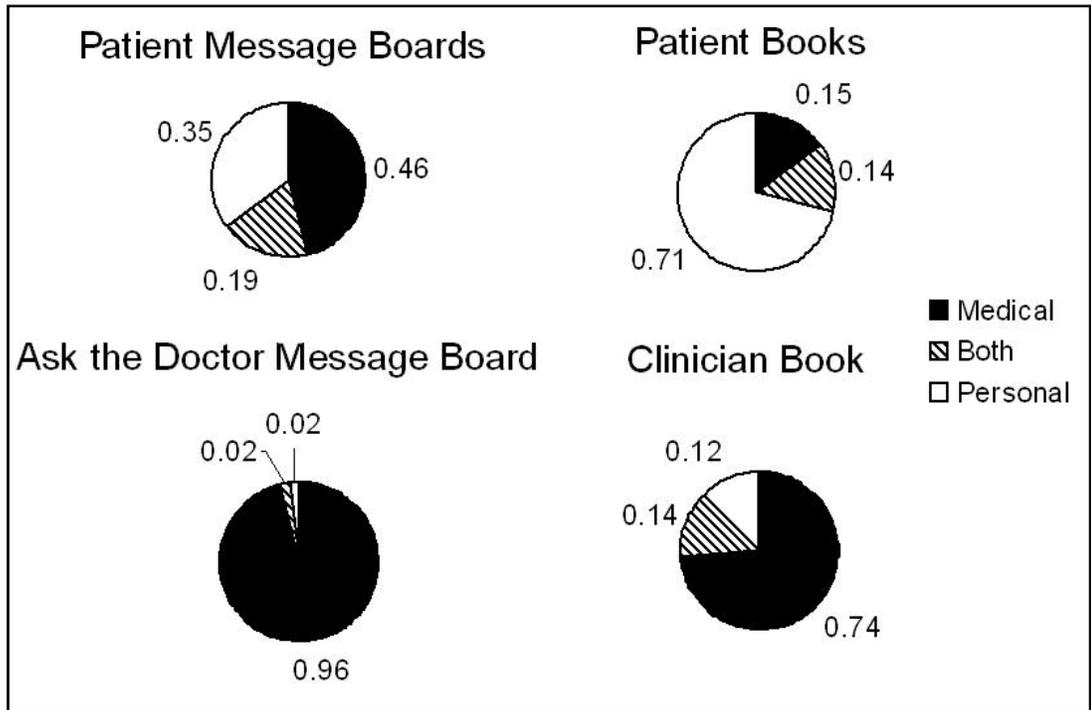
\*proportions reflect weighted averages

**Figure 3.1 Comparison of Topics Discussed in Sources of Expertise**

Although sources of patient expertise showed a high proportion of personal topics on average, the degree to which personal topics were discussed varied across individual books and message boards. For example, 73% of content units from the patient book *Breast cancer? Let me check my schedule* contained personal topics, whereas only

26% of content units from patient message board C did so (see Table 3.5). In contrast, the sources of clinician expertise were both predominantly medical in focus. Only 12% of content units from the clinician book discussed personal topics and only 2% of content units from the 'ask the doctor' message board did so. Although patient sources were more variable, the minimum proportion of personal topics discussed in the patient sources (i.e., 26% in patient message board C) was twice the maximum proportion of personal topics discussed in clinician sources (i.e., 12% in clinician book).

Figure 3.2 shows topic differences between message boards and books among both patient sources and clinician sources. Although the patient message boards contained a greater proportion of medical topics than the patient books (Pearson's  $X^2 = 48$ ,  $df=2$ ,  $p<0.0001$ ) and the 'ask the doctor' message board contained a greater proportion of medical topics than the clinician book (Pearson's  $X^2 = 32$ ,  $df = 2$ ,  $p < 0.0001$ ), the patient message boards discussed a greater proportion of personal topics than the 'ask the doctor' message board (Pearson's  $X^2 = 91$ ,  $df = 2$ ,  $p < 0.0001$ ). Similarly, the patient books discussed a greater proportion of personal topics than the clinician book (Pearson's  $X^2 = 169$ ,  $df = 2$ ,  $p < 0.0001$ ).

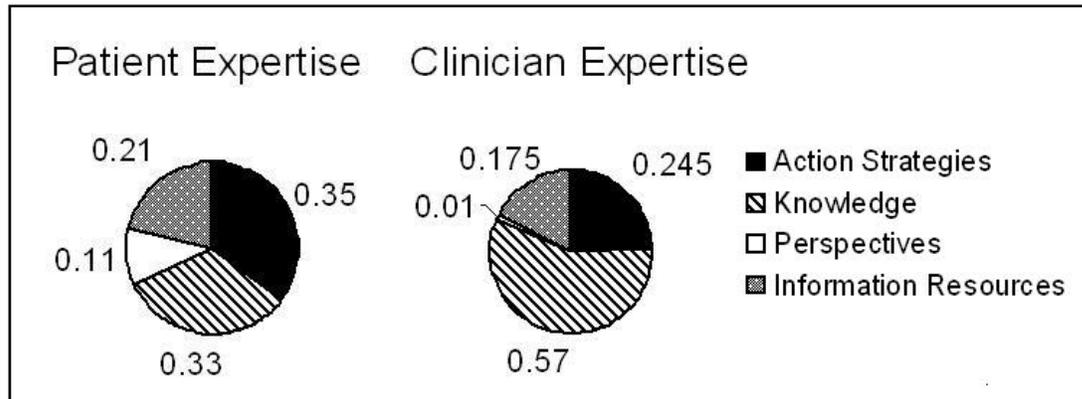


\*proportions reflect weighted averages

**Figure 3.2 Comparison of Topics Discussed in Message Boards and Books**

### 3.3.4 Differences in Recommendations Offered by Sources of Expertise

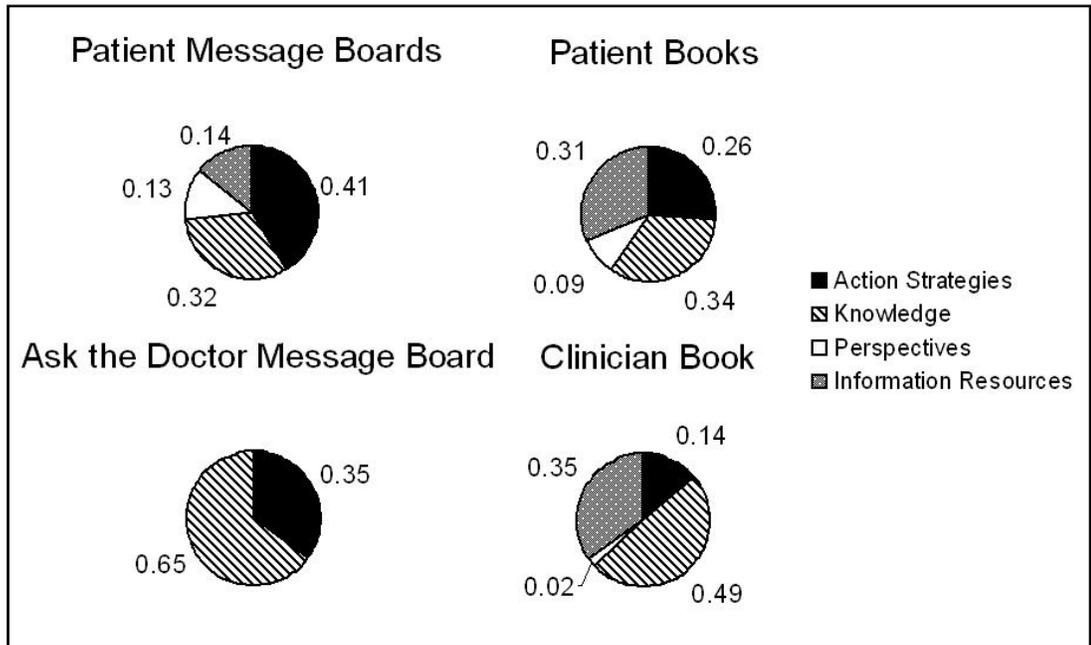
Although content units from sources of patient expertise and sources of clinician expertise offered recommendations falling under all four forms (i.e., action strategies, knowledge, perspectives, and information resources), the proportions of recommendation forms differed significantly between those sources (Pearson's  $X^2 = 482$ ,  $df = 3$ ,  $p < 0.0001$ ). On average, sources of patient expertise offered a greater proportion of action strategies and perspectives and a smaller proportion of knowledge than sources of clinician expertise (Figure 3.3). On average, sources of patient expertise and sources of clinician expertise offered similar proportions of information resources.



\*proportions reflect weighted averages

**Figure 3.3 Comparison of Recommendations Offered by Sources of Expertise**

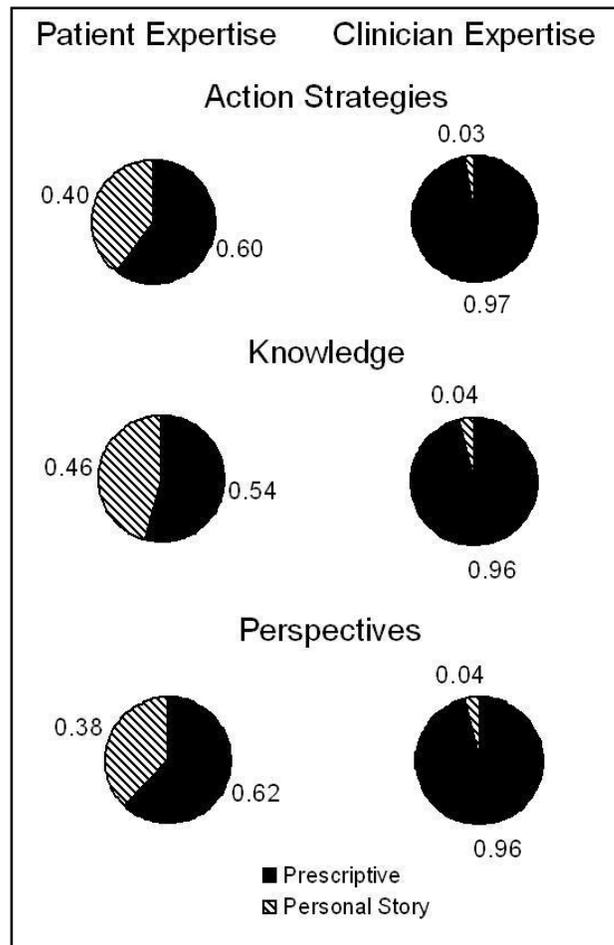
Figure 3.4 shows differences in the forms of recommendations offered between message boards and books among patient sources and clinician sources. Patient message boards offered a greater proportion of action strategies and a smaller proportion of information resources than patients books, but offered similar proportions of knowledge and perspectives (Pearson's  $X^2 = 244$ ,  $df = 2$ ,  $p < 0.0001$ ). Although the 'ask the doctor' message board offered no perspectives or information resources, the clinician book offered a few perspectives and many information resources, but smaller proportions of action strategies and knowledge than the 'ask the doctor' message board (Pearson's  $X^2 = 230$ ,  $df = 2$ ,  $p < 0.0001$ ). The patient message boards offered greater proportions of action strategies, perspectives, and information resources, but a smaller proportion of knowledge, than the 'ask the doctor' message board (Pearson's  $X^2 = 154$ ,  $df = 2$ ,  $p < 0.0001$ ). The patient books offered larger proportions of action strategies and perspectives, but a smaller proportion of knowledge, than the clinician book (Pearson's  $X^2 = 275$ ,  $df = 2$ ,  $p < 0.0001$ ).



\*proportions reflect weighted averages

**Figure 3.4 Comparison of Recommendations Offered by Message Boards and Books**

When delving further into the styles used to express recommendations, it became apparent that recommendations in the forms of action strategies, knowledge, and perspectives were more frequently expressed implicitly through personal stories in sources of patient expertise than through the prescriptive style that was common to the sources of clinician expertise (Figure 3.5). This difference in style between patient sources and clinician sources was significant for action strategies (Pearson's  $X^2 = 281$ ,  $df = 1$ ,  $p < 0.001$ ), knowledge (Pearson's  $X^2 = 621$ ,  $df = 1$ ,  $p < 0.001$ ), and perspectives (Pearson's  $X^2 = 49$ ,  $df = 1$ ,  $p < 0.001$ ).



\*proportions reflect weighted averages

**Figure 3.5 Comparison of the Style of Recommendations in Sources of Expertise**

Although sources of patient expertise and sources of clinician expertise offered similar proportions of information resources on average, the types of information resources that were most commonly exchanged differed between those sources. Sources of patient expertise offered many more web pages and templates, but much fewer contact information and academic journals or research articles, than sources of clinician expertise (see Table 3.3).

In summary, results from this comparative content analysis suggest that patient expertise is distinct from clinician expertise along multiple characteristics. Patient expertise focused on coping with day-to-day personal health issues gained through trial and error of the lived experience; thus, it was predominately *personal*. It offered a wealth of actionable advice that was frequently expressed through personal stories about managing responsibilities and activities associated with family, friends, work, and the home. In contrast, clinician expertise focused on explicit facts and opinions that tied closely to the health-care delivery system, biomedical research, and health professionals' work.

### **3.4 Discussion**

Results from this analysis show that patient expertise differs significantly from clinician expertise in topic (i.e., medical, personal, or both), form (i.e., action strategies, knowledge, perspectives, and information resources), and style (i.e., personal stories vs. prescriptive statements). Whereas sources of clinician expertise were predominately medical in topic, knowledge-oriented in form, and prescriptive in style, sources of patient expertise were predominately personal in topics, and carried a substantial amount of action strategies and perspectives through personal stories. These findings suggest that patients, through sharing their expertise about personal health, meet an important information need unmet by other sources. Thus, this work offers empirical contributions that enhance our understanding about the nature of patient expertise and carry design implications for patient expertise sharing tools.

### **3.4.1 Empirical Contributions**

Differences in the characteristics of patient expertise and clinician expertise support the notion that patients and health professionals possess different domains of health expertise (Coulter, 2002). Rather than filling the role of an ‘Amateur Doctor’ (i.e., claiming professional-like medical knowledge about the treatment of disease without having professional training), the experiential knowledge offered by patients focuses on coping with personal health issues in the context of daily life and is gained not through clinical training, but through the trial and error of managing the lived experience of illness. Patient expertise is much more than the aggregation of a patient’s preferences, values, and beliefs as viewed through the lens of the ‘Every Day Expert’. Instead, these findings support the ‘Experientialist’ lens of patient expertise (See Chapter 2). Although findings do not negate the existence of patients offering advice that can endanger themselves and others because it is beyond their skills and training, support for an Experientialist lens, rather than Amateur Doctor lens, helps to ease fears about the potential danger of patient expertise sharing to professionals (Chesler, 1990). In addition to clinician expertise obtained from health professionals, patients are finding new ways to reach out to other patients to exchange complementary personal health advice based on their own experiences. Patients are filling an important and valuable function that is not fully served by traditional health-care and medical information delivery models.

### **3.4.2 Design Implications**

Findings suggest that patients could benefit from informatics tools to help them share patient expertise with one another. Enhancements to tools that patients already use to exchange personal health information, such as health-related social software (Adams, 2008; Elkin, 2008; Sarasohn-Kahn, 2008), provide a sensible target for future design

efforts that offer opportunities for patients to interact in ways that extend beyond the traditional, text-based message boards of the past. For example, patients can create WisdomCards (<http://organizedwisdom.com/Home>) to share illness experiences and personal health advice, track and share their condition-specific symptoms and treatments (<http://www.patientslikeme.com>), and search member directories to find patients who share the same diagnosis (<http://www.carepages.com>, <http://communities.healia.com>, <http://www.patientslikeme.com>). Findings from this content analysis provide insights into facilitating patient expertise sharing through enhanced support for safeguarding medical misinformation, expertise location, and collaborative document management in this evolving space of health-related social software. These design implications offer strategies for mitigating potential disadvantages of patient expertise sharing I describe in Chapter 2, including medical misinformation, poor fitting information, and conflicting information.

#### **3.4.2.1 Supporting Misinformation Safeguarding Strategies**

As I pointed out in Chapter 2, some fear that facilitating patient expertise sharing could lead to the spread of medical misinformation. Although the potential for inaccurate medical information certainly exists, particularly with the democratization of the internet, studies have examined patient interactions in online health communities and found low levels of, if any, medical misinformation (Kelly et al., 2002; Eysenbach et al., 2004; Esquivel, Meric-Bernstam & Bernstam, 2006; van Uden-Kraan et al., 2008).

I did not assess the accuracy of information exchanged in the patient message boards I analyzed, but my informal observations of message board correspondents were consistent with previous research on strategies utilized to actively safeguard against the potential for misinformation, such as self-correction (Winzelberg, 1997;

Esquivel, Meric-Bernstam, & Bernstam, 2006) and warnings from watchful members (Preece, 1998). I also observed correspondents using additional safeguarding strategies, including source referencing (e.g., “*my oncologist told me that...*”), advice prefacing (e.g., “*everyone has a different experience, [but this is what happened to me]*”), rebuttal (e.g., “*our support group has many women’s experiences that prove otherwise*”), and affirmative vetting of advice offered by other correspondents (e.g., “*I agree with all the ladies so far*”). These observations point to the importance of design enhancements that encourage patients’ natural safeguarding strategies, such as functionality for evaluating the utility of content (e.g., vetting) and public context for collaborative interaction to facilitate collective self-correction.

#### **3.4.2.2 Supporting Patient Expertise Location**

Patients need help finding other patients who can offer knowledge about dealing with specific health situations. When confronted with an unfamiliar problem, people in professional work settings locate needed expertise by identifying potential sources (e.g., other people and artifacts) and selecting specific sources to approach for help (McDonald & Ackerman, 1998). This practice of **expertise location** has informed the design of tools that help professionals find colleagues with the desired, and often specialized, knowledge within a professional organization through features of expertise locators, such as user-profiles and social networks (McDonald & Ackerman, 2000; Ehrlich, 2003; Ehrlich, Lin, & Griffiths-Fisher, 2007). Similarly, social software can help patients to locate other patients who are facing similar health situations. Most user-profiles that facilitate such searches are limited to a single health condition and a small set of demographics. More extensive user-profiles (e.g., HealthCentral’s Breast Cancer Network;

<http://www.healthcentral.com>), incorporate additional location aids, such as role identification (e.g., *living through it, been through it, caregiver*, etc).

Users need easier ways to identify other users who have the specific patient expertise they need. Availability of a wider range of user characteristics could make it easier for patients to locate other patients for support (Frost & Massagli, 2008). We might envision informatics tools that could support the following scenario:

Lily seeks advice about whether to work during chemotherapy. She wants to locate a patient who has already dealt with this situation (e.g., *I want to find another mother of school-aged children who worked throughout chemotherapy*). She enters age, gender, and condition into a directory search service offered by a health-related social networking tool. Unfortunately, she is overwhelmed by the large number of user profiles the system returns, which she must now manually review to find a source of expertise with the specific characteristics she is looking for. In particular, Lily needs awareness about the knowledge and experiences of other users to answer questions, such as, *‘Does this source have the experience I am interested in? If so, how recently? What is the experience level of this source?’*

Enhanced search that incorporates more specific health experiences could make Lily’s work much easier and tailored to her needs. Examples of enhanced support for patient expertise location might include extending user-profiles to represent a larger range of medical and non-medical characteristics (Frost & Massagli, 2008) and building experience maps to communicate which users have which areas of patient expertise. By making it easier to find users who can offer expertise that closely matches one’s needs, these types of features could mitigate potential disadvantages associated with expertise sharing in the context of a ‘poor fit’ (see Chapter 2)

between a patient's health situation and the context from which the expertise they garner is drawn. Access to a fuller range of explicit profile characteristics, such as lifestyle and interests, could also help users assess the potential for 'conflicting information' (see Chapter 2) from users holding contrasting values. Enhancements could also incorporate vetting features that associate level of utility or affirmation to the patient expertise a user contributes to facilitate judgments about which of the most suitable users to approach.

### **3.4.2.3 Supporting Collaborative Management of Documents**

The wide range of information resources that patients exchange suggests the need for tools that enable patients to create, annotate, store, share, and reuse content across a diverse range of formats and topics. Patients need help managing this full range of artifacts they recommend to and garner from one another. Social software has the potential to enhance support for patient exchange of personal health information resources. For example, Weiss and Lorenzi (2008) synthesized community wisdom about local cancer programs and services using collaborative web-based tools for sharing community-based cancer resources. Extending health-related social software to incorporate support for document management functionalities could facilitate the collaborative recommendation of useful artifacts among users.

Medically oriented resources (e.g., medical dictionaries, patient information summaries) could certainly make up a valuable component of these kinds of shared collections. However, findings from this analysis suggest that a fundamental component of shared collections must include non-clinical resources that provide advice on personal topics related to work, family, and social relationships in the context of illness. Shared collections could incorporate a full range of information resources from multiple domains (e.g., medicine, law, social work, art, cooking,

community resources, and finance). Users could annotate resources collaboratively in ways that capture important contextual ties to their specific experiences and facilitate later reuse by other users (e.g., <http://www.diigo.com>). Collaborative tools, such as Google Docs (<http://docs.google.com>) or Microsoft Office Live (<http://workspace.officelive.com>), could also provide a means for creating and sharing user-generated content. A medical library model (Cosgrove, 1994; Zeng & Tse, 2006) might provide only a partial fit for organizing the breadth of information needs such shared collections meet. Broader organizational structures might allow users to organize shared information resources in personally meaningful, yet diverse, ways. For example, tools could encourage users to create *consumer health folksonomies* (Smith & Wicks, 2008) to organize documents around their own conceptualization of health issues, which might resemble collaboratively constructed tag-based systems that have emerged in other contexts, such as social bookmarking (<http://del.icio.us>).

Findings from this analysis provide additional insights for supporting a collaboratively managed collection of documents. The common style of personal stories used to express patient expertise (also see Hoybye, Johansen, & Tjornhoj-Thomsen, 2005; Swift & Dieppe, 2005), suggests the potential value of narrative-based formats that have been a highly valued format for sharing expertise in some professional work settings (Orr, 1996). Repositories of personal health stories that are surfacing through social software, such as personal blogs (Adams, 2008), and ‘Stories of Inspiration’ (<http://www.carepages.com>), might facilitate a natural expression of patient expertise, and provide data upon which to create experience maps that guide patients’ problem solving surrounding specific health situations. Vetting features, whereby users associate comments or affirmations with personal stories, could help users assess the fit of implicit advice those stories provide to their own health situation. Furthermore, patient expertise in the key form of action

strategies could be exchanged through ‘how-to’ pages (Torrey, McDonald, Schilit, & Bly, 2007; Torrey, Churchill, & McDonald, 2009) that communicate strategies for dealing with personal health issues, or through templates that provide guidance by scaffolding action plans around personal health activities (e.g., a ‘preparing for surgery’ checklist). Patients could later share useful personal health practices through templates with other patients for reuse.

### **3.5 Conclusion**

This Chapter offers a characterization of patient expertise that is grounded in a comparative content analysis within the context of breast cancer. Patients offer other patients substantial expertise that differs significantly in topic, form, and style from the expertise offered by clinicians. These findings suggest that expertise offered by patients can meet information needs that are unmet by health professionals, thus, patients can provide a unique and valued resource that complements the biomedical information they obtain from health professionals. Perhaps experienced patients do not serve as ‘Amateur Doctors’ who offer more accessible but less comprehensive or detailed biomedical information. Rather, they offer valuable experiential information that clinicians cannot necessarily provide.

It is likely that neither increasing the amount of time that patients spend with health-care providers nor training patients with biomedical knowledge to become amateur doctors is sufficient to meet the breadth of patients’ needs for health information. Instead, I offer alternatives in the form of social software design enhancements to facilitate patient expertise sharing. The characteristics of patient expertise and the resulting design implications identified through this work can help informaticians design new patient-centered tools to help meet patients’ diverse information needs,

including their need for patient expertise. However, without an understanding of the natural practices patients already use to share their expertise, the design ideas I offer can only go so far to facilitate patient expertise sharing.

Although the work I presented in this Chapter does much to extend our knowledge about the nature of patient expertise (i.e., *what* patient expertise is), observations of messages boards tell us very little about *how* patients come to know who has the expertise they need or who needs expertise they can offer. Unfortunately we lack a description of such patient expertise sharing practices. Before I describe the field I conducted to investigate the natural expertise sharing practices used by patients, I use the next Chapter to overview related work on expertise sharing drawn from extensive prior research conducted largely in organizational settings. This body of knowledge offers systematic descriptions of expertise sharing practices and supportive technologies those practices inform. If patient expertise sharing plays out in ways that are similar to expertise sharing in organizations, then expertise sharing tools designed for use in organizations might be easily applied to patients. However, if differences emerge, then alternative design features could be necessary.



## **Facilitating Patient Expertise Sharing: Related Work**

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This thesis is motivated by the need to enhance our understanding of patient expertise and to facilitate patient expertise sharing (see Chapter 2). Findings from the content analysis meet the first Aim of this thesis by describing the characteristics of patient expertise (see Chapter 3). Patients develop a wealth of expertise from personally managing the day-to-day experience of illness. This experiential knowledge gained by having, managing, and surviving illness can be leveraged by other patients in similar situations. Those findings demonstrate the importance of designing support for patient interactions that facilitate the exchange of this unique form of knowledge, including leveraging the growing health-related use of social software (e.g., internet-based forums, blogs, wikis, and social networking tools). Given the value of patient expertise, what informatics support can we design to facilitate patient expertise sharing?

In this Chapter, I discuss the substantial guidance offered by related research from the field of Computer Supported Cooperative Work (**CSCW**) that investigates expertise sharing more generally. First, I place patient expertise sharing in the context of this foundational body of prior work by conceptualizing informational support, through which patients exchange personal health knowledge, as a type of *everyday expertise sharing*. I draw upon this prior work to survey key features of expertise sharing practices and tools that can facilitate those practices (Section 4.1). Next, I describe the evolving range of social software that provides patients with diverse environments to interact, but that lack solid support for expertise sharing in light of prior work (Section 4.2). Finally, by summarizing those limitations, I identify gaps in our knowledge about how to facilitate patient expertise sharing

through design enhancements to health-related social software (Section 4.3). I conclude this Chapter by arguing for the need to address those gaps by first establishing an understanding of the natural practices patients use to share their expertise in their everyday lives (Section 4.4).

## **4.1 Conceptualizing Everyday Expertise Sharing**

Historically, patients have used both formal and informal channels to interact and exchange informational support (i.e., ‘information used to guide and advise’, Helgeson & Cohen, 1996) based on their own health experiences. Examples of formal channels include patient-led support groups in hospitals (Diamond & Little, 1984), self-help groups (Maton, 1988), chronic disease self-management programs (Lorig et al., 1999; Department of Health, 2001), and pioneering mentorship programs, such as ‘Reach to Recovery’ (Burdick, 1975) and ‘Breast buddies’ (Geiger, Mullen, Sloman, Edgerton, & Petitti, 2000). Experienced patients have offered valuable information to other patients by providing illness narratives as educational resources (Swift & Dieppe, 2005) and by acting as peer navigators who provide newly diagnosed patients with assistance that busy professionals are often unable to provide (Giese-Davis et al., 2006).

Although formal peer support programs can offer informational, emotional, and instrumental support benefits (Campbell, Phaneuf, & Deane, 2004), research points to a number of barriers associated with formal channels of peer interaction, such as lack of awareness about available programs (Campbell et al., 2004) and geographic limitations on access (Hogan, Linden, & Najarian, 2002). Instead, many patients turn to informal channels of informational support from their everyday communities. Examples include chance exchanges between patients in waiting rooms of doctors’

offices, within community-based support groups at local health resource centers, and at health-related fundraisers, such as Susan G. Komen Breast Cancer Foundation's annual 'Race for the Cure' (<http://www.komen.org>). Patients also traverse their own personal networks for informational support (O'Rourke & Germino, 1998; Berry, Ellis, Woods, Schwien, Mullen, & Yang, 2003). Although many patients turn first to these natural sources of help (e.g., friends and family whom might not have experience with the same health situation), some report having more trust in other patients as sources of health information (Elkin, 2008). This inconsistency could point to challenges patients face in finding patients from outside their existing personal networks with whom to establish new relationships that serve as the foundation for supplemental support (Ayers, 1989). Although patients express the need for experiential information that other patients can provide (Rozmovits & Ziebland, 2004), health informatics research has been slow to explore patients' needs for this support in everyday, informal settings.

Just as patients have long exchanged informational support to help one another to manage personal illness, so too have individuals in professional settings shared expertise to manage work in organizations. CSCW research has taken a lead in both describing expertise sharing practices and designing technical support to augment those practices, particularly in the context of professional organizations (Ackerman, Pipek, & Wulf, 2003). However, unlike expertise sharing in professional settings, patients commonly share their expertise through exchanges of informational support in less formal settings of everyday life. Furthermore, the characteristics of the expertise that patients share reflect experiential wisdom, rather than professional knowledge (see Chapter 3). Patient expertise resembles the practical and orienting information that individuals obtain through everyday information seeking from informal sources in nonprofessional settings of daily life, such a hobbies (Savolainen, 1995). More recently, researchers have begun to explore how expertise

sharing behaviors play out in less formal, everyday contexts of internet-based social software, such as ‘how-to’ web pages (Torrey, McDonald, Schilit, & Bly, 2007; Torrey, Churchill, & McDonald, 2009) and question and answer forums (Adamic, Zhang, Bakshy, & Ackerman, 2008).

To leverage this base of foundational research from the field of CSCW, it is useful to conceptualize informational support, though which individuals exchange patient expertise, as a type of *everyday expertise sharing*. Although contextual factors, such as the formality or type of setting, could differentially influence behavior, everyday expertise sharing among patients could share a number of similarities with the expertise sharing behaviors observed more generally in CSCW. Through the following scenario, I illustrate how foundational concepts drawn from prior work can help us to understand how patients assist one another by sharing their expertise:

*Lily, a 36-year old mother of two, was recently diagnosed with breast cancer. She has chosen to have a lumpectomy followed by chemotherapy, but is not sure whether to continue to work throughout treatment. Peggy, one among many of the increasing numbers of breast cancer survivors, underwent a double mastectomy and chemotherapy 10 years ago when she was in her mid 40's. Now that her children are grown and starting families of their own, Peggy is assisting other breast cancer patients in ways that she wished she had been supported throughout her own breast cancer experience. Peggy is a peer support volunteer at her local cancer resource center. After exhausting her personal network for advice, Lily turns to the formal patient matching service offered by this resource center, which she learned about through a suggestion she received from a friend. The resource center matched Lily with Peggy because they shared a similar diagnosis (i.e., breast cancer). When Lily asked Peggy for advice about whether to continue working during chemotherapy, Peggy told Lily the story of her own*

*cancer experience 10 years earlier and how chemotherapy affected her responsibilities as a stay-at-home mom. Although Lily found her conversation with Peggy encouraging, she had not obtained the work-related insight she had hope for and left feeling the need to connect with someone who had experience that more closely resembled her own. Perhaps she could locate another mom with young children who managed to work while undergoing the same clinical trial protocol that she has planned? The next day, Lily phoned Peggy at the resource center and asked her if she knew of anyone who fit that description. Peggy mentioned that she had become acquainted with the front desk clerk from a local store who might be a good fit for the specific expertise that Lily sought about managing work during chemotherapy. The next week, Peggy arranged to introduce Lily and the desk clerk at a local cafe.*

Several elements of this scenario resemble salient features of expertise sharing behavior more generally (Ackerman et al., 2003). The informational support exchanged between Lily and Peggy suggests that patients need channels to both find individuals with specific knowledge they need (i.e., **expertise location**) and to offer others the knowledge that they have gained through their own health experiences (i.e., **expertise provision**). Together, expertise location and expertise provision make up two important aspects of the collaborative sharing practices described in more formal settings, such as workplace organizations (McDonald & Ackerman, 1998; Ehrlich & Shami, 2008) and in less formal internet-based communities (Adamic et al., 2008; Torrey et al., 2009).

This larger body of prior work on expertise sharing offers foundational concepts that can help us to understand and facilitate similar phenomenon that appears in the everyday context of personal health. Several resounding themes are evident in the scenario. First, Lily's attempt to find someone with work-related experience and

knowledge is an example of *expertise locating* behavior (McDonald & Ackerman, 1998; Adamic et al., 2008; Torrey et al., 2009). The assistance offered by Peggy is an example of *expertise provision* (Maltz & Ehrlich, 1995; Torrey et al., 2007; Ehrlich & Shami, 2008). For example, Peggy's use of *storytelling* contextualizes the tacit knowledge she shares to encourage problem solving dialogue (Orr, 1996; Lutters, 2002). Second, the scenario suggests complexity surrounding the need to find a *suitable fit* between the characteristics of the expertise seeker (i.e., Lily) and the source of expertise (i.e., desk clerk rather than Peggy) (Terveen & McDonald, 2005). Third, the scenario conveys the important role played by well-connected *gatekeepers*, who can bridge people with sources of expertise outside of their personal networks (Allen & Cohen, 1969). Finally, the scenario also suggests the important role that one's *personal network* can play as sources of expertise (Nardi, Whittaker, & Schwartz, 2002). For example, people can obtain pointers to valuable resources, or *information gifts*, by keeping friends and family abreast of their needs (Torrey et al., 2009).

Similarities between informational support exchanged by patients and expertise sharing behaviors more generally demonstrate the potential utility of conceptualizing those patient interactions as a type of everyday expertise sharing. Yet, leveraging the insights and guidance offered by prior work to understand and facilitate patient expertise sharing requires understanding what that work can tell us about expertise sharing behavior more generally. Next, I draw upon this body of prior work to describe key features of expertise sharing practices and the tools designed to support those practices.

#### 4.1.1 Key Features of Expertise Location

Ethnographically inspired studies have investigated how people find expertise, most commonly in formal organizational settings. McDonald and Ackerman (1998), through a field study of the expertise search practices of professionals within a medical software company, offer a detailed framework that describes how people find expertise within an organization when they need help solving a problem in the context of their work. **Expertise location** is comprised of complex, iterative, and often interwoven behaviors used by professionals within an organization to determine who has what expertise (i.e., **expertise identification**), to narrow down a pool of candidate expertise sources to approach for help (i.e., **expertise selection**), and to recover from breakdowns in expertise location (i.e., **escalation**). Similar types of collaborative practices have been observed in other professional settings where people often search for expertise to obtain answers to technical questions and to find people with specific skills to engage in discussion (Ehrlich & Shami, 2008). Expertise locating practices address the need to find the people who are the most suitable, not necessarily the most competent, source(s) of expertise (Ehrlich & Shami 2008).

The professionals studied by McDonald and Ackerman (1998) employed a number of techniques that helped them to identify expertise by determining the particular information or skills colleagues could offer (i.e., expertise identification). For example, past experience within the company provided an everyday understanding of ‘who knows what’. Certainly this was an easier strategy for those with senior, as opposed to junior, standing in the organization. Professionals also identified expertise using clues embedded within historical artifacts maintained by the organization, such as a software change history log that records the names of those who have made modifications. Colleagues who made the most recent changes were

often identified as those with the freshest memory of the source code. Other researchers have noted similar utility of workplace artifacts as important markers of expertise in organizations (Lutters, 2002).

Professionals observed by McDonald and Ackerman (1998) also relied on organizational gatekeepers to identify expertise. Similar to ‘technological gatekeepers’ (Allen & Cohen, 1969) and ‘contact brokers’ (Paepcke, 1996), the specialized gatekeeping role of the ‘information concierge’ facilitates connections between colleagues and disseminates external information within the organization. McDonald and Ackerman (1998) ascribe technical competence, organizational tenure, and high status positions to those serving the role of the information concierge, whom use their internal map of the distribution of expertise in the organization to refer colleagues to those most likely to have the requisite information. Other researchers also note the value of other forms of gatekeeping for identifying expertise, such as information mediators who leverage their breadth of knowledge to search for and synthesize information for others in professional contexts (Ehrlich & Cash, 1994) and consumer health contexts (Abrahamson, Fisher, Turner, Durrance, & Combs Turner, 2008).

Once a pool of potential sources of expertise is identified, individuals must then choose who to approach for help (i.e., ‘who do I ask?’). McDonald and Ackerman (1998) observed several expertise selection mechanisms professionals used to narrow the pool of candidates. Common factors considered by professionals when selecting expertise included organizational norms (e.g., ‘keeping it local’ by staying within departmental lines), as well as the workloads and past performance of candidates (e.g., attitude toward and effectiveness at expertise sharing). These selection criteria reflect important social circumstances that can shape expertise sharing interactions through social and organizational norms as well as individual preferences. For

example, prior work highlights the value professionals place on social information, such as social ties, when selecting colleagues for expertise (Nardi et al., 2002; Shami, Ehrlich, & Millen, 2008).

Finally, in their study of professionals searching for expertise within a medical software company, McDonald and Ackerman (1998) discovered a phenomenon they call 'escalation' in which professionals adjust the pool of identified candidates or the selection criteria they apply to narrow that pool after attempts to locate expertise fail to provide the help they need. Escalation helped professionals iterate their location efforts to recover from break downs resulting from under-identification, over-identification, or misidentification of expertise, and from selecting someone who was too busy to respond or who could not fully understand the nature of the problem.

Key features of expertise locating in professional organizations demonstrate the complexity and social nature of finding suitable expertise. Locating expertise clearly involves more than finding a competent person. It also requires considerations about social circumstances that shape common reference points and the probability of garnering a suitable response (Terveen & McDonald, 2005; Shami, Ehrlich & Millen, 2008). Similar conclusions about the importance of social information (e.g., demographics, social ties, personal interests) are reached by researchers who investigate expertise locating in less formal, everyday contexts, such as internet-based social software. For example, Torrey and colleagues (2009) found that craft hobbyists rely on much more than keyword search to locate craft knowledge through how-to web pages. Because it can be difficult to specify a query for a need about which one lacks familiarity or which is procedural in nature (e.g. knitting or metal work techniques), craft hobbyists browse related web sites for serendipitous discovery of craft knowledge that suits their needs. Hobbyists also identify expertise by relying on their personal networks. In particular, they garner pointers to resources

(i.e., ‘information gifts’) from family and friends whom they keep up to date about their craft projects.

Social information is also critical for selecting someone to interact with online. For example, Jensen, Davis, and Farnham (2002) found that similarity in interests and ratings made by friends were much more important than consensus evaluations from the community when selecting someone for social chat, online gaming, and newsgroup discussions on the Internet. Although personal networks are clearly a critical aid for identifying expertise (Nardi et al., 2002; Torrey et al., 2009), they are not always sufficiently diverse to identify the expertise one needs (Constant, Sproull, & Kiesler, 1996; Ehrlich, Lin, & Griffiths-Fisher, 2007). In such cases, online social software offers individuals, in both professional (Millen, Feinburg, & Kerr, 2006) and everyday contexts (Torrey et al., 2009), the opportunity to extend their personal network by gaining awareness of the expertise available from others (Ehrlich & Shami, 2008).

#### **4.1.2 Key Features of Expertise Provision**

I use the term **expertise provision** to refer to the practice of actively passing along expertise to others. Expertise provision is similar to the process ‘knowledge exchange’, which facilitates the reuse of expertise created by professionals (Huysman & de Wit, 2003). One could consider expertise provision as simply the inverse of expertise locating (e.g., push vs. pull), yet this activity appears to carry its own unique set of behaviors and support challenges. Although expertise location forms the foundation of expertise sharing research in CSCW, insights into needs surrounding expertise provision have begun to surface in both professional and everyday contexts. For example, Torrey and colleagues (2007) describe the knowledge creation practices used by computer and electronics hobbyists to capture

and share their knowledge through the Internet. Ehrlich & Shami (2008), through an analysis of professionals' motivations for locating expertise in a technical organization, discovered a few cases in which individuals specifically looked for colleagues to provide with useful information they had obtained. Although those professionals could have broadcasted that information widely to the organization through email, it appeared that they wished to target specific colleagues who would have particular interest.

This difference between **generalized provisioning**, through broadcasts of expertise, and **targeted provisioning** of expertise to specific recipients is somewhat analogous to the differentiation made by Maltz and Ehrlich (1995) between passive and active forms of collaborative filtering among professionals. Briefly, collaborative filtering is an automated technique that recommends new items to a user, such as movies, books, or articles, based on the ratings provided by other users who share similar interests (Goldberg, Nichols, Oki, & Terry, 1992; Terveen & McDonald, 2005). This technique offers a means for individuals to provide expertise by passing along their evaluations of information items to help others judge the relevance of those items for their own use. Like generalized provisioning, in which expertise is broadcasted with no specific recipient in mind, 'passive collaborative filtering' involves the sharing of accumulated knowledge through the aggregation of evaluations provided by many users (Maltz & Ehrlich, 1995).

In contrast, 'active collaborative filtering', like targeted provisioning of expertise, involves sharing knowledge carried by those evaluations with specific recipients (Maltz & Ehrlich, 1995). Thus, generalized provisioning of expertise offers the advantage of reaching the masses by sharing common-purpose knowledge broadly, such as answers to frequently asked questions (FAQ). Needs for generalized expertise provision resonate with the motivations expressed by contributors to social

software, such as Wikipedia ([www.wikipedia.org](http://www.wikipedia.org)), who wish to ‘give back’ to community members through a process of reciprocal altruism (Kuznetsov, 2006). In contrast, targeted provisioning of expertise, such as informing a colleague about an important or interesting document, offers the advantage of highly personalized and contextualized knowledge shared along social ties found so valuable in professional organizations (Nardi et al., 2002) and in everyday life (Dieberger, Dourish, Höök, Resnik, & Wexelblat, 2000).

One critique of traditional knowledge management strategies in organizations is the focus on codifying professionals’ expertise in generalized external representations, such as FAQs, best practice guides, or personnel directories. Although these tools can document and maintain knowledge to facilitate its reuse within the organization (Ehrlich & Shami, 2008), they can also easily deteriorate due to a number of limitations, such as bias towards representing only successful solutions to learn from, risk of becoming quickly outdated, and lack of the ability to capture tacit or situational knowledge valuable to a company (Huysman & de Wit, 2003). Furthermore, codifying knowledge distills away contextual detail (i.e., ‘de-contextualization’), resulting in a rigid and generalized object that must later be interpreted and adapted to the task at hand (i.e., ‘re-contextualization’) for situated reuse (Lutters & Ackerman, 2002). For example, Lutters and Ackerman (2002) investigated how professionals in aircraft technical support reuse organizational knowledge in a database of ‘records of conversations’ (ROC) to resolve emerging problems in aircraft maintenance and repair. ROCs summarize operator requests, stress analyses, answers, and FAA approvals related to resolution of past problems. In some cases, professionals found such records to be outdated, incomplete, or lacking necessary detail due to shifts in time, work procedures, or work conditions, making the reuse of their knowledge they to resolve new issues, such as replacing non-standard aircraft parts, “rough, vague, and sketchy” (p. 273). In such cases,

professionals can leverage expertise embedded in the informal by-products of work, such as the personal notes of colleagues (i.e., ‘mirconotes’) or shared documentation of organizational work flow (i.e., ‘boundary objects’), to augment the interpretative process of re-contextualization (Lutters, 2004). For example, re-contextualization could be supported by the contextual expertise professionals provide by annotating pointers to useful documents they target to colleagues (Maltz & Ehrlich, 1995). Colleagues can also serve as valuable agents for re-contextualization by providing their expertise through workplace storytelling (Orr, 1996; Lutters, 2002). This prior work demonstrates the value of preserving expertise through work by-products and augmenting its reuse by facilitating social interaction.

Use of internet-based social software, such as social bookmarking (Millen et al., 2006), is another way that professionals can represent their interests and expertise for use by colleagues through corporate intranets (Ehrlich & Shami, 2008). This practice is also emerging as a significant means for expertise provision in everyday life. Opportunities for everyday expertise provision are rapidly expanding online through blogs, wikis, and how-to web pages, which serve as informal systems of expertise sharing. For example, Torrey and colleagues (2007) investigated the practices used by computer and electronics enthusiasts to document their projects as ‘how-to pages’, which they broadcast to and receive feedback from the community through blog-like features on personal websites. Unlike traditional knowledge management in many professional settings, computer and electronics enthusiasts have no central organization that structures or organizes their expertise. Instead, they work together as a decentralized system of volunteers, using a range of digital artifacts (e.g., drawings, pictures, and video) to consolidate and represent their knowledge among an interconnected network of individually-maintained how-to web pages.

### **4.1.3 Facilitating Expertise Sharing with Recommendation Systems**

Expertise sharing needs in both professional and everyday settings has led to the proliferation of supportive tools. Designs for many of these tools are directly informed by the research on key expertise sharing practices I have described (e.g., McDonald & Ackerman, 2000; Ehrlich, Lin, & Griffiths-Fisher, 2007).

Recommendation systems can be differentiated in a number of ways. For example, some tools rely on explicit recommendations from users, while other tools infer recommendations implicitly by observing the actions of a user or by mining the information they have interacted with. Alternatively, these tools can be distinguished by the type of artifact they recommend (e.g., an information item or a person).

Recommendation systems can also reflect one or more model of collaboration through which users provide and garner expertise (McDonald, 2000). For example, some tools encourage decentralized participation among users (i.e., ‘democratic’ model), whereas other tools favor the views of recognized leaders in a given area (i.e., ‘opinion leader’ model). Some tools bring people together to share in interaction around a common interest (i.e., ‘birds of a feather’ model), whereas other tools help users to make a recommendation to a specific person, whether through a request or volunteered (i.e., ‘one-to-one’ model). Still other tools leverage users’ social networks to facilitate expertise sharing (i.e., ‘social network’ model).

Next, I survey a range of recommendation systems that can facilitate expertise sharing. I first describe collaborative recommendation systems, which recommend information items. Then, I describe social matching systems, which recommend people.

#### 4.1.3.1 Collaborative Recommendation Systems

Recommendation systems address the problem of information overload by leveraging knowledge about users' preferences to help them to choose from among many possible information items, such as books, movies, and documents, or even people, with which they are unfamiliar (Resnik & Varian, 1997; Terveen & McDonald, 2005). There exist a number of different types of recommendation systems, including content-based recommendations systems, collaborative filtering systems, and social matching systems. These systems can be distinguished by the type of recommendation they provide (i.e., information items or people) and the extent to which they support collaboration among users.

The earliest recommendation systems were **content-based**. This approach encourages the user to evaluate items, and then employs machine learning techniques to predict the kinds of items that user will prefer in the future. Some systems limit the recommendations a user receives to items similar to those they themselves rated highly in the past (Lang, 1995). Other systems aggregate item-evaluations across users, and then provide every user with the same set of global ratings. In contrast, collaborative recommendation systems address information overload by helping users to share their evaluations of information items to help other users select from among many possible items with which they are unfamiliar (Terveen & McDonald, 2005). Collaborative recommendation systems provide users with one means to share their expertise through item evaluations and to benefit from each other's views, opinions, and experiences (Terveen & Hill, 2001). Because two or more people collaborate in that recommendation process, these systems offer 'multiple agency' (McDonald, 2000). This collaborative approach allows users to garner highly personalized recommendations by accounting for influential social information that shapes our natural expertise sharing practices, such as following paths taken by

others or receiving suggestions from friends (Dieberger et al., 2000). Rather than generating global recommendations, collaborative recommendation systems recognize that preferences vary widely across individuals and generate recommendations tailored to a user's specific preferences.

Perhaps the best known expertise sharing tools are collaborative recommendation systems, which have found an important niche online through user-suggestion features offered by services, such as Amazon (<http://www.amazon.com>) or Netflix (<http://www.netflix.com>). This class of recommendation systems uses **collaborative filtering**, which is an automated technique that recommends items based on the evaluations provided by other users who are alike (Terveen & McDonald, 2005). Collaborate filtering encourages people who are alike, through shared interests or shared relationships, to recommend items to one another. Thus, many collaborative filtering tools encourage a 'birds of a feather' model of collaboration (McDonald, 2000).

The first collaborative filtering tool, 'Tapestry' (Goldberg, Nichols, Oki, & Terry, 1992), encourages users to annotate email received at work with their opinions (e.g., 'liked it'). Those annotations serve as evaluations (i.e., ratings), which are leveraged by colleagues to filter their incoming email. By aggregating users' evaluations, Tapestry can produce a collective judgment about which documents are likely to be of interest to other users, as well as point to documents rated highly by opinion leaders in the organization (i.e., 'opinion leader' model of collaboration; McDonald, 2000). Because this system relies on explicit ratings from users, matching profiles for recommendation can become problematic if only sparse data is available when users rate too few items.

Whereas Tapestry (Goldberg et al., 1992) relies on explicit ratings from users, other collaborative recommendation systems mitigate this burden and the associated risk of sparse ratings by incorporating implicit indications of users' content interests. For example, GroupLens (Konstan, Miller, Maltz, Herlocker, Gordon, & Riedl, 1997) applies collaborative filtering to large-scale, public Usenet news by combining users' explicit ratings of articles within a particular newsgroup (i.e., 1-5 scale from “*bad*” to “*great*”) with implicit indications about users' interests in articles, such as the amount of time spent reading. By maintaining a representation of the explicit and implicit ratings of users from specific newsgroups, the system improves the density of data available to match users who have similar tastes.

Whereas Tapestry (Goldberg et al., 1992) and GroupLens (Konstan et al., 1997) support a passive means for users to recommend information items nonspecifically to other users, other researchers have approached collaborative recommendation through ‘active collaborative filtering’ in which users direct recommendations for information items to specific individuals in their social network. For example, Maltz and Ehrlich (1995) describe a system in which users send pointers (i.e., hypertext link and contextual information) to documents they find interesting to specific colleagues. Because this tool targets recommendations to a particular person, it supports a one-to-one volunteer model of collaboration (McDonald, 2000).

Other systems, such as ReferralWeb (Kautz, Selman, & Shah, 1997), also combine collaborative filtering with knowledge about social networks, but do so to recommend *people* rather than *documents*. In contrast, the types of recommendation system I have described thus far provide users with suggestions for information items (i.e., ‘document finders’). Next, I describe this other class of recommendation systems we can consider ‘people finders’ (Ehrlich, 2003).

#### 4.1.3.2 Social Matching Systems

Social matching systems comprise a class of recommendation systems that bring people together by providing users with suggestions for people (Terveen & McDonald, 2005). Like collaborative recommendation systems, social matching systems are also finding their niche online by bringing people together for dating (<http://www.match.com>), social interaction (<http://www.facebook.com>), and even health-related interaction (<http://www.patientslikeme.com>). Yet, social matching systems can be considered distinct from collaborative recommendation systems because searching for people necessary occurs within a social context that influences the selection of a human source, but not necessarily the selection of a document source (Shami et al., 2008).

Social matching systems profile users (e.g., what a user knows and who they know), generate matches between users (e.g., implicitly or explicitly), and provide a way for those users to come together for interaction (e.g., email or IM chat) (Terveen & McDonald, 2005). Some social matching systems leverage the interactions of users as feedback to improve the recommendation process, such as updating profiles or iteratively building repository content (Ackerman & McDonald, 1996). One way to differentiate the range of social matching systems is whether the people finder augments expertise locating ‘actively’, through an explicit request for expertise from the user, or ‘passively’, as an implicit by-product of other information activities.

**Passive social matching systems** recommend people implicitly through information seeking activities. These tools do not rely on an explicit request for expertise from the user. Instead, passive social matching begins with the user seeking documents, which can point to helpful people when documents provide inadequate expertise. For example, ‘PHOAKS’ (Terveen, Hill, Amento, McDonald, & Creter, 1997) begins by

mining Usenet news postings for pointers to web pages (i.e., URLs) that serve as implicit recommendations from posters. This tool then counts pointers to recommend frequently mentioned web pages. Because this tool takes into consideration the recommendations suggested by every user, it supports a ‘democratic’ model of collaboration (McDonald, 2000). PHOAKS serves a people finding function by supplying users with contextual information about who mentioned the web resource in their posting if users wish to contact that source of expertise for further information.

Other systems take an implicit approach to people finding by observing users’ information activities for similarities to generate matches opportunistically. For example, Yenta (Foner, 1997) relies on agents that act as intermediaries to facilitate matchmaking among users who share similar interests. A user runs an agent that examines their email and Usenet news articles for similar topics. If two or more users share an interest in a topic, their agents form a cluster. One agent can send a referral to other agents in the cluster to locate another user with a close match, creating a referral chain that is analogous to finding expertise through ‘word of mouth’. Unlike other social matching systems, Yenta’s observational approach to implicit people finding is opportunistic because it does not require action, such as information seeking or an explicit request on the part of the user.

**Active social matching systems** rely on a direct request for expertise from a user with an information need. These tools are commonly referred to as ‘**expertise locators**’ (Terveen & McDonald, 2005). Expertise locators recommend people to contact for help in a given area by leveraging knowledge about what people know, as well as who they know. A tool called ‘Who Knows’ (Streeter & Lochbaum, 1988) is perhaps the earliest ancestor to expertise locators. This tool applies latent semantic analysis to work samples submitted by professionals and creates profiles that

represent their knowledge and skills. Expertise seekers query the system by key word to identify the matching profiles and contact information. Because Who Knows does not incorporate social information about colleagues' relationships, it is unlike modern expertise locators. Thus, expertise locators build upon earlier approaches by leveraging the social relationships that connect people.

Expertise locators typically employ profiles to represent the types of knowledge and skills users have and the social relationships they have with other users (Ehrlich, 2003; Terveen & McDonald, 2005). Users can be profiled through explicit entry of data or implicitly through automated approaches that mine data, such as work products (Ehrlich, 2003). Explicit approaches to profiling can produce highly accurate representations, but can require significant time and effort to maintain and update. Implicit approaches can make this process less time-consuming, but can risk some accuracy. Whether profiles are constructed explicitly, implicitly or with some combination of the two, expertise locators can leverage this knowledge about the topic expertise of users to facilitate expertise identification (i.e., 'who knows what?'). They can then use knowledge about users' social relationships to facilitate the selection of people with requisite expertise who have the closest social tie to the user requesting help ('who do I approach?').

Examples of expertise locators include ReferralWeb (Kautz et al., 1997), ContactFinder (Krulwich & Burkey, 1996), Expertise Recommender (McDonald & Ackerman, 2000), and SmallBlue (Ehrlich, Lin, and Griffiths-Fisher, 2007), which incorporate a 'social networking' model of collaboration (McDonald, 2000). ReferralWeb (Kautz et al., 1997) generates a 'referral chain' from an expertise seeker to an expertise source by mining web-based technical papers for names of authors. The tool analyzes the content of papers to associate authors with the most common topics that appear in their papers. It also analyzes content to build a social

network based on co-occurrence of authors among papers to represent social ties among co-authors. Users query ReferralWeb for people who have knowledge in a given area, and then are presented with the social path to reach them ('referral chain'). Taking a similar approach to providing users with referrals, ContactFinder (Krulwich & Burkey, 1996) uses heuristics to mine bulletin board messages for key contacts in particular topic areas. The tool identifies topics asked about in bulletin board questions (e.g., messages that begin with '*does anyone know...*'), and then posts referrals to the community that point to key contacts who can address those questions.

Other researchers have designed expertise locators for use in professional organizations. Directly informed by the field research on expertise locating practice I described in the previous section (McDonald & Ackerman, 1998), Expertise Recommender (**ER**) was specifically designed to augment the natural practices of expertise identification, selection, and escalation. ER also employs a data mining approach by analyzing content in work artifacts, such as software change history records and technical support databases (McDonald & Ackerman, 2000). The tool represents knowledge about who knows what and social networks in user-profiles and allows the user to apply identification and selection heuristics to locate expertise. The user queries ER through a request that describes the work problem, which they associate with a topic area to identify relevant expertise (e.g., technical support domain). The user can then apply filters to tailor their search to colleagues meeting specific selection criteria (e.g., social network, departmental affiliation). The tool presents the user with a list of candidates and contact information, which the user can escalate by adjusting or refining their search.

Other researchers have used similar data mining techniques on workplace artifacts to facilitate expertise locating in organizations, such as enterprise email and chat logs

used by SmallBlue (Ehrlich, Lin, & Griffiths-Fisher, 2007). After querying by keyword, users of SmallBlue are presented with a list representing each matching candidate, including their social distance from the user (i.e., degrees of social separation in a social network) and contextual information, such as blogs, social tags and bookmarks that indicate their interests and activities. Social distance and contextual information provide the user with cues to determine for themselves which candidate to select.

Expertise locators are particularly useful in professional organizations when alternative tools, such as social networks, organizational gatekeepers, or personnel directories are unavailable or insufficient. In less structured environments, where these types of tools do not necessarily exist, expertise locators also provide utility. Building upon the use of web-based documents by early expertise locating systems, such as ReferralWeb (Kautz et al., 1997) and ContactFinder (Krulwich & Burkey, 1996), researchers have begun to facilitate expertise locating by leveraging content from social software systems, such as online communities. For example, Zhang, Ackerman, Adamic, & Nam (2007) use historical postings from a Java developers' forum to construct expertise profiles for users that reflect the key words from their posts and their level of expertise based on the extent to which they have helped other users by answering forum questions. These profiles are used to personalize the stream of forum questions by directing specific questions to those best positioned to answer them.

Other researchers also recognize the utility of social software for supporting expertise sharing. In addition to forums, platforms like blogs, wikis, and how-to web pages can be considered informal expertise locating systems (Torrey et al., 2007). It is likely that we are witnessing only the tip of the iceberg with respect to the growing diversity of internet-based social software. Social software is particularly appealing

as a platform for supporting patient expertise sharing because patients are using forums, blogs, wikis, and social networking tools at growing rates to exchange health-related information (Elkin, 2008; Sarasohn-Kahn, 2008). However, it is unclear to what extent leveraging patients' user-generated content and social networks to model features of collaborative recommendation systems or social matching systems could facilitate patient expertise sharing. It is important to look at how well existing health-related social software supports patient expertise sharing given what we know about expertise sharing and supportive recommendation systems more generally.

## **4.2 Sharing Patient Expertise through Social Software**

An evolving range of social software (i.e., blogs, wikis, message boards, social network tools) provides patients with increasingly diverse ways to interact (Adams, 2008; Elkin, 2008; Sarasohn-Kahn, 2008). In Chapter 3, I suggested that social software provides a seemingly rich context for facilitating patient expertise sharing. Drawing upon related work on expertise sharing more generally can provide significant guidance for investigating how to facilitate patient expertise sharing in this environment. For example, health-related social software could provide a number of building blocks for supporting expertise sharing, such as user-generated content, which could be mined to represent users' knowledge and their social ties.

Although many people approach health-related social software more for informational support than emotional support (Sarasohn-Kahn, 2008), it is unclear to what extent these tools help patients to share expertise in the ways that recommendation systems have long helped individuals share expertise in other contexts. In light of the prior work I have reviewed, I next evaluate four variations of

health-related social software for facilitating patient expertise sharing: forums, blogs, wikis, and social networking tools. For each platform, I offer examples of commonly used tools, describe how those tools could support patient expertise sharing, and propose open challenges for facilitating patient expertise sharing. Through this evaluation, limitations of health-related social software surface which we could overcome by establishing an understanding of patient expertise sharing to drive design enhancements.

#### **4.2.1 Interacting through Internet Forums**

An internet forum brings together users to interact around a shared interest, which can be considered a ‘birds of a feather’ model of collaboration (McDonald, 2000). Online support groups, historical online communities, question and answer (Q&A) forums, mailing lists, newsgroups, chat, and bulletin boards are all variations of this platform. Forums have become a common feature offered by health-related social networking sites, such as Trusera (<http://www.trusera.com>) and Carepages (<http://www.carepages.com>). Forum interaction is commonly organized into threads. Each thread is a collection of related message posts. In Q&A forums, posts within a thread are direct responses to a question. In discussion forums, posts within a thread are replies to a previous post. Threads are typically ordered chronologically and some tools also organize threads by topic.

Forums can vary along a number of characteristics, such as size and composition of membership, level of moderation, nomenclature, group dynamics (i.e., lurkers vs. direct participants) and level of structure (e.g., fluid vs. structured dialogue). For example, Q&A forums support a breadth of interaction to answer specific questions (e.g., Yahoo Answers; (<http://answers.yahoo.com>), whereas online support groups often reflect detailed ebb and flow of sharing around one or more topics (e.g., The

Breast Cancer Mailing List (<http://www.bclist.org>). Different types of groups can reflect different dynamics depending on how specialized the roles played by group members become. For example, the ebb and flow of social support forums shows much more homogeneity among the activities of group members than the role specialization that is observed in more technical forums (Adamic et al., 2008) and in technical organizations (Maltz & Ehrlich, 1995; Ehrlich & Shami, 2008).

Obtaining support on day-to-day health issues is a common reason for joining an online community (Horrigan, Rainie, & Fox, 2001; Johnson & Ambrose 2006). Health-related discussion emerges through patients' use of general-purpose online helping communities, such as Yahoo Answers (Adamic et al., 2008) or Usenet Newsgroups (Fisher, 2005). Other forums are designed specifically to support patient discussion around a specific health topic, such as cancer (Shaw, McTavish, Hawkins, Gustafson, & Pingree, 2000; Farnham et al., 2002), sports injuries (Preece, 1998), or disabilities (Finn, 1999). Similar to traditional face-to-face patient support groups, internet forums provide a mechanism for psychosocial benefits of peer-based social support, but this support system is not necessarily constrained by time or geography (White & Dorman, 2001; Hoey, Ieropoli, White, & Jefford, 2008).

Compared to other types of social software, forums have a longer history of use and are associated with a larger body of research on their usage patterns (Rimer et al., 2005; Meier, Lyons, Frydman, Forlenza, & Rimer, 2007) and psychosocial benefits (Winzelberg et al., 2003; Eysenbach, Powell, Englesakis, Rizo, & Stern, 2004; Lieberman & Goldstein, 2005). Prior work suggests that forums can support patient expertise sharing in three important ways. First, the free-form flexibility of forums provides opportunities for patients to capture and exchange detailed patient expertise in the style of their choice (e.g., personal stories). Highly contextualized expertise retains details that are often necessary for reuse when assessing the fit of information

to one's personal situation (Lutters & Ackerman, 2002). Thus, this free-form richness could reduce the potential for misapplication of information with poor fit (see Chapter 2).

Second, forums offer rewards of mutual aid by providing a mechanism for experienced patients to directly help others by sharing information (Rimer et al., 2005). For example, Winefield (2006) describes the emergence of volunteer 'emotion workers' in an online breast cancer support group. Similarly, Meier and colleagues (2007) observed correspondents filling a rewarding 'helper role' on cancer-related mailing lists. These roles are similar to intermediaries observed in other contexts (Ehrlich & Cash, 1994; Abrahamson et al., 2008). Unfortunately, few health-related online forums incorporate functionality to explicitly recognize the different roles that users play (Fisher, Smith, & Welser, 2006; Adamic et al., 2008).

Third, the threaded structure of forums encourages more dialogue among correspondents than other social software, such as blogs and wikis. The interactive structure of forums helps individuals to share tacit knowledge that is not easily codified or retrieved (Ehrlich, 2003). Forums can also support 'birds of a feather' collaboration to exchange expertise through mechanisms, such as voting (McDonald, 2000). These characteristics make forums particularly conducive for learning through participation within a knowledge community that actively co-constructs knowledge through collaborative interpretation (Vygotsky, 1978; Wenger, 1998). Requests for help generally require broadcasting questions to the entire community (Weisz, Erickson, & Kellogg, 2006), which works well if those with the requisite expertise notice and respond. However, once expertise is garnered, users must then determine the suitability of those peers for meeting their needs.

Although forums offer support for the exchange of highly contextualized patient expertise, they limit patient expertise sharing in three ways. First, open broadcasts requesting expertise as well as the content that embeds expertise gets buried deep within and among numerous threads. This problem of fragmentation makes it difficult for users to find all available resources relevant to a particular health problem and stay abreast of updates to previously posted knowledge. Unlike explicit updates in wikis, updates in forums commonly occur by posting an entirely new message or concatenating new posts onto the relevant thread. This can require users to hunt through unwieldy threads for up-to-date coverage. Imposing formal structure to organize threads through controlled medical vocabularies (e.g., Medical Subject Headings (MeSH), <http://www.nlm.nih.gov/mesh>) has the potential to inhibit the free-flow of informal interaction and can conflict with users' mental models. Unfortunately, alternative methods to structure buried content for retrieval and reuse is uncommon among health-related internet forums, such as incremental distillation of knowledge through the aid of human curators (Nam & Ackerman, 2007), data mining to represent implicit relationships between users and the topics they discuss (McArthur & Bruza, 2003), or use of consumer health folksonomies (Smith & Wicks, 2008).

Second, forums don't provide users with an easy way to gain an understanding of the range of expertise available to them without multiple interactions to build rapport and relationships with other users (Hoey et al., 2008). Without this time spent interacting, it is challenging for users to identify valuable roles played by other users (e.g., emotion workers) or to find other users with similar health experiences they can relate to (Rimer et al., 2005). Some forums, such as Google Groups (<http://groups.google.com>), provide simple user profiles with usage statistics. But it is unclear if details about activity level are enough to fully support patient expertise sharing. For example, profiles could be extended to help a user determine other

users' areas and levels of knowledge (Zhang et al., 2007) or the extent to which their personal health situation overlaps with other users. When deciding on a forum to join, who to approach for advice, or whether to follow advice garnered from other users, it is important for users to gain this awareness of 'who knows what'.

Third, although forums can be empowering for patients, some raise concerns over potential disempowerment imposed by 'flaming' (i.e., hostile insults), medical misinformation, and other potential harms (Burrows, Nettleton, Pleace, Loader, & Muncer, 2000). However, studies have examined patient interactions in online health communities and have found low levels of, if any, medical misinformation (Kelly et al., 2002; Eysenbach et al., 2004; Esquivel, Meric-Bernstam, & Bernstam, 2006; van Uden-Kraan et al., 2008). Forums that encourage participation among a large community of users are associated with higher quality content (Harper, Raban, Rafeili, & Konstan, 2008), which could result from protective safeguarding mechanisms users employ, such as memorial threads (Hsiung, 2007), self-correction (Winzelberg, 1997; Esquivel, Meric-Bernstam, & Bernstam, 2006), and watchful warnings (Preece, 1998).

#### **4.2.2 Capturing and Sharing Knowledge through Blogs**

A blog is a website created by an individual (i.e. a 'blogger') to share their opinions, views, and experiences, which they maintain through regularly published commentary (e.g., online journal entries). Blogs encourage an 'opinion leader' model of collaboration (McDonald, 2000) because they showcase an individual's opinions and experiences that serve as influential examples for others to follow.

Popular blogs, such as live journal (<http://www.livejournal.com>), provide readers with commenting features to post public responses to blog entries. Other tools, such

as twitter (<http://twitter.com>) provide a similar awareness of others' views and experiences, but do so by communicating abbreviated one-line answers to simple status questions, such as '*what are you doing right now*'? Still other tools, such as how-to web pages (Torrey et al., 2007) and Goggle's 'Knol' (<http://knol.google.com/k>), offer blog-like mechanisms for individual contributors to easily capture and share their knowledge with others.

Although some blogs, such as Yahoo Health Expert Advice Blogs (<http://health.yahoo.com/experts>), are written by health professionals, many patients increasingly turn to blogs to share their personal health experiences within a public space (Swift & Dieppe, 2005; Adams, 2008; Nguyen, Shanks, Vetere, & Howard, 2008). Early versions of blog-style tools used by patients to share their experiences include DIPEX (<http://www.dipex.org>), which publishes video and transcripts from patient interviews, and Experience Journal (DeMaso, Gonzalez-Heydrich, Erickson, Grimes, & Strohecker, 2000), which provides a collection of personal stories contributed by patients and family members about their management of specific health problems. More recently, blogs have become a common feature offered by health-related social networking sites, such as Trusera (<http://www.trusera.com>) and Carepages (<http://www.carepages.com>).

Blogs can support patient expertise sharing in two important ways. First, consistent with the natural story-based expression of patient expertise (see Chapter 3), blog entries often carry implicit advice through a narrative style (Hardey, 2002). This narrative form of expression represents a natural way to capture and share health experiences and has been highly valued for supporting expertise sharing in other contexts, such as professional organizations (Orr, 1996; Lutters, 2002). Second, blogs can carry rich contextual details that are often lost in platforms that produce generalized expertise through consensus (e.g., wikis). Highly contextualized

expertise retains details that are often necessary for reuse when assessing the fit of advice to one's own personal situation (Lutters & Ackerman, 2002). Thus, the free-form richness of blogs, like internet forums, could enhance the exchange information with good fit (see Chapter 2).

Although blogs could support aspects of patient expertise sharing, this platform is not without limitations. First, although highly detailed personal stories have the potential to facilitate re-contextualization of expertise for reuse (Lutters & Ackerman, 2002), bloggers can exclude pertinent details when broadcasting entries without a specific target recipient in mind. Blogs could also be more likely than other platforms to highlight uncommon or negative experiences. For example, electronics enthusiasts are more apt to capture successful solutions to problems in their how-to web pages (Torrey et al., 2007). Similarly, patients could be more likely to use blogs to share some aspects of their experience (e.g., unusual events or successful solutions) rather than other aspects (e.g., usual care). Thus, lack of pertinent detail relevant for reuse or detail limited to unusual situations can still contribute to the problem of information with poor fit (see Chapter 2). Many patients can benefit from learning about both successful and unsuccessful solutions, as well as both the mundane and unusual experiences of other patients.

Second, although blog search engines, such as Technorati (<http://technorati.com>) or Google blog search (<http://blogsearch.google.com>), help users to access blog-based content across the web, it remains particularly challenging for users to skim through multiple lengthy blog entries to identify and select relevant advice that meets their specific needs. For example, through an analysis of websites that disclosed the illness stories of breast cancer patients, Overberg, Toussaint, & Zwetsloot-Schonk (2006) discovered that not only did these blog-like websites lack structure and search features necessary for filtering content by personal features of the author or

keywords, they also lacked clues to assist users in determining the quality of the content and credibility of the author. Similar to internet forums, this problem of expertise fragmentation leads to substantial time and effort on the part of the user who seeks expertise.

Third, issues of information quality and ownership are common concerns about health-related blogs. For example, Adams (2008) argues for the need to learn more about how third party organizations that have certified online health information in the past (e.g., Health on the Net Foundation, <http://www.hon.ch>) are adapting to the changing web landscape that incorporates patient-generated content. Although many blogs allow readers to comment on content, the perception of the blogger's ownership of content makes this platform less conducive to self-correction than more collaborative platforms like wikis, which encourage frequent and collaborative updating. This issue of content ownership is reinforced through recent stories from the popular press concerning appropriate attribution to authors of health-related content created through this evolving medium (Jones, 2009).

#### **4.2.3 Building Collective Wisdom through Wikis**

A wiki is a web page or a collection of web pages that acts as a communal document or database by enabling anyone who accesses it to contribute or edit content. Unlike blogs that restrict editing to the owner, wikis are well suited to harness collective wisdom through a decentralized process of collaborative consensus building among contributors. Thus wikis reflect a 'democratic model' of collaboration (McDonald, 2000). One of the best known wikis, Wikipedia (<http://en.wikipedia.org>), is the most extensively used platforms for health-related use aside from historical message board forums (Elkin, 2008). Other popular wikis include the communal how-to database of procedural knowledge 'wikiHow' (<http://www.wikihow.com>) and 'wikia'

(<http://www.wikia.com>), which serves as a community hub for wikis across a range of topics.

Whereas general-purpose wikis, such as Wikipedia (<http://en.wikipedia.org>), commonly incorporate a range of health topics, other wikis are health-specific in scope. For example, Fluwiki (<http://www.fluwiki.com>) pools collective knowledge to help local communities prepare for and cope with a possible influenza pandemic (Palen, Hiltz, & Liu, 2007). wikiCancer (<http://www.wikicancer.com>) offers user-recommended articles and websites for personal management of cancer. Similarly, Weiss and Lorenzi (2008) designed a community-driven tool for sharing and synthesizing local knowledge about cancer resources.

Other wiki-style tools incorporate a mixture of ‘opinion leader’ and ‘democratic’ models of collaboration (McDonald, 2000). For example, WEGO health (<http://www.wegohealth.com>) encourages expert reviewers (i.e., a panel of health and wellness professionals) and public community members to work together to find and rate health-related web content. Any user can submit a web site for review. Each featured web page is summarized and rated for quality by an expert reviewer. Community members can then rate and comment on featured content. These examples of health-related wikis are akin to collaborative recommendation systems that help users share their expertise through item evaluations and to benefit from each other’s views, opinions, and experiences (Terveen & Hill, 2001).

Although wikis are thought to be a valuable channel for promoting community health (Crespo, 2007), relatively little research has explored their health-related use (Potts, 2006). However, this brief review, in light of prior expertise sharing research, suggests that the wiki platform can support patient expertise sharing in four important ways. First, wikis synthesize a wealth of patient expertise on specific

topics within a single location. This topic-oriented integration represents an improvement over internet forums that scatter patient expertise among disparate forum threads. Second, wikis produce generalized forms of patient expertise, representing a synthesis of patient contributions. This collective wisdom compliments educational materials obtained from the health-care system by meeting patients' needs for general-level health information that embodies experiential perspectives (Rozmovits & Ziebland, 2004), such as introductory overviews, answers to frequently asked questions (FAQ), or how-to guides for dealing with common health issues. Third, the open and collaborative nature of wikis encourages users to watch for and correct inaccuracies in broadcasted content, providing a natural means for safeguarding against medical misinformation. Lastly, the reciprocal altruism that drives contributions to general-purpose wikis, such as Wikipedia (Kuznetsov, 2006), is likely to drive health-related wikis as well. Thus, wikis can offer patients the opportunity to 'give back' and gain satisfaction from contributing to a knowledge base of collective wisdom about managing the experience of illness.

Although wikis are well-suited for sharing generalized patient expertise, this platform leaves open three specific challenges for patient expertise sharing. First, because wikis generate collective, generalized knowledge broadcasted toward the community at large, this platform can discourage contextualized expertise that is carried through the narrative style characteristic of patient expertise (see Chapter 3). Without a specific recipient in mind, producers of generalized knowledge, such as 'best practices', must distill away potentially relevant detail, making it difficult for a recipient to re-contextualize that expertise when adapting it to their specific, and perhaps unique, circumstance (Lutters & Ackerman, 2002). This distillation of contextual detail can contribute to the problem of information with poor fit, making it easier to misapply sound advice to an inapplicable context (see Chapter 2). This

problem could be particularly relevant for sharing expertise about uncommon or unusual health situations, which patients are likely to turn to social software for help. Thus, wikis could make it challenging for patients to share tailored or highly contextualized expertise or to easily make personal connections for one-to-one targeted exchange. However, features such as update records, comments, or page views may provide ‘fingerprints’ (Lutters, 2004) that can point to other users who may be of assistance for effectively interpreting and re-contextualizing wiki content.

Second, although the collaborative nature of wikis could provide a natural means for safeguarding medical misinformation, information quality is a common concern of wikis, particularly in the health domain (Adams, 2008). Even when information is accurate, conflicting information (see Chapter 2) can still be problematic. Because wikis strive for collective concordance, they are not designed to easily accommodate divergent or conflicting perspectives. Some warn that that user-generated health content from tools like Wikipedia is unreliable and insist instead on reliance upon traditional evidence-based resources (Lacovara, 2008). However, when science entries in Wikipedia were compared to entries in Encyclopedia Britannica, little difference in accuracy was found (Giles, 2005). Similar results were found through an evaluation of the quality of Wikipedia entries for common inpatient procedures (Devgan, Powe, Blakey, & Makary, 2007). Interestingly, Devgan and colleagues (2007) found that quality of an entry was associated with how frequently it was updated. Facilitating frequent updates by users, social mechanisms to vet the validity of user-generated data (Palen et al., 2007) or credence of contributors (Kriplean, Beschastnikh, & McDonald, 2008), and conflict resolution strategies (Jacquemin, Lauf, Poudat, Hurault-Plantet, & Auray, 2008) are potential avenues for mitigating some concerns over the quality of patient expertise on wikis.

Third, a question of concern has long been whether wikis truly represent the collective wisdom of democratic participation, or the uneven voice of a few select opinion leaders. Recent research on usage patterns of wikis and other social media, such as social bookmarking, provides insights into participation patterns over time. For example, although early use of Wikipedia relied on the contributions of ‘elite’ contributors (i.e., administrators and high-edit users), later shifts in the distribution of work from elites to common users suggests a trend towards more decentralized participation (Kittur, Chi, Pendleton, Suh, & Mytkowicz, 2007). In the consumer health context, unique barriers to participation could also come into play. For example, some tools (e.g. <http://www.wegohealth.com>) restrict full editing rights to only those deemed to meet a particular status, such as health and wellness professionals (Sarasohn-Kahn, 2008). Although everyday patients can contribute by way of commenting on or rating web pages selected and posted by these opinion leaders, this barrier to patients’ full participation can exclude the experiential knowledge that patients are best suited to provide (see Chapter 3).

#### **4.2.4 Connecting through Social Networking Tools**

Social networking tools are perhaps the most recent addition to the range of social software used by patients. The defining features of social networking tools include user profiles that represent individual users and social connections (e.g., friends) that represent social relationships among users. Users can represent their interests and perhaps areas of expertise in their user profile and then link their profile to the profiles of other users to establish personal networks of ‘friends’ with whom they share a range of content (e.g., pictures, web pages, videos, etc). Discussion forums and blogs are common components of social networking tools. Because this platform can leverage the information it represents about users’ social relationships, these

tools are akin to social matching systems that support expertise sharing through a ‘social networking’ model of collaboration (McDonald, 2000).

Popular social networking tools include the friendship-focused Facebook (<http://www.facebook.com>) and the professionally-focused LinkedIn (<http://www.linkedin.com>). Other tools, such as Meetup (<http://www.meetup.com>), facilitate the creation of interest groups that coordinate physical meetings in users’ local communities. Social networking tools can be used to stay connected with one’s existing network of family and friends and extend one’s personal network with new connections. For example, cancer patients need ways to keep their personal network up-to-date about their cancer experience, but need ways to reach beyond this network when it lacks sufficient patient expertise. Extending one’s personal network, by establishing weak ties, provides patients the opportunity to garner expertise that can be different from the information available from family and friends (Granovetter, 1973). A number of health-related social networking tools have been designed with these different uses in mind, such as Trusera (<http://www.trusera.com>), Carepages (<http://www.carepages.com>), PatientsLikeMe (<http://www.patientslikeme.com>), MyCancerPlace (<http://www.mycancerplace.com>), and Healia Communities (<http://communities.healia.com>).

Social networking tools can support patient expertise sharing in three specific ways. First, some social networking tools provide ‘people finders’ that leverage user profiles to search for other patients. This people finding functionality provides users with an alternative to broadcasting requests to the entire community. Instead, searching for people can get the user closer to targeting their request to those most likely to provide suitable expertise. For example, user profiles in PatientsLikeMe (<http://www.patientslikeme.com>) form the basis for searching for other users who share the same health condition. Similarly, Healia Communities

(<http://communities.healia.com>) helps users search for other users by community (e.g., diabetes), and then filter those community members by demographics or health practices (e.g., use of alternative therapies).

Second, social networking tools can support patient expertise sharing by providing personalized recommendations targeted at specific users. Rather than searching for information, some tools provide mechanisms for potentially relevant information to come to them automatically. For example, Trusera (<http://www.trusera.com>) provides a facility for users to receive personally relevant recommendations from the system based on their specified interest. Khan, Cohall, & Kukafka (2008) designed a tag-based recommendation system which leverages community ratings of content to rank tailored suggestions it provides to users. Other tools provide a means for targeted provision of expertise from one user to another, similar to the ‘one-to-one’ volunteer collaboration model (McDonald, 2000) of active collaborative filtering (Maltz & Ehrlich, 1995). For example, Frost and Massagli (2008), through a content analysis of profile comments on PatientsLikeMe (<http://www.patientslikeme.com>), discovered that experienced patients who reviewed profiles of peers often picked up on potentially problematic patterns they recognized from their own similar health experiences. These ‘experts’ would then provide peers with feedback to alert them to the potential problem and offer advice to solve the problem.

Third, some social networking tools provide users with the means for generalized expertise provision through a ‘democratic’ model of collaboration (McDonald, 2000), much like passive collaborative filtering (Maltz & Ehrlich, 1995). For example, Trusera (<http://www.trusera.com>) encourages users share their evaluations of information items (e.g., posts) or of users by ‘promoting’ content with ‘heart awards’ or user profiles with ‘karma points’. Some argue that wider adoption of these kinds of consensus-based rating mechanisms is an important next step for

enhancing health-related social software (Sarasohn-Kahn, 2008). PatientsLikeMe (<http://www.patientslikeme.com>) also aims to produce collective wisdom through population-level aggregation of experiences associated with condition-related symptoms and treatments (Adams, 2008; Sarasohn-Kahn, 2008). However, in this case, expertise is obtained implicitly from the graphs users maintain to record their health experiences rather than explicitly through direct evaluation of items.

Although social networking tools provide patients with a number of new routes for expertise sharing, this platform also leaves open two specific expertise sharing challenges. First, unlike expertise locators that are specifically designed to facilitate expertise sharing, health-related social networking tools lack a representation of what users know, which limits their capacity to search for expertise. Although health-related social networking tools excel in connecting people with similar health situations, sharing a similar health situation is not necessarily a marker for patient expertise. Enhancing user profiles with more detailed descriptions of users' backgrounds and areas of expertise has the potential to facilitate expertise locating. This could be accomplished through explicit entry or by implicitly mining the 'by-products' of their work, such as users' forum postings or other information resource contributions (McDonald & Ackerman, 2000; McArthur & Bruza, 2003).

Second, targeted mechanism for expertise provision can require tremendous effort from users. Staying abreast of the experiences other users report on their profiles requires keen awareness and time to continually review on the part of expertise providers. Users who receive targeted recommendations must then assess the credibility of the user who provided the advice. Existing tools provide limited support for either of these needs. However, enhancements could prove useful. For example, users could 'subscribe' to the profiles of patients they wish to follow to stay abreast of opportunities to provide guidance. User profiles could also

incorporate indicators about patients' needs for specific types of advice or about their past community activities upon which to evaluate credibility.

### **4.3 Gaps in our Understanding and Facilitation of Patient Expertise Sharing**

The evolving breadth of social software provides patients with diverse environments to interact. Although these tools provide some building blocks for supporting patient expertise sharing, such as user-generated content and representation of social networks, they present a number of limitations in light of recommendation systems that facilitate expertise sharing in other contexts. Prior work on expertise sharing in other contexts, if transferable to the personal health domain, has the potential to enhance health-related social software to overcome those limitations. Next, I call out limitations of health-related social software to illustrate gaps in our understanding and facilitation of patient expertise sharing.

#### **4.3.1 Broadcasting Limits Diverse Means for Collaboration**

Most health-related social software systems encourage users to share expertise through broadcasting, whereby a user posts a question or a recommendation to an entire community. This dominating broadcast strategy works well in situations that don't raise privacy concerns (e.g., not disclosing sensitive personal information on a forum or twitter), when users can clearly ascertain how their experiences relate, when users wish to contribute to a general-purpose 'marketplace of ideas' (Ehrlich & Shami, 2008), and when users can monitor posted questions or recommendations on an ongoing basis. However, whether locating expertise by sharing one's health experiences through a blog (Adam, 2008), personal profile (Frost & Massagli, 2008),

or posting a forum question, this broadcast strategy works only in so far as someone with the requisite expertise notices that request and responds. Once responses are garnered, the user must then determine who has provided expertise and whether that advice fits their needs. Health-related social software systems provide few examples of more targeted strategies evident in prior work to address this problem by facilitating sharing between specific individuals (Maltz & Ehrlich, 1995; McDonald & Ackerman, 2000).

Broadcasting is but one of many possible means users can rely on to share their expertise with one another. Prior work reflects a number of different models of collaboration that health-related social software could support more broadly (McDonald, 2000), such as private space for ‘one-to-one’ collaboration between members of internet forums or leveraging social relationships to locate expertise in social networking tools. These kinds of extensions could provide support for more targeted exchanges of expertise among patients. However, to determine which support strategies are most useful for patients, we must gain a deeper understanding of the ways in which patients naturally collaborate to share their expertise in everyday life.

#### **4.3.2 Barren Representations of Users Limits Expertise Sharing**

People finders, which are offered by some social networking tools, provide users with an alternative to broadcasting requests or recommendations. These tools profile users and then allow the user to search user profiles for other users. By searching for individuals with specific characteristics (e.g., diagnosis), users can narrow their search for expertise by limiting results to users with similar experiences that are more likely to transfer. People finders are valuable because they help users whom might not otherwise connect through historical channels to establish social ties for

expertise sharing. However, it is unclear whether those user profiles represent the right kinds of rich details required to achieve suitable matches that reduce potential disadvantages associated with poorly fitting or conflicting information (see Chapter 2). For example, sharing the same diagnosis is not necessarily a marker for expertise. Although users could explicitly list their areas of knowledge in their user profile, existing tools don't support this. Unfortunately, people finders in health-related social software provide only limited support for patient expertise sharing because they leave users with the time consuming and effortful task of determining 'who knows what'. As online community membership grows, such limited searches could result in an unwieldy number of profiles to manually sort along additional characteristics interest (e.g., physical proximity, age, availability, or time since diagnosis). Awareness about who knows what can help users determine the specific types of help a particular online health community can offer.

Prior work argues that effective social matching systems, such as expertise locators, require representing users' knowledge as well as incorporating social information that shapes expertise sharing interactions (Terveen & McDonald, 2005). To fully support expertise sharing, health-related social software could enrich user profiling by capturing the kinds of knowledge users have and the kinds of social information patients find useful. As an alternative to explicit entry to represent users' knowledge, implicit capture strategies could mine markers of expertise from the posts or resources a user has contributed. Likewise, tools could capture additional personal details either explicitly through user entry or implicitly by connecting to other social software that patients commonly use (<http://developers.facebook.com/connect.php>). For example, prior work suggests that enhancing awareness of other users' expertise with contextual details about their social relationships (Shami, Ehrlich, & Millen, 2008) or indicators of their reputations (Kriplean, Beschastnikh, & McDonald, 2008) augments efforts to locate expertise. Some researchers have found that similarity in

interests and ratings from friends are even more important for finding someone to interact with online than consensus ratings (Jensen et al., 2002). Thus, social information appears critical for helping users determine how they ‘fit’ with other users, and perhaps sheds light on the potential for conflicting information.

Yet, it is unclear whether the kinds of social information that augments expertise locating in professional organizations are also important to patients. Clearly, details about users’ health situations are important. But patients also look for other qualities when seeking support from peers, such as age, religion, or characteristics associated with personality (Giese-Davis et al., 2006). Tools could also mine these types of personal details from users’ interaction ‘by-products’. For example, some correspondents of the forums I analyzed (see Chapter 3) used ‘signature lines’ to communicate contextual details about their cancer diagnosis, treatments, and health status (e.g., *I’m a stage II survivor, double mastectomy 2007, 6x radiation therapy...*), which could serve as such a by-product. This strategy, like other implicit techniques must consider privacy concerns and provide users with features, such as controls for setting varied levels of data protection (e.g., accessible by friends, the online community, or the public). Some suggest that if the value of expertise sharing is perceived to be high enough, users are likely to disclose the requisite personal information in social matching system (Terveen & McDonald, 2005). Thus, care must be taken to consider longer-term ramifications of disclosing highly sensitive health information, such as genetic test results, in spaces that could later be accessed by employers or family members. Privacy is a major concern associated with expertise sharing tools that certainly requires more research (Resnik & Varian, 1997; Jensen et al., 2002; Terveen & McDonald, 2005). The health domain provides a particularly rich domain for such efforts.

Furthermore, the social connections supported by many social networking tools could be leveraged to facilitate expertise sharing mechanisms, such as recognizing community gatekeepers. Modern social software provides a number of building blocks, including user profiles, content-based by-products, and social connections, that expertise sharing features could leverage. However, prior research provides few clues about the kinds of details that would be most useful for profiling and representing users in the context of personal health. Before we can enrich user profiles to facilitate expertise sharing, we must establish an understanding of the factors patients consider when locating patient expertise.

### **4.3.3 Fragmentation Limits Reuse of Patient Expertise**

Social software tools are designed to encourage peer interaction through flexible features, such as threaded discussions and comments. Although these features provide users the freedom to express highly contextualized experiences, the flexibility of these free flowing exchanges can create volumes of unstructured content in which patient expertise becomes buried and difficult to retrieve for reuse. This problem of fragmentation makes it harder for the user to gather expertise related to a particular health issue as that knowledge becomes more and more distributed among many otherwise unrelated discussion threads and comments. Although this unstructured expertise can carry many contextual details for highly personalized reuse, users must expend effort digging and hunting through content to take advantage of the expertise available or to find targets with whom to share their expertise. Although wikis can help users overcome this problem of fragmentation by consolidating information by topic, the emphasis placed on summarizing knowledge for general purpose use, much like overviews, guides, and frequently asked questions, can distill away contextual details needed to effectively put knowledge to use (Lutters & Ackerman, 2002). Because this generalized technique of integrating

expertise relies on consensus, problems for which there exist varied points of view and many possible solutions are difficult to capture. Furthermore, patients also need ways to ‘give back’ through social software in more targeted ways that are less arduous than digging through the profiles and content of many other users to identify targets for advice.

Strategies for incorporating structure to integrate patient expertise available from forums, blogs, and social networking tools could include features that encourage users to tag content they contribute with meaningful keywords (Smith & Wicks, 2008; Weiss & Lorenzi, 2008), or features that pull together information resources that users exchange, such as pointers to web sites, into problem-based collections for community reuse. For example, Yahoo Answers (<http://answers.yahoo.com>) provides users with space to annotate answers they post to forum questions with pointers to supportive reference materials. Tools could mine these postings to gather reference materials that users recommend in reference to specific problems. Similar data mining techniques could be applied to user-generated content to identify markers of expertise on a particular topic (Lutters, 2004), which could be used to generate a list of knowledgeable users and a consolidated bundle of information those users have contributed on that problem.

Clarity about the characteristics of patient expertise (see Chapter 3) offers significant insights for designing features to structure information for effective reuse. For example, findings from the content analysis suggest that it is likely that many patients will exchange illness narratives they write from scratch and supplement with recommendations for useful books and websites, whereas fewer patients will exchange medical expertise from Medline. This finding carries direct implications for choosing techniques best suited to structure content, such as considering the potential value of a consumer health folksonomy over a controlled medical

vocabulary. However, establishing an understanding of the practices patients use in their everyday lives to provide expertise to other patients has the potential to offer further insights. For example, can we leverage any strategies patients use to tailor their expertise for particular people? What other strategies do they use to provide patient expertise to others? Before we can design features that integrate patient expertise in social software in ways that facilitate retrieval and reuse, we must establish an understanding of the practices patients already use to share their expertise.

## **4.4 Conclusion**

Coping with a new health issue often requires individuals to acquire knowledge and skills to manage personal health. Many patients turn to one another for patient expertise outside the formal bounds of the health-care system. Internet-based social software provides some useful building blocks for facilitating benefits and mitigating disadvantages of patient expertise sharing. Despite growing health-related use, existing tools present a number of limitations which we lack knowledge to overcome. Although prior CSCW research on expertise sharing more generally provides significant guidance for facilitating expertise sharing, the limitations of broadcasting, barren representations of users, and fragmentation in health-related social software raise important questions that demonstrate gaps in our knowledge about the practice of patient expertise sharing. Designing tools that effectively facilitate patient expertise sharing requires filling those gaps by answering key questions this review of related work raises: How do patients collaborate to share their expertise? Do the expertise sharing practices of patients align with the practices of professionals that have informed the design of expertise recommendation systems used in organizations? In particular, how do individuals find patient expertise in their

everyday lives? What factors do patients consider when determining which peers to approach for assistance? What strategies do they use to provide patient expertise to others?

Although observations of online health communities can reflect the characteristics of expertise exchanged (see Chapter 3), they are not well-suited to address such questions about the practices patients use to locate and provide expertise.

Ethnographically-inspired methods have been used by CSCW researchers to describe how individuals find expertise in structured and process-driven contexts, such as the workplace within an organization (McDonald & Ackerman, 1998). Yet, it is unclear if the types of mechanisms at play in those settings also apply to less formal, everyday situations of managing personal health. Thus, features of an expertise locating system designed for use in organizations might be ineffective as an extension to social software for patients in the personal health context of everyday life.

Although ideas drawn from CSCW could prove exceedingly valuable, tools can fail to support the needs of users if designs have not been informed by an understanding of existing practice. For example, the formalism of ‘expertise location’ (McDonald & Ackerman, 1998) offers a useful framework for understanding general problems that professionals confront during their search for expertise (i.e., expertise identification, expertise selection, and escalation). Expertise provision, although less explored in CSCW, offers a way to think about the needs of those who wish to pass along their expertise to others. These conceptualizations offer insights for the design of technical systems that augment expertise sharing practices. Could patients, too, confront problems associated with identification and selection as they search for other patients who can offer the expertise they need? Do patients, too, experience the desire to pass along valuable knowledge to other patients? Just as the employees

studied by McDonald and Ackerman (1998) relied on their past experience to identify expertise and selected 'local' sources, some patients are observed to rely on prior health experiences and turn first to close family members or friends for help (O'Rourke & Germino, 1998; Berry et al., 2003). Other issues, however, such as judging the credibility of advice, could be more problematic in the health domain where many individuals confront a host of unfamiliar and complex medical information without a wealth of background knowledge. Although design implications of CSCW findings might be very useful for patients, we cannot assume that the same kinds of organizational supports are in place for patients who might not operate within the same type of supportive infrastructure.

The power of social software to bring together patients in ways not possible through historical channels is in its infancy. The potential for these tools to facilitate patient expertise sharing must be informed by further empirical footing. Thus, establishing foundational knowledge about the practice of patient expertise sharing could provide the insights necessary to facilitate patient expertise sharing through enhanced social software. In the next Chapter, I describe how I addressed this need by drawing upon prior work on expertise sharing in organizational settings to shape a naturalistic investigation of expertise sharing among breast cancer patients in the context of their everyday lives.



## *Chapter 5*

# **The Practice of Patient Expertise Sharing**

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Growth in health-related use of social software provides increasingly diverse ways to share patient expertise (Adams, 2008; Elkin, 2008; Sarasohn-Kahn, 2008). Yet, this breadth of tools limits patient expertise sharing in numerous ways (see Chapter 4). A deep understanding of the practices patients use to share expertise in their everyday lives could offer significant insights to enhance the design of these tools to support patient expertise sharing. Although it is unclear whether findings from the base of expertise sharing research conducted in the field of Computer Supported Cooperative Work (CSCW) transfers to everyday situations of managing personal health, this body of work provides significant guidance for investigating the practice of patient expertise sharing.

In this Chapter, I present a naturalistic field study of patient expertise sharing that is informed by concepts drawn from prior expertise sharing research conducted in the field of CSCW. The goal of this work is to inform the design of social software to support patient expertise sharing by enhancing our understanding of patient expertise sharing practices. This work meets Aim 2 of this thesis by describing the everyday practices used by patients to share expertise among peers and the broader community outside the treatment center. I first present the conceptual framework of expertise sharing that shapes my investigation by expanding upon formal constructs from prior CSCW research (Section 5.1). I then describe the qualitative methodology that grounds this field study (Section 5.2). Findings from the field study describe how patients value expertise sharing, practices patients use to locate expertise from peers, practices patients use to provide expertise to peers, and barriers patients face in those practices (Section 5.3). Throughout my presentation of findings, I illustrate how the practice of patient expertise sharing relates to practices identified by the larger body

of expertise sharing research. Finally, I describe the empirical contributions of this work that enhance our understanding of patients' needs and of expertise sharing more generally (Section 5.4.1). Building upon the implications outlined in previous Chapters, I propose specific design recommendations for enhancing health-related social software to support patient expertise sharing (Section 5.4.2).

## 5.1 Conceptual Framework

I leveraged prior work on expertise sharing in workplace organizations to shape the field study of expertise sharing practices used by patients in the informal, everyday personal health context of breast cancer. The conceptual framework I used to structure data collection is grounded in the organizational expertise location framework described by McDonald and Ackerman (1998). As I described in Chapter 4, this framework is comprised of three interrelated mechanisms used to find, or 'locate', expertise within the organizational setting of the workplace. **Expertise location** involves:

- **Identification:** Determining who has what expertise to establish a pool of candidate sources of expertise (i.e., '*who knows what?*')
- **Selection:** Narrowing the pool of candidate sources by determining which to approach (i.e., '*who do I ask?*')
- **Escalation:** Repairing breakdowns in expertise location (i.e., '*How do I recover when identification or selection fails?*')

In addition to the location of patient expertise, I was also interested in the broader practices patients used to share their expertise. Given the altruistic spirit associated with the breast cancer experience, it seemed likely that this population could also

provide insights about practices of expertise provision in which patients offer expertise to peers and members of their broader communities. I also sought insight into both the utility, or value, patients associated with these expertise sharing practices, and barriers they faced when sharing expertise. Thus, I extended the conceptual framework that grounds this field study beyond expertise locating to also include the following additional concepts:

- **Expertise Provision:** Mechanisms used to offer expertise to others
- **Value of expertise sharing:** Perceived benefits associated with expertise sharing
- **Expertise sharing barriers:** Challenges associated with expertise sharing

The key concepts that make up my expertise sharing conceptual framework (i.e. value, location, provision, and barriers) are reflected in the methodological design and analysis of the field study that I describe next.

## 5.2 Methods

Through a qualitative field study with 15 breast cancer patients, I investigated patient expertise sharing within the informal context of patients' everyday lives. The field study and data set were part of a larger study that investigated personal health information management (NIH/NLM #R01LM009143). I shared data collection with Kent Unruh, Ph.D. We attempted to reduce the potential burden on participants by selecting an approach similar to Paepcke (1996), in which we conducted interviews and observations in each participant's home. This method allowed us to interact with multiple participants and observe them in their natural 'work' setting (Unruh, 2007) with the supportive artifacts they use (e.g., personal information collections,

calendars, email, web pages, online communities). The portion of this larger data set I report in this Chapter focuses on the practices patients use to share expertise with peers and the broader community, rather than with their formal team of health-care providers. IRB approval was obtained through the University of Washington for this work.

### **5.2.1 Study Context**

Marked by information-intensive ‘patient work’ (Unruh, 2007), the breast cancer experience offered a rich context to investigate patient expertise location in the informal context of everyday life. The breast cancer setting can be viewed as an integrated support community that crosses both formal, the health-care system, and informal, peer and community-based, contexts. As I described in Chapter 3, many patients turn to other patients who have faced similar health situations to obtain experientially-based patient expertise on managing treatment decisions, side effects, social relationships, and daily responsibilities. In this work, I focus on this informal, everyday context in which individuals seek patient expertise from their peers and the broader community.

The breast cancer setting shares a number of similarities with workplace settings that serve as the context for much prior research on expertise location. Both are highly complex, social, and collaborative settings where expertise sharing facilitates work to reach common goals. Just as organizations structure work through specialized roles, patient work is often distributed among patients, their formal health-care team, and their informal support system of relatives and friends, who collaborate to manage the patient’s health (Unruh, 2007). In addition to role specialization, the expertise in both settings shows more or less topical specialization. For example, a software engineer might have experience with operating systems or web

development, just as a cancer survivor might have experience with chemotherapy or radiation therapy.

Yet, the structured and process-driven context of workplace organizations and the less formal, everyday context of breast cancer have important differences. The boundaries and roles of a patient's informal support community appear less fixed and less clearly defined than those of structured and process-driven workplaces. Incentive structures that can limit expertise sharing in work settings, such as competition and hierarchy (Hinds & Pfiffer, 2003) or trade secrets (Paepcke, 1996), appear greatly diminished in breast cancer. Instead, cancer survivors' desires to 'give back' reflect a highly altruistic spirit (Petersen, 2006), similar to other informal contexts of expertise sharing (Torrey, McDonald, Schilit, & Bly, 2007; Torrey, Churchill, & McDonald, 2009). Furthermore, the breast cancer experience is laden with emotional complexity not typical of workplace settings. These differences could influence patient expertise sharing and shape the design of supportive tools in unique ways.

### **5.2.2 Data Collection and Analysis**

In collaboration with Kent Unruh, Ph.D., I collected data through semi-structured interviews spaced at roughly equal intervals over six weeks with each of 15 participants. We interviewed participants twice in their homes for 90 minutes and twice over the telephone for 30 minutes. We audio-recorded and transcribed interviews. During home interviews, we photographed the artifacts participants' used to manage their health. We observed their use of this information by accompanying each participant to a clinic appointment of their choosing. Two of the 15 participants became too busy with their cancer experience to complete the second home interview. The interview guide for this field study is provided in Appendix B.

I created a case report for each participant by collecting excerpts from transcripts in which they discussed expertise sharing. I coded data from case reports using the conceptual framework of expertise sharing (see Section 5.1). The categories of the coding scheme included expertise locating mechanisms for (1) identifying sources of expertise, (2) selecting which sources to approach, and (3) repairing breakdowns in expertise location, as well as (4) expertise provision mechanisms, (5) value of expertise sharing, and (6) barriers to expertise sharing (Table 5.1). I present common themes associated with expertise sharing that appeared across participants in each of these conceptual categories.

**Table 5.1 Coding Scheme for Field Study**

<b>Code</b>	<b>Definition</b>
Expertise identification	Mechanisms for determining the particular information or special skills offered by others (i.e., <i>who knows what?</i> )
Expertise selection	Criteria for choosing which source(s), from among sources with requisite expertise, to approach (i.e., <i>who do I ask?</i> )
Location repairs	Mechanisms for dealing with breakdowns or failures in expertise location (i.e., <i>how do I recover from breakdowns?</i> )
Expertise provision	Mechanism used to offer expertise to others
Value of expertise sharing	Perceived benefits associated with expertise sharing
Expertise sharing barriers	Challenges associated with expertise sharing

All participants were women who ranged in age from mid 30's to early 70's and were highly diverse in socioeconomic status, level of education, use of technology, and extent of their support networks. One participant identified herself as Hispanic, one as Native American, and the remaining participants identified themselves as Caucasian. Eleven participants were experiencing breast cancer for the first time and four were experiencing a recurrence. Participants received different treatments, some

more than one type. Eleven participants were undergoing chemotherapy, 7 underwent surgery, 3 were undergoing radiation therapy, and 1 was undergoing hormone therapy.

## **5.3 Results**

Common themes emerged from the field study surrounding participants' perceptions of the value of expertise sharing, their expertise locating practices, their expertise provision practices, and the barriers to expertise sharing they experienced. Next, I describe findings and provide illustrative quotes from participants for each of these four themes.

### **5.3.1 Value of Patient Expertise Sharing**

Participants associated a number of benefits with patient expertise sharing. These findings confirm my conclusion from the content analysis that expertise sharing offers patients unique value (see Chapter 3). The value participants described echoes the advantages of peer-based support mechanisms called out by prior work (see Chapter 2), such as modeling of skills and strategies (Bandura, 1989), mutual aid (Reissman, 1965), and opportunities to 'give back' (Petersen, 2006). Common examples described by participants were that locating other people from whom specific expertise is available can be valuable because those individuals help them work through difficult decisions, offer insights that might otherwise go unknown, and serve as role models. For example, one participant described the encouragement she gained from role models:

*Relying on other people and relying on the information that they have, and that they've already been through it, and they've gone through it, their hair's coming back, so I can get through it too. (P2)*

The quote above also highlights the important role that other patients play as sources of expertise. Another participant pointed out the unique insight that she believed only other patients with a similar health situation could provide:

*Until you've been there, you don't know... [on my blog] there were certainly comments from different types, you know, some of them were just words of encouragement and some of them were all these kind of cancer questions that only someone who'd gone through cancer would think to ask. Because not that they necessarily would not assume, but they would write about it because it wasn't something they would normally think to write about. (P13)*

A common reflection of several participants was the value of mutual support that often burgeoned when they connected with other cancer patients:

*I think we all share [in the support group] and it's not just one person, we all share, and so I'm starting to go through Taxol so those that have gone through it, you know, can give me advice on what I'm looking towards and the new lady that's there, she's going to glean information from the rest of us in starting her treatments and everything. (P2)*

In addition, expertise sharing was valued because it offered an opportunity to 'give back' and help others through the provision of advice to those in need:

*I'm going to make a list of things that they [staff at the treatment center] should be telling women in pre and post-surgery instead of going home and wondering is this - you know, you don't want to call the doctor every 5 minutes and say this is happening, that's happening, this is happening. (P12)*

### 5.3.2 Expertise Location

All participants sought expertise from informal sources, such as friends, family, researchers, and health professionals who were not members of their health-care teams, as well as from other patients. Participants sought expertise to help them solve problems that were medical in nature, personal in nature, or a mix of the two (see Table 5.2). Many problems participants discussed can be considered *high stakes* because of the critical implications of their solutions for the health, livelihood, and lifestyle of the participant, such as making treatment decisions or deciding whether to work during treatment. Participants did not always identify health professionals as sources of expertise for issues that were medical in nature. Nor did they always identify other patients as sources of expertise for more personal issues.

**Table 5.2 Examples of Problems for which Patient Expertise is Sought**

Medical	Personal
Reading & understanding a pathology report	Deciding to work or go on disability during treatment
Deciding between single & double mastectomy	Finding a yoga class for cancer patients
Understanding the process & implications of genetic testing	Discovering self-care remedies, such as goji tea

### 5.3.2.1 Initiating the Identification Process

We identified two conditions that trigger expertise identification. First, participants described several cases in which they, like professionals in organizations, clearly recognized their own need for expertise, which motivated an active and explicit search to identify suitable sources who could offer the requisite expertise. However, just as prevalent were cases in which participants located expertise as a result of *unsolicited offers* of advice from others. In these cases, it was after such encounters that participants assessed whether they recognized their own need and actively initiated expertise location. Before describing the mechanisms participants used to identify expertise, we describe how participants understood and reacted to their initiation of expertise location that resulted from unsolicited offers.

Ten participants discussed multiple examples of being the target of unsolicited offers from friends, family, and even strangers. In just over half of the cases, participants found unsolicited offers helpful, particularly when those offers were proactive, took account of their personal situation and preferences, or provided pointers to supportive background information. Some participants took specific measures to signal their openness to unsolicited offers from others. For example, one participant received unsolicited offers through comments left on the blog she maintains about her health situation:

*I let people come to me ... I've gotten all these comments, not because I'm commenting on people - I comment back but I don't really go out and pursue it.*  
(P13)

Other unsolicited offers were less helpful, often because of a poor fit with participants' specific health situation and preferences or a lack of supportive background information:

*She brought over this little goody bag of just stuff that she said was helpful for her when she was going through breast cancer ... But interestingly some of the stuff she had in there was not anything that would be at all helpful for me. (P4)*  
*Everybody thinks that they got the best care, or that they have the best surgery or they had the best reconstruction, but that's more of an affirmation to make them feel like that they can go on. (P1)*

*I run into one woman that I don't even know that overheard a private conversation and she got all oh! I'm a two time survivor! And for the next like hour that was all I got from her, and it was horrible. It's like – you know? Go away. Don't want or need that. So like I said, if there's somebody that can't be positive, then I can't have them around. (P15)*

Although the participant in the first quote appreciated the “goody bag”, she recognized that the implicit advice it carried did not meet her preferences for self-care. As reflected by the second and third quotes, some participants reacted negatively to unsolicited offers perceived to meet the source's needs rather than their own needs.

Unsolicited offers are similar to ‘gift queries’ (Gross, 2001) and ‘information gifts’ (Torrey Churchill, & McDonald, 2009), in which someone seeks information in anticipation of another person's needs. Abrahamson and colleagues (2008) associate altruism and helping behaviors with a similar pattern of unprompted consumer health information seeking by ‘lay information mediators’. The diagnosis of cancer could

‘mark’ a patient, signaling a perceived need for similar forms of social support from their community and beyond. Patients, like the participant who blogged about her experience, might also encourage social support by making themselves ‘open’ to receive it. Similar strategies are observed in other informal settings, such as online helping communities for other health conditions (Frost & Massagli, 2008) and for crafts (Torrey, Churchill, & McDonald, 2009). Although encountering information, such as ‘gift queries’, is commonly portrayed as helpful (Erledez, 1999; Gross, 2001), nearly half of the instances of unsolicited offers observed in the field study were perceived as unhelpful by participants because they did not meet their specific needs and preferences or created unanticipated work to corroborate with additional information.

### **5.3.2.2 Identifying Expertise**

Participants described four general mechanisms that helped them come to know about potential sources of expertise. These expertise identification techniques include: past experience with personal networks, gatekeeping, localization of expertise through grouping, and artifacts. Because some identification behaviors have been described in prior research (McDonald & Ackerman, 1998), I focus on unpacking new expertise identification behaviors that emerged, including use of multiple gatekeeping strategies, reliance on grouping mechanisms, and minimal use of artifacts.

#### ***5.3.2.2.1 Past Experience with Personal Networks***

Participants drew upon their everyday knowledge about the skills and backgrounds of their family and friends to guide their identification of sources. This identification aid aligns closely with ‘everyday experience’ reported in prior work (McDonald &

Ackerman, 1998). Participants drew upon their everyday experience across multiple contexts (e.g., family, work, community, health). Participants who experienced a recurrence drew upon relationships developed during their prior cancer experience. Newly diagnosed participants discovered expertise available within their personal network through word of mouth:

*I was also really surprised when I started talking to people how - they said oh yeah, my mother had breast cancer 15 years ago, or oh yeah, my sister has had it. It's amazing how many people either had it or knew someone who had it. Like my next door neighbor, I didn't even realize, she had breast cancer 12 years ago, I didn't know. (P4)*

Use of personal networks was the most common identification aid described by participants, particularly by those participants with rich personal networks. Participants valued trusted relationships of long-time friends. However, some participants worried that their information requests could burden family or friends who were dealing with their own serious personal issues:

*I haven't talked to her for a while because this [her granddaughter's surgery] was a big ordeal and everything. (P14)*

#### **5.3.2.2.2 Use of Gatekeepers**

Participants relied on key individuals in their personal networks who played three variations of the gatekeeping role to assist with expertise identification: *conduits*, *contact brokers*, and *champions*. Eleven participants discussed their use of two or more of these variations. The variations we found appear to be specializations of a

general notion of gatekeeping as a result of how each spans the border between one or more organizations or communities.

Briefly, prior expertise sharing work notes how gatekeeping roles could specialize in different work contexts (McDonald & Ackerman, 1998). For example, the conduit function of ‘technological gatekeepers’ (Allen & Cohen, 1969) funnels information resources into organizations from external sources. Others highlight the referral function offered by ‘contact brokers’ (Paepcke, 1996) and ‘information concierges’ (McDonald & Ackerman, 1998), who connect colleagues with others. Playing a central organizational role, the ‘information mediator’ (Ehrlich & Cash, 1994) leveraged their breadth of knowledge and trouble shooting skills to filter, synthesize, and translate information for colleagues in a customer support organization. Abrahamson and colleagues (2008) identify similar ‘go-to’ sources as ‘lay information mediators’ in the consumer health context. Similar to our findings, variations of gatekeeping, rather than a uniform gatekeeping role, have emerged in studies of other contexts (Metoyer-Duran, 1993).

#### 5.3.2.2.2.1 Conduits

Participants identified expertise through gatekeepers who functioned as *conduits* by carrying information resources between participants and sources outside their support community. Serving a conduit function resembles aspects of the technological gatekeeper (Allen & Cohen, 1969). In some cases, gatekeepers funneled in information to the participant and at other times the gatekeeper acted as a point of contact to pass messages between the participant and an external source. Ten participants discussed their use of conduit forms of gatekeeping. In several examples, these gatekeepers channeled stories about the experiences of friends who were breast cancer survivors or informal recommendations from friends who were health

professionals. Other examples demonstrate how gatekeepers relayed messages between participants and external sources. For example, the sister of one participant served this conduit function:

*I talk to other people to find out what questions they would ask. My sister asked a nurse practitioner if she knew what she would ask related to –I can't remember if it was the genetic testing or if it was –oh, it was about what does it mean that this tumor is disappearing and so this woman had some questions related to that that I wouldn't have thought of asking. (P11)*

#### 5.3.2.2.2 Contact Brokers

Gatekeepers also served the function of introducing participants to sources of expertise outside their support community, resembling the referral function of 'contact brokers' (Paepcke, 1996) and 'expertise concierges' (McDonald & Ackerman, 1998). Nine participants discussed gatekeepers who introduced them to sources they did not yet know (i.e., a friend of a friend). These gatekeepers were often networked with other specialists through tenure in a particular social context, such as a long-time church member who knew several fellow members who were breast cancer survivors:

*At church my aunt introduced me to a lot of people, this person's had breast cancer and this person's had breast cancer. And then so I mean I would have never known and so that's been kind of interesting to find - I go to a small church and the amount of people - I belong to a Bible study and there's 22 of us, there's 11 women and 11 men, and out of the 11 women five of us have had breast cancer. (P2)*

### 5.3.2.2.2.3 Champions

Participants also identified expertise through gatekeepers who were distinguished *champions*, resembling 'information mediators' (Ehrlich & Cash, 1994; Abrahamson et al., 2008). Champions were themselves key sources of expertise who bridged knowledge across two or more domains and helped participants fill in gaps and synthesize information they obtained. Like information mediators, champions leveraged a breadth of knowledge that crossed multiple domains (e.g., a breast cancer survivor and a registered nurse). The champion was commonly a close family member or friend, much like lay information mediators (Abrahamson et al., 2008). Eight participants discussed repeated interactions, covering multiple problems, with champions whom they referred to as “*a godsend*”, “*my sponsor for confirmation*”, “*my guiding post*”, or “*my source to go to*”. For example, one participant described how the expertise of her champion, who was a coworker, a breast cancer survivor, a registered nurse, and worked in medical research, spanned many boundaries:

*I talked with a woman that I work with who is a research coordinator and who had breast cancer. I asked her to review the consent form and then I kind of talked to her about it ... I was able to get that study protocol from the coordinator. And she was able to send that to me so I'm able to review the protocol ... [she is] just really knowledgeable. She's a nurse, she's an RN, she's very knowledgeable about BC, she's very knowledgeable about research, and she is just someone I trust because I've worked with her so long. (P13)*

The common characteristics of gatekeepers are just as critical in the personal health context as they are in an organizational context. For participants, it was particularly important for gatekeepers to know specific details about their situation and needs to provide the most effective help. Two participants described their use of community

gatekeeping programs, such as the American Cancer Society, to obtain referrals to connect with local support services or other cancer survivors. Sometimes these attempts to facilitate expertise identification are not effective. For example, one participant used a local patient mentor program, but the matched mentor seemed to lack resources the participant needed:

*I went to the cancer center and they have this thing where they try and hook you up with somebody ... I got a phone call from a lady. Well, she's 72 now, and a wonderful, wonderful lady ... but the unfortunate thing was this lady had just been re-diagnosed again with breast cancer so just starting chemotherapy. So she kind of was in the beginning of - not in a place where she would really be able to be as much support as I would want, because she has her own things to deal with. (P3)*

#### **5.3.2.2.3 Localization of Expertise through Grouping**

Participants described both physical and virtual mechanisms that brought together sources of expertise in a single location. These mechanisms create groups of individuals who deal with similar situations and who share similar interests or contexts. These groups are key sources for expertise.

Localizing expertise was often, but not always, the reason for creating the group. For example, an explicit goal of many face-to-face or internet-based cancer support groups is to facilitate the exchange of information and support among cancer patients. Other mechanisms localized expertise by happenstance, such as clinic spaces, where patients sharing the same health-care providers or treatments come into regular contact. In addition to support groups and clinics, participants described a wide range of other locations that group individuals with cancer-related expertise,

including cancer retreats, cancer-related social networking web sites, community-based cancer resource centers, special interest groups, lectures, classes, fundraisers, and parties.

Participants used localization of groups as a technique for coming in contact with a wide range of individuals likely to have the desired expertise. Both face-to-face and online cancer support groups were seen as key potential locales that often provided valuable exchanges:

*That [support] group probably was the most powerful group of people and women that made, helped me make my [surgery] decision to where I came to in the end, truly. (P3)*

*I think we all share ... and so I'm starting to go through Taxol so those that have gone through it, you know, can give me advice on what I'm looking towards and the new lady that's there [at the support group], she's going to glean information from the rest of us in starting her treatments and everything. (P2)*

*It [comments on my blog by other patients] kind of helped me sort through logically why I wanted - why I was interested in the [clinical trial] study itself. So I was able to kind of check it out in my mind. (P13)*

Prior expertise sharing research describes the value of analogous localization mechanisms, such as intranets, team meetings, brown bag lunches and company picnics that foster interaction among professionals (Ehrlich & Cash, 1994; Paepcke, 1996). Community-based groupings (e.g., clinics, special interest groups) share characteristics with 'information grounds' (Fisher & Naumer, 2006) that serve as locations for information-rich exchanges. Face-to-face cancer support groups share

similarities with the workplace 'war stories' among photocopy technicians (Orr, 1996), while online cancer support communities share similarities with newsgroups, bulletin boards, and other forms of online help communities (Torrey et al., 2007; Zhang, Ackerman, Adamic, & Nam, 2007; Torrey, Churchill, & McDonald, 2009).

Prior work also describes potential barriers, such as social loafing, to group participation in social matching systems (Terveen & McDonald, 2005). However, the localizations described by participants in this field study suggest an absence of motivational barriers in the personal health context. Instead, patients reflect an altruistic nature of self-help groups because they are often eager to share their knowledge with other patients (Petersen, 2006).

Despite the advantage of grouping mechanisms to bring together people with similar diagnoses, localized groups did not always guarantee effective identification of expertise. Geography, time, and treatment side effects were all barriers participants associated with expertise identification through support groups. A common complaint was the need to travel long distances to support groups while suffering treatment side effects. Others noted limited time to share expertise at support groups:

*We were only there [at the support group] for about an hour, so - and when there's nine people sharing, you only have a small amount of time. (P3)*

*I haven't been very active online because being on the computer made me kind of nauseated, you know? And so I haven't really kept up with - I haven't really been detailed with my cyber friends if we can call them, about what's been going on. (P13)*

The second quote highlights the common challenge of identifying expertise in the face of treatment side effects that can also limit participation in virtual support groups. Another participant noted the challenge of finding expertise given the unstructured nature of tools like blogs:

*Blogs give you lots of problems, people with serious problems, but they rarely give you people who solved it. (P7)*

Although the infusion room or the waiting room provides opportunities for localized grouping, these clinic spaces can also be problematic because their primary function is for cancer care, rather than patient expertise sharing. For example, one participant indicated the suboptimal setting of the clinic for dialogue and sustained connection with another cancer patient:

*I had wanted to ask this one gal that I had run into in the chemotherapy room ... she had been given a premedication that was making her really drowsy. So she was having a hard time talking. She was really sleepy ... I just didn't have enough information to find out what exactly she meant by her chemo not working. (P4)*

#### **5.3.2.2.4 Identification of Expertise through Artifacts**

In work settings, historical artifacts can significantly assist the identification of expertise (McDonald & Ackerman, 1998). However, only a few participants described substantial use of artifacts for this purpose. Handouts from clinics and cancer resource centers that contained lists of local cancer support groups were one of the most common artifacts used by participants to identify expertise. One participant used ratings on Amazon (<http://www.amazon.com>) to determine which

breast cancer books would be most helpful. Participants who were experiencing breast cancer recurrence described retrieving information from their own archive of personal health information related to their prior treatment experience. For example, one participant maintained an archive of personal calendars dating back several years, which she used to look up contact information.

Participants' lack of artifact use is surprising in contrast to the prevalence of this identification aid in prior expertise locating studies. However, organizations serve as a formal infrastructure wherein artifact sharing and reuse within organizational boundaries can be encouraged (Halverson & Ackerman, 2003). In contrast, most patients lack an integrative infrastructure that crosses the multiple contexts in which they identify expertise.

### **5.3.2.3 Selecting Expertise**

Once participants identified candidate sources of expertise, they relied on key criteria to determine which source(s) to approach for help. Similar to prior work on expertise locating in organizational settings, participants used criteria such as performance characteristics (McDonald & Ackerman, 1998) and social ties (Shami, Ehrlich, & Millen, 2008), to judge the suitability of potential sources for meeting their needs. The most common selection criteria described by participants included source knowledge, sharing a cancer bond, strength of relationships, similarity of interests, lifestyles and preferences, source availability, and source transparency. Some criteria appear unique to the personal health context, such as the importance of the cancer bond and transparency. Although some selection criteria (e.g., strong social tie) were common across a number of problems for which participants sought expertise, other criteria (e.g., specialized knowledge) were tightly coupled to the specific type of problem.

### **5.3.2.3.1 Source Knowledge**

Participants frequently described selecting sources based on the specialized knowledge they offered. Those areas of knowledge were offered by sources ranging from health professionals, lawyers, caregivers, beauticians, breast cancer foundation workers, artists, researchers, to cancer survivors. Source knowledge, as a selection criterion, is similar to competence and performance-related criteria used by professionals to locate expertise in organizations (McDonald & Ackerman, 1998).

The area of knowledge suggests the role played by the source (e.g., health professional, informal caregiver, patient, and survivor) in relation to cancer. Several participants repeatedly selected a particular source with specialized knowledge in multiple domains, thus filling multiple roles (e.g., had specialized knowledge from being both a cancer survivor and a cancer researcher). *Champions* commonly met this criterion.

Some sources, particularly gatekeepers with professional health-care ties, could facilitate the provision of insider knowledge that participants could not directly access on their own, such as drug package inserts, clinical trial protocol documentation, or contact information for health-care providers who were also cancer survivors. One participant obtained recommendations for breast specialists by targeting her selection of sources to those working in health-related fields:

*The kinds of people that I contacted were people who were in health-care related fields. So they had reason to know who, you know - but if you're a doctor who would you want your wife to see? Right, so you have reason to know about that individual surgical skill. (P1)*

### **5.3.2.3.2 Shared Cancer Bond**

The second most frequent selection criteria described by participants was the special relationship they have with others who share a cancer diagnosis, as one participant told us:

*We share a bond ... it's a sisterhood and that's exactly what it is. (P2)*

Two participants even maintained lists of contact information for breast cancer survivors they had become acquainted with for sustained contact. Participants associated the cancer bond with sources who offered insights, comfort, and understanding that family members or friends who had not experienced a cancer diagnosis could not:

*I can talk to my friend and I can talk to my family about what's going on with me, but they don't really understand what that means. They understand that you don't feel well, and they're empathetic and they're sympathetic to that, but there's still a bit of a barrier, a bit of a wall because they don't know what I'm going through. They don't know if I'm stressed out. They don't understand what if I get stressed out because I can't do something that should be so simple, I can't make a decision about something or whatever. To them, they're like just do it. Whereas with someone who's going through the same thing that I am, you're kind of going yeah, I couldn't do that either today. And sometimes you just can't. (P13)*

For some problems, such as dealing with common cancer treatment side effects, the specific type of cancer a potential source had been diagnosed with did not play a significant role in selection. For example, advice for dealing with hair loss was just

as useful coming from a source with ovarian cancer as a source with breast cancer. For other problems, such as treatment decisions, sharing not only a similar diagnosis but close alignment of treatments or experience of side effects played a vital role in selection. Sources with recently completed treatment were also selected because they were thought to provide timely and accurately recalled advice. For example, one participant told us about valuable advice she obtained by selecting a friend who had already completed treatments she was considering:

*I talked with - it was a new friend I've made ... she's had two breast cancer diagnoses and the first time was a lumpectomy and the second time was a mastectomy. And so my friend put us in touch with each other and she was a really great resource and she's very free with her information and very willing to share, she's great. So I was able to ask her really direct questions as far as the surgery itself and her recovery and I asked her were there any hints or tips or anything that might help me with recovery or make things a little easier. And she had some good ideas for that. (P8)*

Participants highlighted barriers to expertise sharing that stem from variability among the diagnoses, treatments, and side effects experienced by patients. Thus, close similarity of health situations, perhaps like departmental similarity of professionals who tend to keep selection 'local' (McDonald & Ackerman, 1998), was a particularly important selection criterion associated with the cancer bond. One participant expressed frustration at failing to locate other patients who were also dealing with the same rare side effect:

*Well, no one has been in my situation. That's the problem [with locating advice]. (P7)*

### **5.3.2.3.3 Strong Social Ties**

The next most frequently discussed selection criterion was the strong social tie of a long-standing and/or close friendship. Sources who were close friends provided familiarity, trust, likability, and dependability that made it easy for participants to seek expertise. Participant ‘P2’ described the “*camaraderie*” that developed as she connected with and incorporated breast cancer survivors into her personal network. Many participants described the importance of trust and honesty in sources of expertise and commonly associated those characteristics with long-standing relationships:

*So when they said you'll also need to meet with a radiation oncologist, I said what in the world's going on, and so forth. And I did a little reading and it said yes, sometimes radiation is required, but I called [radiation oncologist] who's a close friend, we ski together every year, and said this is what's happening, they want me -and she said, yeah, I think they're right. So you know, she's not any better than - in fact she's retired so she's not as up to date as the people I will have here, but somehow because she's a friend there's a certain amount of trust there. And I do trust my doctors, but when you have friends that are specialists in certain areas. (P7)*

The importance of social tie strength as a selection criterion could stem from the highly emotional experience and intimate topic of personal health situations, such as breast cancer. Abrahamson and colleagues (2008) also note the importance of close social ties with lay information mediators. The *champions*, relied on by so many participants, might have been particularly instrumental because they provided a breadth of source knowledge as well as likability through the strong social tie they shared with participants. Social relationships also play an important role in expertise

selection among professionals in organizational settings that are not necessarily as emotionally charged (Shami, Ehrlich, & Millen, 2008). Like professionals, sources with strong social ties to others also make good candidates as *contact brokers*.

#### **5.3.2.3.4 Similar Interests, Lifestyles, and Preferences**

Participants also described selection criteria related to shared interests (e.g., art), interaction preferences (e.g., email), health preferences (e.g., naturopathic medicine), lifestyle factors (e.g., profession), similar world views and values (e.g., religion), and demographics (e.g., age and education). The importance of similar indicators about the social circumstance in which expertise is shared is highlighted in prior work (Terveen & McDonald, 2005). Our youngest participant, for example, told us how she selected both books written by cancer survivors and online health communities that were “*geared towards young people with cancer*” (P13). In many instances, participants found expertise sharing easier when sources were familiar with their interests, lifestyle, or preferences. For example, one participant described the importance of the world view she shared with her friend, who was a breast cancer survivor, for sharing expertise:

*Having cancer affects your life in terms of meaning and that kind of stuff and so [my friend] and I have talked a little about that. Like I said though, I don't know that's something that people necessarily think about, or if they do it doesn't seem like something that they - I don't know - maybe can articulate very well? But I think one of the things that kind of, a connection that I have with [my friend] is just that I think we are both sort of that way and so we both kind of talk about that kind of thing in general, not necessarily just in terms of cancer ... I think we know enough about each other to know that those kind of things are things that*

*we both are concerned about and that would be something that we could talk about with each other because we both have similar concerns like that. (P4)*

#### **5.3.2.3.5 Source Availability**

Accessibility of the source and the expectation of obtaining a response were also key selection criteria. Participants often selected the most accessible sources, such as those with whom they interact with frequently (e.g., coworkers), who were easy to meet (e.g., lives nearby), or had fewer commitments than other sources (e.g., a single and retired friend). For example, one participant maintained a list of accessible sources in her files:

*There's a file with basically notes about various ... people who are good, [who I] might want to contact, people who had mastectomies who are willing to talk to me or people who've had breast cancer who are willing to talk to me. (P11)*

Another participant told us about her plans to meet with other breast cancer patients who live nearby:

*There are a couple of people who I've talked to [through my breast cancer blog] who I would like to try and meet. We've kind of talked that idea around about meeting and kind of sharing our common experiences. (P13)*

Participants also selected sources likely to respond to their requests. For example, participant 'P1' selected sources for whom she had done favors for in the past with the expectation of a reciprocal response: "So I was calling in chips all over the place." In addition to offering a trusted relationship, friends may be more likely to

respond to requests for help than others. For example, one participant told us how she could depend upon a response from a good friend:

*I know I can reach my friend. You know, my doctor, I'm leaving a message with you know, at least one intermediary. And they're very good about passing the messages on and all that, but it's just - you know, I know I can talk directly to my friend. If I leave a message somewhere she'll call me back. (P11)*

Participants also selected sources who were proactive in their prior support efforts. Just as the employees accounted for the 'load on the source' using call lists and word-of-mouth (McDonald & Ackerman, 1998), our participants also took into account the workload on candidates. For example, participants told us that they chose not to select sources who were consumed with personal issues:

*So her sister just passed away like a week ago from breast cancer and I just ran into her a few days ago ... so I told her a little bit, I didn't want to freak her out because she's already got enough on her plate. (P15)*

#### **5.3.2.3.6 Source Transparency**

Sources who offered honest, straightforward, and traceable advice were commonly selected by participants. Participants described transparent sources as being “*no nonsense*” (P7) and “*upfront and very free with her information*” (P8). This was particularly true of sources who were breast cancer survivors. For example, one participant valued sources who were open to “*show and tell*” their surgeries and offered honest explanations:

*I just think it's beneficial to have more people explain it in real terms, not so they want to make it look good in a pamphlet so it reads nicely and all that kind of stuff. Doesn't have to read nicely all the time, because reality is it's not all nicely. It's what it is. (P3)*

In addition to the trustworthiness participants associated with honest and open sources, a few participants highlighted the value added by sources who provided them with pointers to supporting reference information (e.g., a research article or book). When sources could not provide reference information for the advice they provided, participants experienced a barrier. They felt uneasy about utilizing the advice until they could “*check it out*” (P4) with other sources, such as the internet or one of their health-care providers.

Although research in organizations has not necessarily highlighted the importance of honesty or reference information as selection criteria, these issues of transparency share similarities with ‘performance criteria’, such as suitability of explanations (McDonald & Ackerman, 1998). The need for accountability in an organization could result in a lack of need for the same level of explicit transparency, yet equivocation certainly needs to be managed in many different social settings.

#### **5.3.2.4 Anticipating Breakdowns in Expertise Locating**

The discussion above highlights a range of techniques for expertise identification and selection. However, the patient expertise location behaviors this field study uncovered also reveal a number of barriers participants faced, such as the challenge of locating sources who share not only the same diagnosis, but similar treatments, side effects, and stage of care. Similarly, gatekeepers who lack specific details about

the participant's situation often led to dead-ends, which initiated a new search for expertise.

A cancer diagnosis generates 'high stakes' problems; problems for which an error in judgment has dire consequences. As a result, something distinct from the repair mechanisms previously observed during identification or selection emerged (i.e., 'escalation'; see McDonald & Ackerman, 1998). Instead of waiting for a failure in expertise identification or expertise selection, participants engaged in two distinct forms of *triangulation* in the anticipation of potential breakdowns. Participants relied, in parallel, on strategic applications of selection to garner expertise covering a topic area.

First, participants polled multiple sources, by requesting the same information from each, to see if they were getting the same answer. However, triangulation was not an undifferentiated broadcast request:

*[I sent] out emails to people I thought would be knowledgeable to say 'who's the best in town on these issues'? And what I was doing was almost like a triangulation or whatever you'd call it, to see what names came up again and again and again. And to see what the patterns were. And so a number of key patterns emerged in terms of who folks thought were the best medical specialists for breast cancer in the area. (P1)*

*Of course he thought I should go on a fast ... he just offered this piece of advice, which is interesting. I find that lots of people have all kinds of advice that they just kind of give spontaneously ... This was actually a couple weeks ago I was talking to him, and I just said well, you know, I really can't see any particular - I haven't seen anything documented ... and so normally I think I would have*

*heard something about fasting if it was supposedly - I mean there's some pretty alternative things out there, which I've actually heard of from different sources, I mean they sort of corroborate, collaborate or whatever. Which actually makes me think well, maybe there's something to this and I've not heard anything about fasting. I mean even in the alternative press, I haven't even run across it and I even looked for it on the Internet. (P4)*

In the first quote the participant sought health professionals in her personal network to determine their collective judgment about the most qualified breast surgeon in the area. While in the second, the participant worked to “corroborate” the unsolicited offer she received with additional sources.

Second, triangulation occurred when participants gained insights into a problem by collecting viewpoints from specific, yet varied perspectives. For example, one participant, who was deciding among different treatment options, attempted to approach breast cancer survivors who had both undergone and decided against each option she was considering:

*[I] tried to, you know, ask as many questions to as many people that I meet that have, you know, had mastectomies or had radiation, trying to get opinions ... I spoke with women in the support group and there's been a few of them that had mastectomies, not had reconstruction. There's only one woman in there that's had a mastectomy that also had to have radiation and is now having reconstruction. (P3)*

Another participant integrated the different bits and pieces of advice she collected from several different sources:

*... but meditation, it took me a while to be convinced that that would be helpful to me ... I heard research on it that indicated there was something to this, I think I went to the library and I just checked out some CD's and stuff by meditation teachers and after listening to or reading quite a bit, I finally - it was interesting to me because what I found out worked for me wasn't something that I could necessarily go to any one meditation teacher and have them say this is how it works and if you keep at it, this is how it can work for you. It was more me listening to a lot of different stuff and sort of picking out what ultimately worked for me. (P4)*

Triangulation requires identifying and selecting a set of sources with specific characteristics. This process was easier for participants who had rich personal networks offering a range of characteristics, expertise, and perspectives. Without access to such a network, locating a set of candidate sources required significant effort. In addition, when unsolicited offers were perceived as potentially fruitful, it could spawn additional, and unexpected, work to corroborate through triangulation. When unanticipated, this process can be particularly taxing for patients who have little energy for tasks other than keeping up with daily life in the midst of treatment. Extending the prior quote, after failing to corroborate advice on fasting with alternative sources, participant 'P4' shared regrets associated with this effort:

*I tried to be really tactful, I said I'm not saying I don't think this was a bad thing, I think it was a good thing for you, because you felt you like you needed to do it and you did it, I think that's great. But I don't think it's the right thing for me. I should have just kept my mouth shut and said okay, thank you, like I do with most unhelpful advice. (P4)*

### 5.3.3 Expertise Provision

Rather than solely locating expertise, participants also described instances of offering expertise to other patients. Several participants described their strong desire to ‘give back’ by sharing what they had learned, and continued to learn, through their experience with others in need:

*There’s this kind of, yeah, there’s this kind of connection. People just – you really want to kind of reach out and ease people’s minds about it. (P8)*

Instances of expertise provision took two basic forms: generalized and targeted. Participants discussed both their efforts and plans to offer broad and de-contextualized advice that was not targeted to a specific individual (i.e., **generalized expertise provision**). Examples of participants’ generalized expertise provision included writing an article for the school newsletter for breast cancer awareness month, writing a book about the breast cancer experience (e.g., “*it’s all about my journey*”, P2), and sharing information management strategies with other patients. For example, one participant attempted to initiate a system of providing newly diagnosed breast cancer patients with information packets at her treatment center:

*What I decided to do was I’m going to see what it’s going to take to get this kind of thing set up - the bag and all this information set up so that when somebody like me comes in at the [clinic] and you find out you have breast cancer, you can - they give you a packet like this at the start? So that’s my goal. (P6)*

Participants also described instances in which they targeted their provision of expertise in a personalized manner to a specific individual due to their specific situation (i.e., **targeted expertise provision**). Examples of targeted expertise

provision used by participants included collecting specific information resources for a friend who was recently diagnosed with cancer and being approached by other patients for specific treatment advice. The latter occurred frequently in breast cancer support groups. For example, when asked what type of advice she was planning to give to a friend who was recently diagnosed with cancer, one participant told us that along with looking up information on the internet for her friend, she would also provide:

*Just emotional things that you know, you're going to go through all of this and someday you're going to sit there and go, I wish it wasn't me, and someday you're going to sit there and go, why me? And those are all normal things, and she's not the only one in the world going through it, I mean I've gone through worse than what she's going through now, but I know she's scared. Because that's what I was. And to let her know there are support groups out there, if she wants to talk to people about what she's going through. I'll help her anyway I can to get into support groups and if she has to go through chemotherapy, you know, I'll go through that with her too. I'll be by her side and help her through a lot of stuff. If she wants somebody to go to her doctor visits with her that understands and can ask questions with some knowledge, then I'll do that too. So I just want to be as much of a support to her as I can. (P2)*

Expertise sharing research conducted in professional settings has focused relatively little on practices surrounding expertise provision compared to expertise location. However, practices professionals use to provide colleagues with expertise share some similarities with participants' discussion of their desire to pass along information to other patients, particularly those patients who are newly diagnosed. For example, through an investigation of reasons for expertise search among professional workers in an organization, Shami, Ehrlich, & Millen (2008) noted a

few cases in which workers looked for colleagues who might have interest in the information they could provide, rather than to seek information from others. Similarly, participants' targeted expertise provision resembles 'active information filtering' in which users of collaborative filtering systems offer expertise by distributing contextualized pointers to interesting content to specific recipients (Maltz & Ehrlich, 1995). In contrast, participants' generalized expertise provision resembles 'passive information filtering' (Maltz & Ehrlich, 1995), in which users of collaborative filtering systems contribute towards community wisdom by casting votes on content, rather than targeting recommendations to specific recipients.

Although prior work (Maltz & Ehrlich, 1995; Ehrlich & Shami, 2008) notes that professionals in organizations often fall into the category of either information senders (i.e., those providing expertise) or information receivers (i.e., those locating expertise), the pattern that emerged from the field study, in which participants both located and provided expertise, lacks clear role specialization. Furthermore, when participants provided expertise outside of support groups, it was more often generalized in form even though one might expect targeted expertise to be more personalized and useful. When asked about their interest in helping other patients by sharing their expertise in a targeted way (e.g., patient mentorship program), many participants expressed interest but noted the real and undue burden of such an effort during treatment.

#### **5.3.4 Expertise Sharing Barriers**

Participants did not always perceive patient expertise sharing as easy or useful. At times, some participants expressed particular challenges. I have described several barriers to patient expertise sharing throughout the preceding discussion of findings. In summary, barriers to patient expertise sharing spanned the range of practices from

managing unsolicited offers and triangulation to expertise location and provision. For example, participants described a host of unsolicited offers that they found unhelpful because either those offers didn't meet their specific needs, or those offers resulted in extra work to track down supportive reference material. Strong reliance on personal networks to locate specific expertise, whether on one's own or with the aid of gatekeepers, was particularly challenging for participants with uncommon situations or for participants who lacked rich networks they could traverse. Under both conditions, scarcity of suitable expertise was problematic. Selection of a suitable source was highly specific, problem-dependent, and often depended on a much broader range of criteria than a shared diagnosis or domain of expertise. For example, one participant described the poor fit of advice she received from a friend, who was a breast cancer survivor, for organizing her personal health information:

*Somebody sent me this book, it's supposed to be for going through cancer treatment, an organized treatment tracker - I could never quite get it, I can't fit into their organization ... But the person that sent it to me had breast cancer and she went through treatment nine years ago and then got ovarian cancer and basically she's been on chemo more than not for the last nine years. And to her she said this is the best thing that she's had. (P5)*

Although most barriers described by participants related to locating expertise, participants also expressed barriers to providing expertise to other patients. For example, one participant described the emotional investment involved in offering advice to newly diagnosed cancer patients:

*I think the hardest part [about offering other patients advice] is reliving what I've been through. I think that's what it is. (P2)*

The range of patient expertise sharing barriers participants described was wide. However, three common issues are evident among those barriers that point to problems related to poor specificity in the fit of expertise, excessive demands on personal resources, and the lack of a supportive infrastructure. Next, I describe each issue in turn.

First, patient expertise sharing requires a **highly specific fit** between the needs of the patient seeking expertise and the experiences and circumstances of the source of expertise. Participants' expertise sharing needs were much broader than solely locating someone like them (e.g., same diagnosis). They used a broad range of selection criteria to meet their needs. This requirement highlights the significance of the problems I introduced in Chapter 2 surrounding 'poor fit of information' (i.e., misapplication of expertise to needs that do not align with the context from which that expertise is drawn) and 'conflicting information' (i.e. expertise that operates from an opposing value system or model of health). Barriers related to this requirement for a highly specific fit surfaced on two fronts.

On the first front, poor specificity in the fit of expertise occurred when participants lacked the information or means required to locate sources with specific knowledge and social circumstances that best suited their needs. The types of problems for which expertise was sought varied over time, and each specific problem largely determined the type of expertise sought, and thus, the priority of certain selection criteria over others. For example, a close fit was not always satisfied with a source who shared the same diagnosis. Several participants found it challenging to identify other patients who were 'unlike them' in that those sources had experience in specific areas that they themselves lacked (e.g., treatment, work-related, or professional experiences). Furthermore, the social circumstances in which a source shared their expertise (e.g., world view, preferences, transparency) played heavily in

participants' selection of sources. Participants needed ways to identify sources that fit one or more selection criteria, such as lifestyle or world view, often in highly specific and problem-dependent ways. Patient matching services (e.g., patient mentoring programs or people finding features in social networking tools) that determine fit based on a general matching criterion (e.g., same diagnosis) could miss opportunities to support the breadth of patients' highly specific expertise sharing needs.

On the second front, information to determine highly specific matches was also required for the success of gatekeepers. Poor specificity in the fit of expertise also occurred when gatekeepers lacked details about the participant's specific needs or about the particular expertise or social circumstances of potential sources. Many participants overcame this barrier by incorporating champions into their support system. In addition to the champion's breadth of knowledge, it is likely that these gatekeepers were so successful because they had a detailed understanding of the participant's needs stemming from their close relationships. Unfortunately, participants who lacked rich social networks were less likely to have the support of champions. Other participants traded some privacy by sharing details about their situation with potential gatekeepers with whom they did not share a close relationship:

*I would say that one of the things that I chose to do is be very transparent with people. That is a choice, right? You can pretend it's not happening or you can very matter of factly say unfortunately I'm dealing with the following challenge. I chose the latter and as a result things came to me without asking. I also did some asking but the transparency brought many good things. (P1)*

This participant's strategy of 'transparency' was also resource-saving because it staved off her effort to actively request expertise. This strategy helped this participant to overcome the second common issue associated with patient expertise sharing barriers: patient expertise sharing places **excessive demands on personal resources** of patients and members of their support community. Geography, time, and the experience of side effects limited the extent to which participants took advantage of opportunities to share expertise through support groups. Use of virtual means to share expertise, such as online support cancer communities and other social software tools (e.g., blogs), was still limited by side effects for some participants. For others, many of these tools were perceived as too unstructured to locate expertise without expending great effort. Receiving unsolicited advice, triangulation processes, and uncertainty about the transparency of a source all created more work for participants to track down reference material and corroborate with other sources. Participants also discussed worry over the burdening of excess work their requests could place on others. Demands to invest time, energy, and emotional resources can limit patients' efforts to share expertise in the context of an already taxing experience. For example, one participant went to great lengths to build an intimate connection with acquaintances from which expertise could be obtained:

*I found out about him not through, just through an acquaintance whose husband had I think it was testicular cancer ... he opted not to do chemo ... I didn't know them well enough to know their situation, but ... they went and bought over the Web this thing called a beam ray thing? ... But she [wife of testicular cancer patient] does facials ... I'd feel funny just calling her and saying ... how's your husband doing? In case he's not doing well. But I was thinking once I get some money I might go book a facial over there and ask her how he's doing. (P4)*

The third common issue evident among patient expertise sharing barriers was the **lack of a supportive infrastructure** for their expertise sharing efforts. Participants who experienced a recurrence often fell back on the information and network of resources they established during their previous bout of breast cancer, as a starting place for expertise location, for example. It seemed easier to locate expertise through established social connections who were already familiar with the participant and their circumstances. This supportive infrastructure could be akin to workplace structures that encourage colleagues to share expertise (Halverson & Ackerman, 2003). In contrast, many participants who experienced breast cancer for the first time were in the midst of gathering information and forging personal connections to build a supportive infrastructure for their breast cancer experience. This emergent construction of a supportive infrastructure appeared easier for some participants than others: *“The more people I talked to about this with, the more I found out just how many people it has affected”* (P8). However, this work was especially challenging for those participants who lacked rich personal networks whom could provide opportunities for gatekeeping, provide suitable expertise, or provide strong social ties to aid expertise selection. The work to build a supportive infrastructure was also particularly challenging for those who found themselves spending large amounts of time away from home (e.g., a move in residence) to be closer to the treatment center.

## **5.4 Discussion**

Findings from this field study establish an understanding of the practices breast cancer patients use to share their personal health expertise with peers and the broader community in the context of everyday life. The practices patients use to locate expertise share both similarities and differences with the practices used by professionals in organizations. Similarities suggest that some support strategies could

apply in both contexts. For example, support from an expertise locator to identify potential sources of expertise and access to background information to support selection among candidates could be useful for both patients and professionals. Similarly, a collaborative recommendation system could help patients provide expertise to others.

However, this field study uncovers a number of unique expertise sharing practices unlike those used by professionals. For example, unsolicited advice often triggered patients to locate expertise. Furthermore, the high-stakes nature of problems patients faced also led them to use triangulation strategies in anticipation of breakdowns in expertise location. These differences suggest patients' needs for additional support strategies not captured by prior research. Thus, findings from this field study carry empirical implications that extend our understanding of both patients' needs and expertise sharing more generally, as well as carry design implications for tools that can facilitate patient expertise sharing. After summarizing the key empirical contributions of this work, I present design recommendations for enhancing health-related social software to support patient expertise sharing.

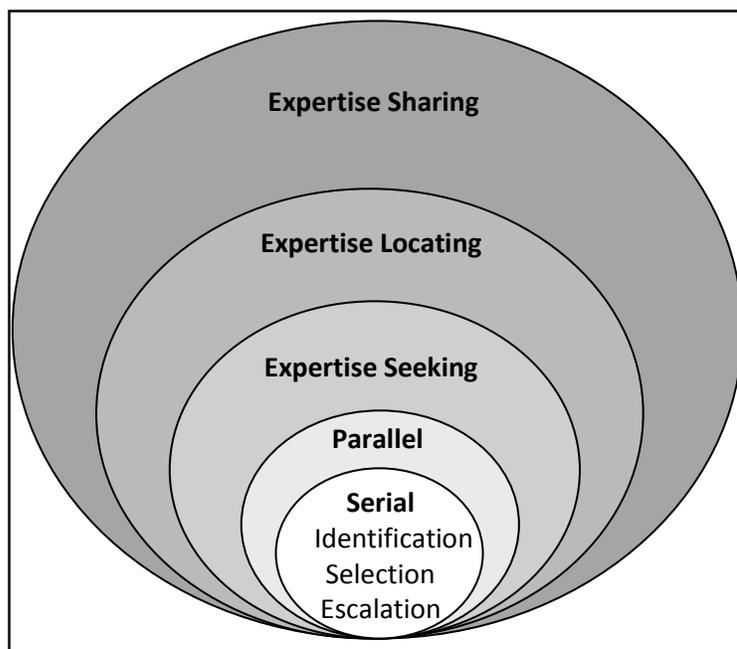
#### **5.4.1 Empirical Contributions**

Although many efforts to enhance patient empowerment focus on enhancing patients' access to biomedical knowledge and facilitating patient and health provider communication (Gibson, 1991), the findings I have described point to the wealth of valuable and complimentary information that peers and the broader community provide to patients outside the treatment facility. The health-care system is but one of the many settings in which patients operate to build supportive infrastructures. Thus, patient expertise sharing only partially addresses traditional views of empowerment motivated by the desire to balance power between patients and health professionals

within the health-care system. While peers can certainly offer strategies that impact personal health management, much of that advice (e.g., which wig shops to visit, which lotions best dull treatment side effects) won't necessarily have a direct effect on the health-care system, nor the balance of power between patients and health professionals. It appears that patient expertise sharing, viewed as a means for empowerment, aligns more closely with alternative perspectives that stem from the desire to foster social support among members of the broader community (Rappaport, 2000). Acknowledging the range of perspectives on empowerment through collaborative processes, such as expertise sharing, enhances our understanding of the breadth of patients' needs.

Findings from this field study also enhance our understanding of expertise sharing more generally. By demonstrating how analytical constructs drawn from expertise sharing in organizational settings play out in the context of personal health, this field study provides significant insight into systematic, everyday expertise sharing behaviors used by individuals facing high stakes situations. The application of expertise sharing constructs in this new setting also uncovered unique expertise identification techniques, expertise selection techniques, and anticipatory breakdown recovery techniques that extend the growing body of expertise sharing research. Expertise sharing practices not highlighted in prior work include (1) the initiation of identification through unsolicited offers, (2) the identification of expertise through multiple variations of gatekeeping, numerous grouping mechanisms, and minimal use of historical artifacts, (3) the vital role that specificity of health-related experiences and source transparency plays in selection, (4) the use of triangulation to mitigate potential breakdowns for high stakes problems, and (5) the manifestation of expertise provision as well as expertise location.

These findings enhance our understanding of expertise sharing by extending prior empirical descriptions drawn from organizational contexts to initiate a bridge between our understanding of expertise locating in formal organizations and in the informal context of everyday life (Torrey et al., 2007; Torrey, Churchill, & McDonald, 2009). For example, the appearance of unsolicited offers of advice suggests an interesting and potential parallel to the evolution in theories of information behavior (Wilson, 1999). Figure 5.1 depicts a nested representation of expertise sharing modeled after Wilson's nested model of information behavior.



**Figure 5.1 Nested Representation of Expertise Sharing**

In Wilson's model (Wilson, 1999), 'information seeking' represents a subset of 'information behavior' and can focus on seeking of professional information for use within more formal contexts (e.g., workplace tasks). Information seeking can also focus on practical and orienting information for use in less formal settings of everyday life, such as health-care or hobbies (Savolainen, 1995). Similarly, expertise

location could represent a subset of a larger range of expertise sharing practices that include expertise provision and that cross contexts of varied formality. Just as information behavior reflects both active forms of information seeking and passive forms of information encountering (Erledez, 1999), expertise location reflects a similar distinction between the initiation of expertise identification through both active seeking (i.e., solicited advice) and passive encountering (i.e., unsolicited advice). Whereas positive implications are commonly associated with information encountering (Erledez, 1999), my findings suggest that expertise location through unsolicited advice can also carry negative associations. In addition, patients' use of triangulation suggests an important distinction between expertise location in organizations and in illness - patients simply cannot afford to fail in their one shot to solve a high stakes problem. Rather than risk failure, patients garner expertise by selecting many sources in parallel to build sound and personalized solutions *a priori*. Thus, processes of identification, selection, and escalation follow once expertise is actively sought and can occur serially or in parallel to facilitate triangulation.

Findings from this field study also raise a number of questions for future research. For example, it remains unclear to what extent the high stakes nature of problems patients face, and the everyday context in which they solve those problems, shape patients' unique expertise locating practices. Could triangulation arise from a patient's need to think through potential solutions thoroughly, or from their need for redundancy in an emerging support system that lacks the time-tested reliability of established structure and processes, or some combination of these conditions? Future work that compares expertise sharing practices over a range of informal contexts or between 'newcomers' and 'veterans' could bring useful insight. This field study only began to uncover other interesting issues of great importance for expertise sharing, particularly in the personal health context, such as trade-offs between one's desire for personal privacy of intimate health details and the potential benefit of

sharing that information to locate expertise. Future research in the personal health context can contribute to the larger body of expertise sharing work by teasing out issues, such as the influence of contextual formality on expertise sharing practice or the influence of information type on tradeoffs people are willing to make to share expertise (Terveen & McDonald, 2005).

#### **5.4.2 Design Recommendations**

Design implications from the field study about *how* patients share expertise build upon the insights I have drawn about minimizing potential disadvantages of patient expertise sharing (see Chapter 2), *what* patient expertise is (see Chapter 3), and limitations of health-related social software for supporting patient expertise sharing (see Chapter 4). Although patient expertise sharing could carry potential drawbacks associated with the spread of misinformation, poor fit of information, or conflicting information (see Chapter 2), the characteristics of patient expertise suggest designs that minimize those drawbacks by supporting collaborative management of diverse information resources in ways that help patients locate suitable expertise and exercise misinformation safeguarding strategies (see Chapter 3). Health-related social software provides a number of building blocks (e.g., user profiles, interactions forums, and social connections) for designing this type of supportive infrastructure (see Chapter 4), yet the expertise locating and provision practices patients use in everyday life suggest the need to extend those tools in specific ways. Given similarities between practices used by patients and expertise sharing more generally, expertise locators and collaborative recommendation systems provide suitable guiding posts for design extensions. Practices unique to patients (e.g., triangulation, managing unsolicited advice) suggest the need to expand upon those support strategies.

Designing a supportive infrastructure for patient expertise sharing could rely on the understory of a collaborative document management system made up of user profiles, a shared range of artifacts (e.g., personal stories, web pages, templates), and user connections. A collaborative document management system could minimize the potential for misinformation through group-level interaction forums that encourage collaborative self-correction and watchful warnings, shared judgments about content utility (e.g., content ratings or vetting), and methods to reference source materials. Collaborative tools, such as Google docs ([docs.google.com](http://docs.google.com)) or Microsoft Office Live (<http://workspace.officelive.com>), could be leveraged to create and share user-generated content. Users could annotate content with important contextual ties to their specific experiences to facilitate later reuse by other users (e.g., <http://www.diigo.com>). Such tags could provide the basis for consumer health folksonomies that organize content in meaningful ways (Smith & Wicks, 2008).

This type of supportive infrastructure could leverage the content from tools patients already use. For example, designers could save users the time and effort required to create yet another user profile by leveraging users' existing user profiles maintained through social networking tools, such as Facebook with Facebook Connect (<http://developers.facebook.com/connect.php>). Users could then extend their profiles with health-related information from their Google Health (<http://www.google.com/health>) or Microsoft HealthVault (<http://www.healthvault.com>) personal health record. Similarly, designers could help users import their connections (e.g., friends) or make user-generated content (e.g., forum posts) easier to find and reuse. Leveraging the tools and content already in use by patients can help to reduce personal resources required to establish the supportive infrastructure patients need to built relationships and share their expertise.

Whether building upon or borrowing from popular social software, support for patient expertise sharing calls for specific enhancements to enable expertise location, expertise provision, triangulation, and management of unsolicited advice. Designers could build upon the base of a collaborative document management system, leveraged from existing tools, with the additional functionality of expertise locators or collaborative recommendation systems. Following this approach to design, I propose specific design recommendations to support patient expertise sharing (Table 5.3). These recommendations represent a synthesis of the design implications carried by the stream of research I have conducted.

**Table 5.3 Design Recommendations to Support Patient Expertise Sharing**

Design Recommendation	Examples of Social Software Extensions
<p><b>Support Expertise Location</b></p> <ul style="list-style-type: none"> <li>• Support expertise identification through collaboratively managed artifacts that reflect users' knowledge and experiences</li> <li>• Support expertise identification by recognizing gatekeepers</li> <li>• Support expertise selection along diverse social criteria</li> </ul>	<p><b>Design an Expertise Locator that:</b></p> <ul style="list-style-type: none"> <li>• Searches <i>knowledge clouds</i>, which represent users' areas of knowledge and experience, to identify candidate sources of expertise</li> <li>• Searches for <i>profile badges</i>, which flag and suggest potential gatekeepers</li> <li>• Presents <i>detailed user profiles</i> for candidate sources, which represent their knowledge and social circumstances</li> <li>• Provides <i>query filters</i> for users to specify social circumstances of importance</li> <li>• Organizes candidate profiles for comparison with <i>visual representations</i></li> </ul>
<p><b>Support Expertise Provision</b></p> <ul style="list-style-type: none"> <li>• Support generalized provision through broadcasts of general recommendations</li> <li>• Support targeted provision through tailored recommendations to individuals in need</li> </ul>	<p><b>Design a Collaborative Recommender that:</b></p> <ul style="list-style-type: none"> <li>• Collaboratively filters public evaluations of content through <i>voting or vetting</i></li> <li>• Encourages users to reference source material through <i>wikis, hotlists, FAQs, newsfeeds</i></li> <li>• Searches <i>needs clouds</i>, which represent users' areas of sought knowledge, to identify candidate targets for recommendations</li> <li>• Supports the formation of <i>special interest groups</i> to exchange topic-specific information</li> </ul>
<p><b>Support Triangulation of Expertise</b></p> <ul style="list-style-type: none"> <li>• Support requests issued to multiple sources of expertise in parallel</li> <li>• Support collection, integration, and synthesis of multiple streams of advice on a particular problem through polling and sampling of multiple perspectives</li> </ul>	<p><b>Design a Problem-specific Canvas that:</b></p> <ul style="list-style-type: none"> <li>• Integrates related advice in <i>one place</i></li> <li>• Integrates with a forum for <i>polling</i> the community or <i>targeting requests</i> to subgroups</li> <li>• Sorts and filters advice according to <i>ratings</i> or <i>contextual tags</i></li> <li>• Integrates <i>contextual links</i> to reference material</li> <li>• Tracks and summarizes patterns using <i>poll counts</i></li> </ul>
<p><b>Support Management of Unsolicited Offers</b></p> <ul style="list-style-type: none"> <li>• Support users in expressing their preferences for receiving or not receiving particular types of advice</li> <li>• Support the filtering of advice</li> </ul>	<p><b>Design Features that:</b></p> <ul style="list-style-type: none"> <li>• Enables users to <i>mark their user profile</i> as 'looking for' particular types of advice</li> <li>• Enables users to send private <i>thank you notes</i></li> <li>• Enables users to <i>filter</i> advice by user, type, or other characteristics</li> </ul>

#### **5.4.2.1 Supporting Expertise Location**

Patients use a broad range of mechanisms to locate patient expertise, yet health-related social software provides only limited support for those practices. As I described in Chapter 4, prior work on expertise locators provides guidance for enhancing social software to overcome their limits on location and support the kinds of locating mechanisms that surfaced in this thesis. Following the features of expertise locators that help users understand what expertise another person has, as well as the social circumstances in which that expertise would be shared (McDonald & Ackerman, 2000; Ehrlich, Lin, & Griffiths-Fisher, 2007), I propose 3 recommendations for enhancing social software with specific features to support patient expertise locating. An expertise locator could leverage these features to assist the user in identifying and selecting other users who could serve as sources of expertise to meet their needs.

##### ***5.4.2.1.1 Identifying Expertise through Collaboratively Managed Artifacts***

Patients need easier ways to gain awareness about the types of knowledge that other users of health-related social software can offer. Extending social software with functionality to extract metadata about users' knowledge from shared collections of artifacts can support expertise identification by helping the user determine what expertise other users can offer (i.e., 'who knows what'). Social software could be enhanced with features that capture and organize a range of shared artifacts (e.g., message posts, pointers to web pages) in problem-based collections for community reuse. For example, related discussion forum posts could be tagged and organized by topic. Alternatively, users could collaboratively manage documents by creating, extending, and annotating evolving collections of artifacts specialized to support

common problems such as managing breast surgery (e.g., finding a surgeon, questions to ask about surgery, post-surgery recovery tips).

Beyond synthesizing collective wisdom (Khan, Cohall, & Kukafka, 2008; Weiss & Lorenzi, 2008), metadata from these collections could help users identify candidate sources of expertise by providing cues about ‘who knows what’. For example, the trail of users who have interacted with an artifact (e.g., change history record on a wiki) suggests those users who can likely offer additional information (i.e., candidate sources). Alternatively, the topics that a user frequently discusses in forum posts could be represented by a tag cloud in their profile that reflects the areas of knowledge they can likely offer (i.e. the user’s **‘knowledge cloud’**). Expertise maps, such as a directory of the skills and knowledge of community members, could combine users’ knowledge clouds to summarize the expertise available within the community and point to groups of candidates knowledgeable about specific topics. An expertise locator could leverage this metadata by providing the user with the means to issue a query for candidate sources by topic, and then identify candidate sources with matching knowledge. An expertise locator could also observe a user’s recent interactions (e.g., questions posted to a forum, keywords from content searches), and then automatically suggest candidate sources to the user.

#### ***5.4.2.1.2 Identifying Expertise by Recognizing Gatekeepers***

The range of gatekeeping mechanisms that emerged in the field study suggests the value of recognizing potential gatekeepers within a community of social software users. Extending social software with features, such as **profile badges** that reward users for their efforts, can support expertise identification by helping the user to recognize and leverage available gatekeepers. Users could publicly note thanks to other users who have acted as contact brokers, champions, or conduits by rewarding

them with a profile badge, such as Wikipedia's 'Barnstar' award (Kriplean, Beschastnikh, & McDonald, 2008). Alternatively, users could volunteer to serve as a gatekeeper by listing one or more gatekeeping roles in their user profile. Gatekeepers could also be elected automatically, based on their interaction history or social connections in the community. For example, an expertise locator could suggest conduit gatekeepers who offer other users many resources (e.g., URLs, book or article titles, etc), or could suggest contact brokers who are richly-networked with other users (e.g., friend connections, frequent interactions). An expertise locator could also compare the social networks of the expertise seeker and a potential source of expertise to elect a common friend to act as a contact broker to introduce them (i.e., friend of a friend).

#### ***5.4.2.1.3 Selecting Expertise along Diverse Social Criteria***

Once patients have identified candidate sources having the knowledge they seek, whether through knowledge-oriented metadata associated with shared artifacts (e.g., knowledge clouds) or through the help of a gatekeeper, they require additional details about the social circumstances of those candidates to determine who to approach. Extending the breadth of personal information represented by user profiles in existing tools provides a natural solution to help the user select candidates that specifically match the selection criteria they find most important. For example, **detailed user profiles** could incorporate a user's areas of knowledge (e.g., knowledge cloud) as well as the types of social characteristics that emerged as selection criteria in the field study (e.g., social relationship, lifestyle and interests, availability). Although the extent of personal information a user is willing to display on a profile to locate expertise remains an important focus for future work (Terveen & McDonald, 2005), supporting expertise selection along these diverse social criteria

has the potential to improve the fit of information obtained from others and minimize the potential for conflicting information (see Chapter 2).

After identifying candidate sources of expertise, an expertise locator could then provide the user with links to the detailed user profiles of candidates to explore. Such a tool could also organize the profiles of candidate sources into groups that differentiate the pool of candidates along selection criteria of greatest importance to the user. For example, **visual representations** could organize profiles in ways that help users explore and compare candidates along multiple dimensions (Civan & Pratt, 2007b). The development of meaningful categories could also be explored to organize profiles in useful ways (Pratt, 1999). Alternatively, an expertise locator could leverage detailed user profiles by providing users with **query filters** (McDonald & Ackerman, 2000) that offer fine granularity for specifying the characteristics of sources they prefer.

Populating and maintaining a detailed user profile to facilitate these expertise locating techniques can require substantial effort on the part of the user. To reduce the effort required by patients, some user profile information that can augment expertise selection could be directly imported from other social software tools. For example, interests and lifestyle information could be pulled from popular social networking sites (e.g., Facebook, <http://www.facebook.com>). Health status information (e.g., diagnosis, treatments, side effects) could be pulled from internet-based personal health records (e.g., Google Health, <http://www.google.com/health>; Microsoft HealthVault, <http://www.healthvault.com>).

#### **5.4.2.2 Supporting Expertise Provision**

Patients seek expertise from, as well as look for opportunities to provide expertise to others. This finding suggests the need for tools to support mechanisms for expertise provision without first having to be ‘located’ and asked. Unlike tools that distinguish system access by role-based interfaces (e.g., ‘for patients’ versus ‘for professionals’), the field study suggests that tools that support patient expertise sharing should provide every user with functionality to both locate and provide expertise independent of their role or health status. As I described in Chapter 4, prior work on collaborative recommendation systems provides guidance for enhancing social software to overcome limits on provision. Following this guidance to support the provision mechanisms that surfaced through the field study, I propose two specific recommendations for enhancing social software to support patient expertise provision. Social software could leverage these collaborative recommendation features to help users make both generalized and targeted recommendations. I describe these design recommendations in the following two sections.

##### ***5.4.2.2.1 Supporting Generalized Recommendations***

Based on field study findings, users need functionality to broadcast generalized recommendations to a larger community of people with interest in breast cancer. Functionality to support generalized expertise provision could include features that encourage users to broadcast recommendations by casting **votes** on content and providing the community with pointers to reference material through wikis, FAQs, or hotlists of useful web pages. Similar to ‘passive collaborative filtering’ (Maltz & Ehrlich, 1995), such features do not require a direct connection between the users providing recommendations and the users who later garner those recommendations. For example, a collaborative recommender could provide simple **vetting** features for

users to mark or annotate content they find particularly helpful. Through passive collaborative filtering, other users then make use of those judgments to locate content that could be most useful to them. Such a tool could also help users collaborate to create **wikis**, **FAQs**, or **hotlists** of useful web pages on specific topics. Users, such as community gatekeepers, could distribute **newsfeeds** on a particular topic to the community to which interested users could subscribe. Users could also be given the opportunity to collaborate on newsfeeds by adding relevant content for broadcast within the community. These generalized expertise provision features support public broadcasts that provide source referencing and content evaluation, both of which are useful strategies for safeguarding against misinformation (see Chapter 3).

#### ***5.4.2.2 Supporting Targeted Recommendations***

Findings from the field study also suggest that users need functionality to make targeted recommendations to individuals who face specific situations. Similar to ‘active collaborative filtering’ (Maltz & Ehrlich, 1995), a collaborative recommendation system could incorporate features that help users share their expertise with specific users in the community. For example, functionality to support targeted expertise provision could look similar to features that facilitate expertise locating. In both cases, the user is looking for other users with specific characteristics. Rather than looking for candidates who are suitable sources for expertise (i.e., expertise locating), the user looks for other users who might need the expertise they can offer (Shami, Ehrlich & Millen, 2008).

Support for targeted expertise provision could evolve from extending the expertise location features I have proposed, such as tag clouds and query filters. For example, in addition to posting a knowledge cloud on their user profile, users could also post a

**needs cloud** that represents the topics appearing in their recent content searches. Users looking for targets to provide specific recommendations could search the needs clouds of other users to identify targets in need of tailored expertise on a particular topic. Once such a collaborative recommender has identified potential targets, expertise providers could invite targets to email, chat, or subscribe to a **special interest group** to exchange useful information over time.

#### 5.4.2.3 Supporting Triangulation of Expertise

Unlike professionals' escalation practices, participants in the field study anticipated breakdowns in expertise location by asking several different people for advice through polling or sampling multiple perspectives. These triangulation strategies suggest the need for patients to not only issue information requests to multiple sources, but to do so in parallel. They also need ways to track and synthesize related bits and pieces of advice they obtain from many different sources. Features, such as a **problem-specific canvas**, could help users collect, integrate, and synthesize multiple streams of advice related to a common problem in **one place**. A dedicated problem-specific canvas could integrate with a public forum through which users issue requests to the community (i.e., **polling**). Alternatively, the canvas could incorporate communication with subgroups to enable users to **target requests** at certain types of users (e.g., patients, survivors, caregivers). Such a canvas could also provide methods for users to sort and filter multiple streams of advice using **ratings** (e.g., thumbs up/down) or **contextual tags** that describe characteristics of users who provided the advice. **Contextual links** to background information could be added by users. Methods, such as **poll counts**, could also provide users the means to track and summarize patterns in advice they receive.

#### 5.4.2.4 Supporting the Management of Unsolicited Advice

Patients also need ways to manage unsolicited offers of advice. As the field study demonstrated, sometimes unsolicited advice is welcomed, leading to further expertise location. At other times, unsolicited advice is unwelcomed. Unfortunately, it is challenging to predict when unsolicited advice will occur or whether a recipient will be open to receive it. Certainly if a patient has encountered unhelpful advice from a source on multiple occasions, it is more likely that unsolicited advice will be perceived as unhelpful in subsequent encounters. In this situation, tools could provide users with an easy way to filter content from that user or send them a carefully worded, **private note** to say *'I appreciate your effort, but no thank you'*. **Filters** could also be designed to sort content by user, type, or other characteristics to weed out undesired types of advice.

An alternative to predicting unsolicited advice is to provide the user with a way to express when and what topics they are open to receive. For example, some participants signaled their 'openness' to specific advice by sharing information about their situation with others. Similar phenomena have been observed in other informal contexts, which can lead to receiving useful 'information gifts' (Torrey, Churchill, & McDonald, 2009). This strategy can save the user time required to search for expertise, but can lead to undesired advice. Features that allow users to express their preferences for advice by **marking their user profiles** as 'looking for' particular types of information could help them leverage this low-cost strategy. These features could be modeled after social networking tools, such as Facebook (<http://www.facebook.com>), that allow the user to mark their profile as "*looking for*" friendship, dating, networking, etc. For example, patients might mark their profile as *'looking for tips on managing pain from radiation therapy'*.

## 5.5 Conclusion

This Chapter offers a description of the practice of patient expertise sharing that is grounded in a field study with 15 breast cancer patients. This investigation demonstrates how patients both find patient expertise and offer patient expertise to others during breast cancer treatment. Although these expertise sharing behaviors overlap with some behaviors observed in organizations, locating expertise in the illness context required new strategies and behaviors. Unique issues associated with patients' behaviors do much to enhance our understanding of the complexity and collaborative nature of patients' information work. These findings offer key empirical contributions and suggest specific design recommendations for extending health-related social software to support patient expertise sharing. Patient-centered functionality that supports expertise provision as well as expertise location through the recognition of gatekeepers, artifact sharing and reuse, selection along diverse criteria, management of unsolicited advice, and triangulation can greatly enhance the design space of internet-based social software. In Chapter 6, I describe the user-centered design of a patient expertise locator that implements select recommendations to support patient expertise location. Although it addresses only one issue (i.e., expertise location) and just begins to explore the possibilities, it provides one concrete example of supportive design for patient expertise sharing in the context of health-related social software.



**User-Centered Design of the Patient Expertise Locator**

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Managing personal aspects of health can be challenging for many patients, particularly those facing a serious condition, such as breast cancer. Through this thesis, I investigate patient expertise sharing as one means for overcoming such challenges. Through Aim 1, I described the characteristics of patient expertise that individuals develop by managing the day-to-day experience of illness (see Chapter 3). Although social software can help patients share this valuable form of expertise with one another, existing tools lack the kinds of functionality needed to fully support expertise sharing (see Chapter 4). However, through Aim 2, I described a range of patient expertise sharing practices that can inform the design of supportive enhancements to health-related social software (see Chapter 5).

In this Chapter, I describe the work I conducted to meet the third and final Aim of this thesis: To design a prototype to facilitate patient expertise sharing. Following select design recommendations from Chapter 5, I present the user-centered design of a patient expertise locator that provides a concrete example of extending health-related social software to support patient expertise location. After discussing the importance of expertise location as a design focus (Section 6.1), I describe how my initial design of the patient expertise locator fulfills two patient expertise locating design recommendations within the context of an online cancer community (Section 6.2). I then demonstrate how a patient would use this prototype to locate patient expertise through a use case (Section 6.3). Finally, I describe feedback and design guidance obtained through a focus group with breast cancer survivors (Section 6.4). I conclude with directions for enhancing the prototype through future work (Section 6.5).

## 6.1 The Importance of Patient Expertise Location as a Design Focus

Given the range of patient expertise sharing practices that innovative designs can ultimately support, I chose to focus my design effort on supporting patient expertise locating. The stream of research I have conducted clearly points to the importance of helping patients locate suitable peers for personal health advice. It also provides insights for overcoming limitations to expertise locating using existing tools. Thus, rather than focusing the design on helping users find content in social software, I focused on helping users find other users who have knowledge that meets their needs (i.e., people finding). Following select design recommendations for supporting patient expertise locating, I designed a specialized type of people finder, which I call a **patient expertise locator**. The purpose of the patient expertise locator is to help users find other users whom are best suited to meet their specific needs. This prototype provides a concrete example of extending social software to support one important aspect of patient expertise sharing.

Growth in health-related use of social software, such as online health communities, offers increasingly diverse means for patients to exchange their expertise (Adams, 2008; Sarasohn-Kahn, 2008). Yet, users face challenges locating expertise that reflects a highly specific fit between their needs for expertise and the knowledge, experiences, and circumstances of expertise sources. Although many individuals use these tools more often to exchange patient expertise than to obtain emotional support (Sarasohn-Kahn, 2008), users can find it difficult to relate to the health experiences of other users (Rimer et al., 2005) or to gain awareness of the expertise available without multiple interactions that build relationships (Hoey, Ieropoli, White, & Jefford, 2008). Whether users locate peers for advice by detailing personal experiences on their profiles (Frost & Massagli, 2008) or by posting forum

questions, this common broadcast strategy works only if those with the requisite expertise notice and respond. Once that expertise is garnered, users must then determine the suitability of the peers who provided it for meeting their needs.

Although some online health communities offer people finders that search for community members with similar diagnoses, having a similar diagnosis is not necessarily a sole marker of patient expertise. As community membership grows, such limited filters could result in an unwieldy number of profiles to review. Prior expertise sharing research offers insights for helping users determine who can offer expertise that best meets their needs. As I described in Chapter 4, field work in workplace organizations has informed the design of specialized people finders, called expertise locators (McDonald & Ackerman, 2000). An effective expertise locator requires both helping a user understand what expertise another person has, as well as the social circumstances in which that expertise would be shared. For example, enhancing awareness of users' expertise with contextual details about their social relationships (Shami, Ehrlich, & Millen, 2008) or reputations (Kriplean, Beschastnikh, & McDonald, 2008) can augment efforts to locate expertise. Similarly, a patient expertise locator can provide users of an online health community with awareness of the knowledge and social circumstances of other users who represent the pool of potential sources of patient expertise.

Practices associated with patient expertise locating that emerged from the field study were both extensive and fraught with challenges, providing a wealth of insights and specific recommendations that can inform the design of a patient expertise locator (see Chapter 5). Similar to prior expertise sharing research, the field study indicates that locating patient expertise involves more than awareness of the type of knowledge peers can offer. Determining which knowledgeable candidate to approach relies on a number of socially-embedded selection criteria, including a peer's availability,

lifestyle and interests, relationship to cancer (e.g., patient, survivor, caregiver), social relationships, and their transparency (e.g., honest, straightforward, and traceable advice). These findings ground the design of the patient expertise locator through the following specific design recommendations:

1. Help users identify candidate sources of expertise by leveraging metadata in shared artifacts that indicates ‘who knows what’
2. Help users select candidate sources of expertise along diverse social criteria

By providing users of health-related social software with awareness of the kinds of expertise community members can offer as well as the social circumstances in which those members would share their expertise, the patient expertise locator can help users locate other users who can offer patient expertise that best meets their needs. Such functionality for producing highly specific matches between the needs of the seeker and the knowledge and social circumstances of the expertise source has the potential to minimize disadvantages associated with poorly fitting or conflicting information (see Chapter 2). In collaboration with Chris Powell, M.S. and Meredith Skeels, Ph.D. Candidate, I explored how the approach of a patient expertise locator can extend online health communities by developing an initial design and conducting a focus group with breast cancer survivors for feedback and guidance.

## **6.2 Initial Design of the Patient Expertise Locator**

Starting with the design recommendations for supporting patient expertise locating that emerged from the field study (see Chapter 5), I worked closely with Chris Powell, M.S. to develop the initial design of a prototype patient expertise locator.

Our initial design builds upon existing social software by extending the functionality of an online community modeled after a peer-based question and answer (Q&A) forum. We chose a forum because we believed this platform would incorporate dense interactions among a greater number of users who could serve as expertise sources than other social software platforms, such as blogs or wikis. We chose a Q&A forum because we believed that message posts within Q&A threads would be more concise, closely related, and thus simpler to work with for our initial design than the more fluid threads common to discussion forums, such as those I analyzed to fulfill the first Aim of this thesis (see Chapter 3).

Rather than creating an online community that would need to be populated with new users and content, we leveraged existing cancer-related question and answer threads from Yahoo Answers (<http://answers.yahoo.com>) to simulate an online cancer community. Serving as a development corpus of data representing a collection of shared artifacts, we collected breast cancer-related question and answer threads from Yahoo Answers. We replaced user names with identifiers, and then constructed a database of questions, answers, and user profiles. Because Yahoo Answers is not designed to support extensive profiles, we created and embellished user profiles with fictitious personas to enable rich discussion during the focus group. We used this database to design interface mock-ups for an online cancer community featuring a Q&A forum, detailed user profiles, and a patient expertise locator.

Our initial design reflects the decisions we made to fulfill the two specific design recommendations for supporting patient expertise locating through this simulated online cancer community. The first recommendation, *helping users identify candidate sources of expertise by leveraging metadata in shared artifacts that indicates 'who knows what'*, supports the need for users to have awareness about the types of expertise available from other users in the online community We fulfilled

this recommendation by designing an expertise locator that leverages keywords in the Q&A threads to search for candidate sources of expertise by topic.

We first created a **knowledge cloud** for each user (i.e., persona) in our simulated online cancer community (Figure 6.1). As I described in Chapter 5, a knowledge cloud represents the topics that a user frequently discusses, which can reflect the areas of knowledge they can likely offer. Although the extent to which someone discusses a topic could be a limited reflection of their interests rather than their expertise, we believe that knowledge clouds provide a reasonable surrogate for the kinds of things users know about and have learned by providing forum answers (Zhang & Ackerman, 2005). We generated knowledge clouds from keywords appearing in the answers a user has posted to questions on the Q&A forum. We filtered common English stop words from users' forum answers and extracted significant terms and phrases using Yahoo's Content Analysis Web Service (<http://developer.yahoo.com/search/content/V1/termExtraction.html>). We used the tag cloud format to display the resulting term vector, representing the user's terms and their frequencies, in their user profile. We then designed the patient expertise locator to use this set of knowledge clouds to identify potential candidates of expertise by topic. The locator accepts a keyword query from the user, and then searches the knowledge clouds to identify users with keywords matching the query. Thus, users' knowledge clouds provide a map representing 'who knows what' in this community. Users can use the patient expertise locator to search this expertise map for potential candidates with knowledge that meets their needs.



**Figure 6.1 Example Knowledge Cloud**

We know from the field study that awareness about the types of knowledge others can offer (i.e., ‘who knows what’) is necessary, but not sufficient to locate suitable expertise. Patients also need awareness about the social circumstances of candidate sources to help them select those who can best meet their needs. This need underlies the second design recommendation, *helping users select candidate sources of expertise along diverse social criteria*. We fulfilled the second recommendation by designing detailed user profiles that provide users with access to the kinds of personal information they need to select among candidate sources identified by the patient expertise locator. In addition to the user’s knowledge cloud, each user profile incorporates the range of social circumstances that emerged as selection criteria in the field study. This range includes the user’s availability, lifestyle and interests, relationship to cancer, social relationships, and their transparency.

To locate patient expertise, the user provides the patient expertise locator with a keyword query representing the topic(s) of interest. The locator searches the profiles

of community members for knowledge clouds that contain the queried topic. Matching profiles are referred to as ‘candidates’. The locator then presents the user with an alphabetical list of user profiles for candidates, which they can explore along the social circumstances they find important. We chose keyword, topic-oriented queries and an alphabetical list of results in our initial design to allow room to explore alternative methods for locating expertise through the focus group, including advance search with query filters and suggestions generated automatically by the locator similar to an opportunistic approach to social matching (see Chapter 4).

### **6.3 Use Case**

Features of our initial design of a simulated online cancer community, including a Q&A forum, detailed user profiles, and a patient expertise locator, are the concrete results of our design decisions to fulfill recommendations for extending social software to support patient expertise location. Through the following use case of a fictitious breast cancer patient, ‘Lily’, I demonstrate how this tool can be used to locate patient expertise. Through the use case, I highlight the open questions we addressed through the focus group concerning the usefulness of the patient expertise locator and potential design enhancements.

Lily, a 39 year-old mother of two, was recently diagnosed with breast cancer. While recovering from surgery, she considered whether to continue full-time work through her upcoming chemotherapy. Could side effects interrupt her productivity? How would she cover her piling bills if she leaves her job? After talking with her health-care team and exhausting her personal network, Lily turns to our online cancer community for advice from peers who have first-hand experience with this difficult decision.

This community provides a Q&A forum, resembling a bulletin board, where Lily can post, answer, or read questions shared among the community. Lily provides personal details about herself to community members through her user profile. She can extend her personal network by building connections with other users through the forum. She can also use the patient expertise locator to search for other users who can provide her with advice.

This community shares a wealth of patient expertise, drawn from the stories of patients, survivors, and their families and friends. Yet which of the hundreds of users can offer expertise that best meets Lily's needs? Can Lily best locate them by broadcasting a question to the community on the Q&A forum or by using the patient expertise locator this online community features? Lily begins at the Q&A forum (Figure 6.2). She browses the threads contributed by community members, particularly those threads awarded stars by users who find them helpful. Unfortunately, Lily does not find the kind of work-related advice she seeks. She decides to look for community members who are well-positioned to help her with her decision.

**Figure 6.2 Q&A Threads are Displayed on the Forum in the Main Panel**

The left panel of the Q&A forum in Figure 6.2 pulls details from Lily’s user profile. The left panel also provides Lily with two choices for locating expertise. She can either (1) broadcast a request to the entire community by posting a question to the Q&A forum (i.e., ‘Post a question’), or (2) use the patient expertise locator, labeled ‘Find people who know about’, to target her request to those users who are most likely to offer expertise on topics relevant to her dilemma.

If Lily chooses the patient expertise locator, she would enter query topics, such as ‘chemo’, ‘work’, and ‘disability’, to identify other members who have discussed those topics frequently in their answers to forum questions. The expertise locator

returns a set of synopses linked to the user profiles of candidates it identified (Figure 6.3). Unlike other people finders, the patient expertise locator identifies candidates based on a match between queried topics and terms that appear in users' answers, rather than on a common diagnosis.



**Figure 6.3** A brief synopsis, pulled from the user profile, is displayed for each of 12 candidates the patient expertise locator returned.

The patient expertise locator helps Lily become aware of other users who could offer expertise relevant to her dilemma. She can now explore candidates' user profiles to select whom to ask for help. Lily can click on the name of a candidate, such as 'Alysa W', to view her user profile (Figure 6.4). Alysa's user profile resembles

profiles common to other social software (e.g., displays a user name, picture, and connections to other users). However, Alysa's profile incorporates additional information about her knowledge and social circumstance that can facilitate expertise location.

The screenshot displays a user profile for Alysa W. The profile is organized into several sections:

- Contact information:** Available after 3/1/09. Status: Sorry-Busy with sister's surgery.
- Health situation:** Sister's Health situation. Diagnosis: Stage II Breast cancer (12/08). Treatment(s): Lumpectomy (2/09). Side effect(s): Lymphedema (4/09).
- Personal Information:** Birthday: November 11, 1971. Gender: Female. Livelihood: School teacher. Hometown: New Monty, PA. Marital status: Married. Prefers: Allopathic, CAM. Interests: Yoga.
- Connections:** 13 connections listed: Jodie H, Marietta B, Kathryn G, and Robert R.
- Knows about:** A word cloud containing terms like cancer, certification, children, confident, difficult, employees, feel, health, insurance, life-insurance-coverage, limit, medicare, options, part-time, personal-experience, plans, post-surgery, private-policy, qualify, questions, services, standard, uninsured, and worry.
- Alysa W's Answers (141):** A question is highlighted: "Any tips on working from home during treatment?" with a star icon. The answer reads: "I'm a single mom with breast cancer. I need to keep working and want to exploring options from home..." Asked by Chelsey L - 8/2/08 2:17 am - 10 answers.
- Alysa W Recommends:** A link to <http://www.myworkandlifestyle.org> with a note: "Useful list of 'work from home' Jobs" and a "...see more" link.

**Figure 6.4** Alysa's profile displays the types of details patients need when selecting among informal sources for expertise.

The information in Alysa's user profile is organized around the selection criteria patients use when determining which peers to approach for patient expertise (see Chapter 5). Table 6.1 provides the design decisions we made to represent each

selection criterion in user profiles. Next, I will walk through Alysa’s profile to illustrate these design features, which are highlighted in bold.

**Table 6.1 Design Decisions for Representing Selection Criteria in User Profiles**

<b>Selection criteria</b>	<b>Representation in User Profiles</b>
Type & level of source knowledge	Knowledge cloud
Having experience with a cancer diagnosis (i.e., ‘cancer bond’)	Status line Health situation
Strength of social ties with others	User connections
Similarity in interests, lifestyles, & preferences	Personal information
Source availability (i.e., accessibility and expectation of response)	Contact information Last login
Source transparency (i.e., honesty, straightforwardness, and traceability of advice)	Contributed answers Recommended resources Star awards

The main panel of Alysa’s profile (Figure 6.4) provides insights into the types of knowledge she can offer. The tag cloud at the top, which we refer to as Alysa’s ‘**knowledge cloud**’, depicts frequent terms that appear in answers she has posted to the Q&A forum. More frequent terms appear larger than less frequent terms, indicating the major topics Alysa is likely to know about. Alysa can modify her knowledge cloud by adding or deleting keywords or by changing the weight of a keyword.

Whereas knowledge clouds provide the locator with data to identify matching candidates, other parts of the profile display contextual details the user can explore to narrow their selection to the most suitable candidates. For example, Alysa’s

**contributed answers** to the forum are shown below her knowledge cloud. Lily can gain insights about Alysa's transparency by reading the first few lines of her answers. Alysa has also **recommended resources** by posting URLs and descriptive notes for useful websites below her answers, providing Lily with examples of the kinds of information resources she might expect from Alysa.

The left panel of Alysa's profile displays her picture and a **star award** that indicates the 9 threads she has participated in that other users have found helpful. Any user can award a pink star to a thread they find helpful in the Q&A forum (see Figure 6.1). Once a thread receives a star, each user who participated in that thread, by asking or answering the question, is also awarded a star on their user profile.

Consensus-based rating mechanisms, such as star awards, are suggested as an important next step for extending health-related social software (Sarasohn-Kahn, 2008). We incorporated star awards following the lead of social software, where similar awards are an increasingly popular means for recognizing the contributions made by individual users. We opted for thread-level, rather than user-specific awards for two reasons. First, it is likely that no one user would rate more than a small fraction of answers as helpful, leading to potentially sparse ratings attributed to individual contributors (Konstan, Miller, Maltz, Herlocker, Gordon, & Riedl, 1997). Second, we felt that encouraging the rating of individual users could be misguided in the context of breast cancer, where the exchange of advice can stem from an altruistic desire to help and where there can exist many different, yet sound, strategies for solving personal health problems. By supporting the rating of an entire thread and then awarding all users who participate in that thread, we hoped to mitigate disadvantages associated with both sparse ratings and ratings of individuals.

Alysa's **status line** (i.e., 'is the sister of a cancer patient') is displayed below her picture, which communicates her relationship to cancer. Alysa can update her status

line to reflect her evolving experience as a support person for her sister. Below the status line, the date of Alysa's **last login** cues users about her availability for requests. Since Alysa is the sister of an individual facing cancer, Alysa lists her sister's **health situation**, including her sister's diagnosis, treatments, and side effects, to provide more detail about her relationship to cancer. A list of **personal information** follows to capture Alysa's lifestyle and interests, such as her livelihood. If Alysa chooses, she could update much of this information by pulling content from other tools she and her sister already use, such as Facebook (<http://www.facebook.com>), Google Health (<http://www.google.com/health>), or Microsoft HealthVault (<http://www.healthvault.com>).

The top of the left panel displays Alysa's **contact information** and the bottom of the panel displays her **connections** with other users. Alysa will be busy with her sister's upcoming surgery and communicates this with a note indicating her lack of availability until after the surgery. When ready to accept requests from other users, she will replace this notice with a link for contacting her directly. Alysa's connections represent social ties she has made by participating in forum threads with other users. The 13 users that Alysa has interacted with through question asking and answering on the forum are listed.

Given the choice between posting a question to the Q&A forum and using the patient expertise locator, how should Lily locate expertise for her dilemma? If she posts a question to the entire community, who might respond and what expertise might they offer? Alternatively, if Lily searches for knowledgeable users with the patient expertise locator, which of the returned candidates should she approach for advice? We posed this choice to a group of breast cancer survivors through a focus group to inform our design effort.

## 6.4 Focus Group

In collaboration with Chris Powell, M.S. and Meredith Skeels, Ph.D. Candidate, I conducted a focus group to obtain feedback from breast cancer survivors on our initial design of the prototype. The goals of the focus group were twofold. First, we wanted to gain insights into the perceived usefulness of the patient expertise locator. Would participants find that a Q&A forum provided sufficient functionality for users to locate suitable patient expertise? Second, we wanted to obtain guidance on design enhancements for our prototype. If participants found the approach of a patient expertise locator useful, we were particularly interested in their feedback and ideas on options for improving the design through additional features, such as advanced search, filtering, and system suggestions.

We recruited four breast cancer survivors to take part in the 2-hour focus group. Breast cancer survivors, who could reflect on their breast cancer experience, were well-suited as participants to provide considerable feedback and guidance. If participants affirmed the usefulness of our approach, then design enhancements they suggest could serve to guide future development efforts.

Participants ranged from 45-60 years of age and were diagnosed within 2-11 years. All were college educated with livelihoods ranging from teaching, to theater and real estate. All described themselves as very experienced in daily computer use, both at home and at work, and had used online communities, such as breast cancer discussion forums or Facebook (<http://www.facebook.com>).

The protocol for the focus group is provided in Appendix C. IRB approval was obtained through the University of Washington for conducting the focus group. We began the focus group by asking participants to introduce themselves by describing

past experiences exchanging advice about the breast cancer experience with peers (e.g., friends, family members, and other patients). Each participant had both sought such advice from and provided it to peers. We asked participants to draw upon those experiences, from the perspective of both the advice seeker and advice provider, during the focus group.

Next, we presented participants with our initial design of the online cancer community as a storyboard using the use case of Lily. We projected slides of the interface to walk through the use case and provided each participant a paper copy of this storyboard to make notes. After the use case, we facilitated discussion to assess participants' perceived usefulness of the patient expertise locator by asking participants whether Lily should post a question to the Q&A forum or search for knowledgeable users with the patient expertise locator. To ground this discussion, we encouraged participants to draw upon their personal experiences to describe situations best suited for a Q&A forum and for a patient expertise locator.

After assessing the perceived usefulness of the patient expertise locator, we engaged participants in a profile sorting activity to seed discussion about design enhancements for the patient expertise locator. We gave each participant paper copies for 3 of the 12 candidate profiles the patient expertise locator returned to Lily in the use case. The group explored the 12 profiles together to determine whom Lily should approach for advice. Through this exercise, we enhanced our understanding of the selection criteria of greatest importance to users, and participants engaged us in a fruitful discussion of design enhancements. During this discussion we asked participants for feedback on optional extensions to our design. The first was an advanced search option that would allow the user to filter their query for sources of expertise along various selection criteria (Figure 6.5). The second option provided users with candidate suggestions generated automatically by the locator (Figure 6.6).

Without requiring Lily to specify an explicit query, the locator matches the keywords appearing in Lily’s recent forum questions to the knowledge clouds of other users, and then suggests matching candidates to Lily.

Role	<input type="text"/>	Topic	<input type="text"/>
Age range	<input type="text"/>	Diagnosis	<input type="text"/>
Town	<input type="text"/>	Treatment	<input type="text"/>
Interests	<input type="text"/>	Side effect	<input type="text"/>
Livelihood	<input type="text"/>	Health Preferences	<input type="text"/>
<input type="button" value="Search"/>			

**Figure 6.5 Advanced Search Option to Filter Queries by Selection Criteria**

The screenshot shows a forum interface with two tabs: 'Forum' and 'People'. The main content area displays a question: "What should I know about recovering from lumpectomy?" posted by Lily on 2/1/09. Below the question are two user responses: one from Fatima D. and another from Aditya P. On the left side, there are sections for "Post a question", "Find people who know about" (with search terms "chemo, work, disability"), and "Connections" listing users like FatimaD, Aditya P, and LisaG. On the right side, a vertical panel titled "People you might find helpful" lists users Kathryn G. Chemo and Jodie H. Disability work, each with a small profile picture.

**Figure 6.6 Candidate suggestions with matching terms are displayed in the right panel**

### 6.4.1 Perceived Usefulness of the Patient Expertise Locator

Although participants thought that both the Q&A forum and the patient expertise locator could help users locate patient expertise, they found the locator more useful for identifying peers with both knowledge and specific social circumstances matching their needs. In addition to the selection criteria we incorporated into the design (Table 6.1), participants noted additional selection criteria through their discussion, such as generation, family status, ethnicity, neighborhood, and religious views:

*So it's like finding specific similarities, the people finder helps you do that - find someone who's really in your niche. (P1)*

After card sorting, this participant told us:

*In terms of the design, I think that the concept of what is going on here is really good because we did just talk about these 12 people [the profiles the locator returned from Lily's query], who of course we don't know any more from this piece of paper. It seems like we were able to come up with a couple who we think would be really helpful, a couple that nobody should ever call, and there seemed to be, if you read carefully, there seemed to be a lot of good information to help base those choices on. And it seems to be findable. (P1)*

Participants found the locator to be useful when: *"I just want to know about people who know about this [topic], and then I want to know what they know"* (P2). They agreed that the locator's functionality to *"weed out...people who are in such a different place"* (P1) is not well supported by existing social software, such as breast cancer discussion boards. One participant described the time and effort the locator

could save when searching for expertise in tools that segment discussion topics into separate forums:

*I have to go to that particular forum ... go through and read all of the stuff to find someone that matched ... so there is no way to go search and say find 'somebody that knows this'. I think that is something that that one [locator] would help. (P3)*

Participants discussed a range of situations for seeking expertise from peers using either a Q&A forum or a patient expertise locator. Yet, the nature of the problem and specificity of advice sought was a factor that could determine which tool they would turn to. They found the Q&A forum more suitable for situations requiring broad, general, or high-level information (e.g., survival statistics), but found the locator more useful for situations requiring highly specific advice. One participant explained this difference through an example:

*What's good for Q&A is a question that's going to have multiple answers ... so you can get all of their answers and decide which ones to use or not. Whereas with this [locator], I want to find that one person ... the more serious the diagnosis or news, then I would be more inclined to use [the locator]. Q&A for more general, for new things. But like for recurrence and mets ... I think that the more serious your diagnosis ... someone who is stage IIIB is going to have more specific questions, more urgency ... the questions are different. (P1)*

Associated with usefulness of both the Q&A forum and the patient expertise locator, personal privacy surfaced as an important trade-off. Participants agreed on the need, particularly for new members, to view content anonymously:

*Early on, I think any of us could say 'I did not embrace this, I lurked'. (P2)*

Although participants clearly found value in making profile information accessible to both the locator and to other users to support patient expertise location, they also wanted users to have private space to interact and the option to hide segments of their profiles if they wished. After recognizing the potential usefulness of the patient expertise locator participants noted:

*P2: It's interesting because earlier I said to hold back on the personal information, but if I am going to, if I am thirty years old and have kids, I need to see that [personal information on the profile] to see if I want to talk with them.*

*P1: But I assume that you can decide what to show or not. So if there is something you don't want people to know, you either don't enter it or provide it.*

## **6.4.2 Design Enhancements**

After participants described the ways a patient expertise locator would be useful, the profile sort and discussion of design enhancements pointed to specific directions to guide future design efforts. Design ideas included improvements in identification methods (e.g., queries), user profiles, and presentation of results returned by the locator.

### **6.4.2.1 Expanding Methods for Locating Patient Expertise**

Through the storyboard, we presented participants with just one method for querying other users with the patient expertise locator (i.e., by topic). This method assumes the user has an information need and can specify a keyword query that represents that need. Participants were also enthusiastic about incorporating additional methods for finding users who can offer expertise, including advance search, automatic suggestions, and identifying gatekeepers and friends of a friend (FOAF):

*I think what is nice about this is that there are a lot of different options. So someone that gets on and is just dizzy, you know I don't even know where to begin. You don't want to give them one hundred options, but it's nice to have a couple different ways. They are probably going to do similar things and lead you to similar people, but it's great to have the different ways to get there depending on which is going to work better for you. (P1)*

Participants agreed that advanced search was a critical extension to the functionality of the patient expertise locator. Although this option could require more structured entry of profile information, the high specificity participants sought in finding users that matched Lily's needs along various social circumstances suggests the potential utility of this design enhancement. Before we had even introduced our own design of an advanced search option to filter queries along selection criteria (Figure 6.5), participants had already engaged in much discussion pointing to the need to support queries from “*the other direction*” (P2):

*For narrowing things [results] down a little bit, what would be helpful would be a way so that when you did the search you could maybe click on and put the ones at the top of the list the ones that match something here [points to the personal information section of user profile]. Like what I would do, is like teachers, I am around kids, should I be going through chemotherapy and working and staying in the classroom? So, I would want to know from other teachers ... if there was some way you could link the search saying hey, the first people I want to look at to get that information, I want to key on, me right now it's like 'person with the same job'. Or in your case [referring to Lily], it's like you 'having kids that age'. So if there was some way to narrow the search a little bit as far as who is coming up number one. (P3)*

When we showed the group our advanced search option, they suggested adding drop-down options to make it easier for users to specify complex queries along various selection criteria that “hone in” (P2) on user characteristics of interest:

*P2: I'm a drop-down person, you know [specifying] the 'survivor', 'going through it now', the 'husband', 'spouse', 'child'. Because I looked at this [advance search option] and thought, 'role', hmm? And so helping people get to where they need to go. And there could be 'other'.*

*P3: But make them as drop-downs instead of typing in.*

*P1: Yeah, and I think what drop-downs do is help the sorting process.*

*P2: Yeah, and obviously like 'town' or 'state' or whatever ... because I might want to go locally and if I was just diagnosed, I might want to ask 'who is the best surgeon there ever was' .... I think that there are some that you kind of have to help people get to where they need to go. Because, again, I'll go back to the first diagnosis, cuz, I don't know, what is my 'role'? Because you just can't think.*

A second design enhancement we discussed was a method for obtaining automatic suggestions from the patient expertise locator. In our design, the system would ‘watch’ the questions a user recently asked in the forum to pull out salient key words. Without requiring the user to actively specify an explicit query, the patient expertise locator could search the knowledge clouds of other users for matching terms and present the profiles of matching candidates as suggestions. This option is appealing when users wish to locate expertise concerning new problems for which they lack familiarity with specific vocabulary to specify explicit queries (Torrey, Churchill, & McDonald, 2009). Other users could also volunteer to be contacted for

help by sending the user a note to suggest they get in touch. Participants were enthusiastic about including the option to garner suggestions because it could reduce the effort required to locate expertise, particularly for people who are newly diagnosed or who are experiencing treatment side effects that limit online activity. For example, one participant commented on this option as a low-effort alternative to actively constructing queries:

*I think that's what's nice about suggestions because if I'm dizzy and I don't know what to do I can just click. You know that's what I do in Amazon all the time. People who liked this book like this other one. Well sure, why not? It's easy, it's one click, and it gets me to something related. (P3)*

Participants also expressed interest in leveraging content and users' connections as aids to identify expertise through community gatekeepers or FOAF relationships. For example, one participant suggested gathering frequently asked questions (FAQ) to provide new users with a place to start. Each question could then link users to others who have asked a similar question. This participant also described a method for identifying community gatekeepers for specific areas of knowledge:

*If I was going through these 12 people [returned by the locator], I don't know if there would be some way to click on connections and find out, you know, is there someone who's on all of these [connection] lists? You know, these are the 12 people that came up from the search from Lily's entry. Is there some way to say 'is there any one person who is connected to all of these people'? Because you could search through each one to see which would be a good match, but maybe that would be another indicator. (P1)*

Another participant suggested leveraging the connections of other users, through FOAF relationships, to discover other users with similar situations:

*Let's say I am looking for recent chemotherapy, so I end up with Fatima [one of the 12 fictitious profiles from the use case], I may go there [Fatima's connections] to see if they are also recent chemotherapy, and I probably would now that I am talking about it that way. If someone has come up, and then my assumption is - and it's a gross assumption - that those folks had something to do with chemotherapy in 2009. (P2)*

#### **6.4.2.2 Enriching User Profiles to Facilitate Patient Expertise Selection**

Profile sorting led participants to suggest several enhancements to profiles. Observing this activity enriched our understanding of users' selection criteria when deciding whom to approach for advice. As participants explored the profiles to determine whom Lily should approach, they attended most to the user's relationship to cancer noted in the status line (e.g., self, family member, friend, etc), their health situation, personal information (e.g., geographic location, age, livelihood), knowledge cloud, answers, and recommended resources. Participants recommended additional profile details, such as the date joined, familial status (e.g., children's ages), and a representation of connection strength to other users. Cancer-related experience (i.e., shared cancer bond, relationship to cancer, and health situation) was a particularly important criterion providing '*street cred*' (P3) for selection:

*P3: [If someone's status line is] just 'interested in breast cancer'... it's like well what kind of information are you giving me if you're not claiming to be related to somebody going through it, you're not going through it.*

P2: *That brings up an important thing. The difference with this one and the [other profile with the status ‘interested in breast cancer’ is] those two don’t give health situations - everyone else’s [profile] does, which gives them credibility to respond to a certain extent ... if you’ve got credibility there’s some value.*

Although participants did not emphasize users’ availability during the sorting activity, discussion afterwards highlighted the usefulness of incorporating this information to allow users to “*opt out for a period of time*” (P1) and for maintaining awareness about other users:

*If you don’t hear from people for a while, so to have something helpful where they can say ‘Oh I’m on vacation for two weeks, really I am o.k’. You know some sort of notification that they haven’t just disappeared. (P3)*

In contrast to prior work (McDonald & Ackerman, 2000; Shami, Ehrlich, & Millen, 2008), participants attended least to users’ connections and star awards during profile sorting. However, they noted the potential utility of users’ connections for discovering community gatekeepers: “*any one person who is connected to all of these people*” (P1). Similarly, representing connection strength could cue like-minded ‘friends of a friend’ (FOAF):

*I think what I would love to see though is a counter on that [connections] ... to see that she and Lisa have exchanged questions and answers 30 times, whereas with Lena it’s been 10, now that could perhaps tell you that Lena is recently diagnosed and for Lisa it’s been a while. But it also tells you that this is someone simpatico. (P1)*

Unlike award-based mechanisms that flourish in other contexts (Kriplean, Beschastnikh, & McDonald, 2008), star awards held little value for participants as a selection criterion because they did not always relate directly to a user's specific needs.

*P1: I noticed we didn't do anything with the stars. I see that the people [profiles] I have in front of me, I have a 1, 2, and a 9 [stars]. So I think, hmm, do I care that he's been helpful on 9 different streams? I don't know.*

*P2: What I keep going back to is that every body's situation is so different.*

*P1: Yeah, so if the stars are sort of voted by the people, then what does 9 stars tell me, really? (P1)*

Participants preferred the contextual detail of other profile information over the consensus-based star award for determining highly specific matches along multiple selection criteria. For example, one participant described this preference while discussing user profiles belonging to fictitious users 'Carol' and 'Mabelle':

*Since every situation is different, 'Carol' could be great when it comes to mastectomy, but you could have 25 people that that is not their diagnosis. So, it doesn't matter if it is a thumbs up or not, because they don't have to deal with that. So it's 9 stars for those who are going through mastectomy, but its zero for [the others] ... Mabelle, to me, she had possibilities because she is a cancer survivor. She's actually a patient navigator, which to me would be very beneficial. One of her responses [in a contributed answer] starts with 'In my own experience I found the most support from' ... so that would get me to read more. And then she's got*

*some recommended places [websites] to go. So it strikes me that she's done some things that make her credible to give some advice. (P2)*

One participant suggested replacing star awards with the number of posts each user has contributed to the forum. Although it is unclear whether a user's track record based on the number of answers they have contributed can predict the quality of their answers (Zhang, Ackerman, Adamic, & Nam, 2007; Adamic, Zhang, Bakshy, & Ackerman 2008), participants thought that a user's number of posts would be a more useful aid for location than their star award:

*I know when I am looking for information [on online communities], I look for people who have made more posts because I know they have been in conversations and I would tend to take their information at a higher value over some that's made say 3. In fact when I [posted to a community], I actually prefaced [prefaced] it by saying you know 'I am a lurker, you'll see that because I only have [this many] posts where I have actually said something. Yes I read things, but'. So you know, they may not believe the things that I say ... because I know people look at that ... and I find that handy, you know, and so we do look, like when was the diagnosis? How many posts have you made? Are they recent ones? So that is the kind of thing I would want to look at here [on a profile] instead of thumbs up thumbs down. (P3)*

With the exception of user connections, the types of selection criteria that focus group participants attended to most during profile sorting aligns fairly well with the selection criteria that appeared most frequently in the field study (see Chapter 5). Participants in both studies emphasized cancer-related experience over other issues, such as source availability or transparency. This similarity suggests a trend of convergent validity over the kinds of selection criteria most critical for locating

patient expertise. Although focus group participants could have discounted user connections due to profile layout, it is more likely that social ties carried less meaning in the simulated online cancer community they lacked experience with than the everyday context of field study participants' real personal networks. In fact, focus group participants thought that connections were important to incorporate into the design and provided insights for making better use of them for patient expertise locating, such as adding a counter on connections to represent relationship strength based on the number of question and answer exchanges. This importance of social ties over consensus-based ratings is consistent with prior work that found that ratings made by friends were much more important to users than consensus evaluations from the community when selecting someone for social chat, online gaming, and newsgroup discussions on the Internet (Jensen, Davis, & Farnham, 2002).

With so many selection criteria to survey in user profiles, it is no wonder one participant commented:

*If you read carefully, there seemed to be a lot of good information to help base your choices on, but like anything else, if you don't read the entire thing it doesn't work. (P1)*

Future work could enrich profiles by incorporating the additional details suggested by participants, and then improve the layout of profiles to enhance the salience of key selection criteria for efficient review.

#### **6.4.2.3 Organizing the Presentation of Results to Facilitate Expertise Selection**

In addition to improving the layout of user profiles, exploring meaningful ways to organize and present results returned by the locator could help make the selection

process more efficient. As a group, we spent more than 20 minutes sorting the profiles to determine who Lily should approach for help. Reviewing and comparing profiles was cumbersome for even the small set of 12 user profiles we explored together. This work could become overwhelming as the number of profiles returned increases. Participants offered insights into ways to make this selection process easier:

*P1: If you've got 175 responses [profile results] to 'x' word, how do you figure out who's on top?*

*P3: Out of 175, it's who do I have connections with.*

*P2: Right. That's who is at the top of the page.*

Our discussion led to alternatives for presenting locator results of profiles in more useful, and perhaps scalable, ways than an alphabetical list. Similar to the advantage of filtering queries through advanced search, participants also suggested filtering results along characteristics of interest after they are returned by the patient expertise locator. They believed that sorting the returned profiles by factors, such as geographic proximity, marital status, and connections with other users, could offer the user flexibility and control to achieve a tailored fit that meets their specific needs:

*P1: There are so many websites where you can pick to reorder, do you want it by price, do you want it by proximity, do you want it by - to be able to choose which is the highest, which way to sort.*

*P3: Yeah, a way to have a sort, so the first ones that come up here as the possible connections.*

*P1: If you come up with more than 12, you're not going to come up with those end ones. I bet, thinking back, no one is going past the first 20 – and even 20 would be a lot. So you do want a way to get the closer ones at the top.*

*P2: Yeah, so a question might be 'can you tell me how your husband handled breast your cancer, or how did your spouse, your partner, handle it'. That could be a question. And then the other thing would be to turn around and say, 'well I really want to take a look at answers from people that are married or have partners', because I want to talk with them ... and so it is kind of going in two different ways, but ending up in the same spot.*

We could also explore additional alternatives through future designs that categorize results in meaningful ways (Pratt, 1999). For example, profiles could be clustered by subtopic or grouped by roles according to their relationship to cancer (e.g., patients, survivors, relatives and friends, and professionals). Profiles could be represented on a map to indicate geographic proximity or on a social network that represents strength of connections, and perhaps potential contact brokers, among users in the set of results. Visual representations could also be explored to compare results along multiple dimensions (Civan & Pratt, 2007b). For example, a scatter plot display could help users compare dimensions of interest, such as term frequency and strength of user connection, across a set of candidates returned by the patient expertise locator. The usefulness of these alternatives for presenting results will require future design work, but have the potential to help the user compare a set of candidates in more personalized ways than a ranked list based on consensus-oriented summary measures, such star awards.

## 6.5 Conclusion

Health-related social software embodies a large base of patient expertise, but existing tools provide users with only limited support for locating peers with expertise that best meets their needs. In this Chapter, I have described the user-centered design of a patient expertise locator to support this critical need to locate patient expertise.

Informed by the research I have conducted to meet Aim 1 and Aim 2 of thesis, the initial design provided an example prototype to extend online health communities by providing users with awareness of the knowledge and social circumstances of other users who serve as sources of expertise. Through a focus group evaluation with breast cancer survivors, participants concluded that such a tool proved useful for extending social software. This group also provided substantial guidance for enhancing the design with features, such as expanding the detail of user profiles, filters, and user suggestions. These findings offer empirical contributions, design contributions, and identify challenges for future work.

Findings from the focus group support the argument that locating patient expertise with existing social software is challenging. Of critical importance is overcoming the problems of information fit and conflicting information (see Chapter 2). Focus group participants indicated that good fit can result from flexible tools that provide them with control to determine a match that specifically meets their needs for a given situation. Fit does not always follow from the same diagnosis. Instead, it appears to follow from close similarity between the user's need for expertise and the knowledge and social circumstances of an expertise provider. Because situations vary from person to person, and even across an individual's breast cancer experience, support for expertise location must be designed with this situational dependence in mind. For example, consensus ratings could be more limited than we might expect for some needs patients turn to health-related social software to meet. Although users could

locate a single ‘champion’ (see Chapter 5), it is just as likely that they will search for many different people to meet a variety of expertise needs over the course of their breast cancer experience. Thus, awareness of ‘who knows what’ and the social circumstances in which peers share their knowledge are both important when locating patient expertise in online communities. A patient expertise locator can provide this awareness.

By evaluating the initial design, focus group participants generated guidance on specific features that social software should incorporate to facilitate patient expertise sharing. Profiles that illustrate contextual details, multi-dimensional filters, and user suggestions could help users locate community members with the knowledge and circumstances best suited for their needs. Patients need help from peers, and this work points to specific enhancements necessary for social software to support those needs. Thus, these results help inform designers of social software on how to incorporate expertise locator functionality and, therefore, provide even more valuable tools for patients seeking help from peers.

Lastly, findings from this work identify several challenges for future work. For example, techniques for presenting results from patient expertise locators could be explored to make it easier for users to efficiently compare potential candidates to select for help. The scoped design work I presented explores only one aspect of patient expertise sharing. Future design efforts could also explore designs that implement other design recommendations for supporting patient expertise sharing, including the provision of patient expertise, management of unsolicited offers of advice, and triangulation of patient expertise (see Chapter 5). In addition, providing users with access to the personal information of other users has the potential to improve the fit of information obtained from others and to minimize the potential for conflicting information (see Chapter 2). Yet, it is unclear to what extent users are

willing to trade-off personal privacy for those potential benefits. The focus group noted that although users should be able to hide portions of their profiles, access to this personal information is critical for the selection process. Enhancing our understanding of this trade-off and developing designs that can support expertise locating while preserving privacy are clearly important areas for future work both inside and outside the health domain (Terveen & McDonald, 2005). Various models of collaboration, in addition to the one-to-one model explored in this work, could be explored with respect to needs for personal privacy.

The user-centered approach I have described offers substantial guidance for enhancing the design of social software to meet users' patient expertise sharing needs. This work also provides empirical contributions and illustrates challenges for future work. In Chapter 7, I summarize the work I have completed to meet the three Aims of this thesis and discuss the broad contributions this work makes.

## *Chapter 7*

### **Summary and Conclusions**

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In this concluding Chapter, I summarize the research I conducted to understand and facilitate patient expertise sharing (Section 7.1), discuss the contributions of this research (Section 7.2), report on its limitations (section 7.3), and propose avenues for future work (Section 7.4).

### **7.1 Understanding & Facilitating Patient Expertise Sharing**

Learning to manage personal health can take substantial time and effort when patients do so through trial and error on their own. Although informatics support has the potential to help patients overcome this challenge by facilitating patient expertise sharing, we have lacked the knowledge necessary to meet this potential. Prior work provides little clarity about the nature of patient expertise and has not explored the practices patients use to leverage the expertise of other patients in similar situations. This dissertation offers foundational knowledge about *what* patient expertise is and *how* patients share this valuable resource. The comparative content analysis I conducted demonstrates that patients have substantial expertise that differs significantly from biomedical expertise offered by health professionals (see Chapter 3). The field study I conducted establishes an understanding of the practices patients use to share that expertise with one another (see Chapter 5).

**Patient expertise** is highly personal in nature. This experiential knowledge reflects practical strategies for coping with day-to-day personal health issues gained through the lived experience. Patient expertise offers a wealth of actionable advice that is frequently expressed through personal stories about managing responsibilities and

activities in the context of illness, including self-care, social relationships, work, and the home. Although the exchange of biomedical knowledge (i.e., the ‘Amateur Doctor lens’) might be desirable to some patients, findings from my work align more closely with the ‘Experiential lens’ for conceptualizing patient expertise. Thus patient expertise can be distinguished from the biomedical expertise of the health professional.

**Patient expertise sharing** reflects social mechanisms patients use to locate and provide patients expertise. Locating expertise is initiated through patients’ recognition of their needs and active search for patient expertise, as well as through unsolicited offers of advice they receive from others. Patients leverage family members and friends, gatekeepers, and social groupings to identify patient expertise available within and beyond their personal networks. They use diverse personal and social criteria to select the patient expertise that best suits their individual needs. The high-stakes nature of problems patients face leads to triangulation strategies in anticipation of breakdowns in expertise locating. Patients also take advantage of opportunities to provide their expertise to individuals facing similar health situations through both generalized and highly targeted strategies.

This dissertation applies this foundational knowledge about patient expertise and patient expertise sharing through a wealth of recommendations for the design of informatics support to facilitate patient expertise sharing. The user-centered design of a patient expertise locator offers a case example for putting those recommendations into action by positioning patients centrally in the design effort (see Chapter 6).

## **7.2 Thesis Contributions**

The primary contribution of this thesis is to the interdisciplinary field of Health Informatics. My rich descriptions both of patients' personal health knowledge and of patients' strategies to share that knowledge advance our understanding about the fundamental nature of patient expertise and establish a foundation of knowledge about the practice of patient expertise sharing. My user-centered design effort offers new insights for facilitating patient expertise sharing through informatics support. In particular, this stream of research makes a significant contribution to understanding and meeting individuals' health information needs in the field of Consumer Health Informatics. In addition to unearthing critical needs of patients for supportive peers, contributions of this work reach further by expanding on ideas from related fields of Computer Supported Cooperative Work and Health Services, and by offering insights for enhancing community-based support mechanisms.

### **7.2.1 Consumer Health Informatics**

What distinguishes this thesis from many other research efforts in Consumer Health Informatics (CHI) is its in-depth focus into what it means to consider patients as vital sources of health expertise. The experiential and personal nature of patient expertise makes it a valuable resource for patients who are learning to manage their personal health. Rather than relying on trial and error alone, patients can learn from the personal stories told by other patients in similar situations. Furthermore, scaffolding the learning of others, by offering the knowledge they have gained through their own health experiences, provides patients with a fulfilling outlet to give back.

Although many CHI research efforts have demonstrated benefits associated with emotional support that patients obtain from peers, there is a paucity of research that

delves deeply into other forms of information-rich social support that can meet patients' information needs. Much prior research on patients' information needs has focused on access to biomedical expertise and enhancing the patient-doctor relationship, to the exclusion of patient expertise available from peers, as a means for empowering patients to manage their personal health.

My research begins to fill these gaps by demonstrating that patients, too, contribute significant and complimentary value to the process of patient empowerment through patient expertise sharing. Informed by this knowledge, the design recommendations I offer provide substantive provisions for facilitating patient expertise sharing through patient-centered informatics designs. Thus, this thesis makes a significant contribution to our comprehensive efforts aimed at understanding and meeting the breadth of individuals' consumer health informatics needs.

I undertook this research because I want to create new opportunities for patients to help one another. I want to acknowledge the value of patients that so often gets overlooked. By investigating patient expertise sharing from a number of different angles, including content analysis, field study, and user-centered design, I have illustrated the value of acknowledging the range of contributions that patients can, and do, make. I hope that my work offers both an empirical and a practical basis for researchers seeking to conduct similar work using patient-centered approaches and qualitative methodologies.

### **7.2.2 Computer Supported Cooperative Work**

By examining expertise sharing in the informal context of everyday personal health, this thesis also contributes to the general research base on expertise sharing established in the field of Computer Supported Cooperative Work (CSCW).

Although much prior CSCW research has investigated expertise sharing in professional organizations, recent efforts are exploring how people share everyday expertise in less formal contexts, such as the Internet. By applying analytic constructs derived from the base of prior CSCW research to understand the practice of patient expertise sharing (see Chapter 5), I demonstrate the transferability of formal expertise location concepts, including the processes of expertise identification and expertise selection, which also play out in the informal personal health context of breast cancer.

In addition to identification of expertise through the use of gatekeepers and social networks and selection of expertise along a range of social criteria, new expertise sharing mechanisms emerged from the field study I conducted. These mechanisms include the initiation of identification through unsolicited offers of advice, the use of triangulation to mitigate potential breakdowns in expertise locating, and the significance of expertise provision. These findings enrich CSCW research by providing insights that help to bridge our understanding of expertise location across formal and informal contexts. Thus, these findings serve to elaborate the design space for expertise locating systems for informal settings in general, as well as for patients.

### **7.2.3 Health Services**

This thesis also offers contributions that have the potential to influence health-care practice and policy. Acquiring knowledge and skills to manage personal health can empower individuals to cope with a new health issue. This concept of patient empowerment is a central tenet of efforts to improve the quality of health-care in the United States (Institute of Medicine, 2001) and abroad (Department of Health, 2001). Much research has focused exclusively on formal sources of privileged

biomedical expertise, such as one's team of health-care providers, as the critical means for such empowerment (Gibson, 1991). However, everyday information seeking from peers and the broader community is also an empowering force (Savolainen, 1995; Rappaport, 2000). In particular, this thesis suggests that patient expertise sharing could substantially fuel community-based empowerment.

Although biomedical expertise certainly contributes to patient empowerment, the community-based patient expertise sharing I observed supports Borkman's (1990) differentiation of experiential, professional, and lay frames of reference, suggesting the need to expand our conceptualization of patient empowerment, and consequent support efforts, to acknowledge the complimentary contribution that patient expertise can make. Despite the growing emphasis placed on the importance of patient empowerment (Laine & Davidoff, 1996; Brennan & Safran, 2003; Taylor, 2009), conventional wisdom across our interdisciplinary fields rarely makes this important distinction between knowledgeable patients and lay bystanders (Borkman, 1990). Findings from my work suggest that patient expertise differentiates experienced patients from laypersons. Acknowledging this important distinction allows us to reorient our lens of patient empowerment and incorporate the valuable roles that both professionals and knowledgeable peers can play. A wider perspective could make patient support efforts of health-care practice and policy better positioned to tailor services and to leverage a wider range of resources, including collaboration with knowledgeable patients. We all agree that patients are a part of the health-care team. Facilitating patient expertise sharing in addition to effective patient-doctor relationships can help this team work together even more effectively.

### **7.2.4 Community-based Support**

Patients can take advantage of a number of community-based mechanisms for support, both online and offline. In particular, this thesis offers recommendations for local and national patient advocacy organizations (e.g., Susan G. Komen Foundation, <http://www.komen.org>), as well as for designers of patient-centered technologies, including health-related social software (i.e., Trusera, <http://www.trusera.com/health>).

Many cancer support organizations offer formal peer mentoring services, such as the American Cancer Society's 'Reach to Recovery' program (Burdick, 1975). These services are designed to match a patient with a volunteer cancer survivor. Serving as a mentor, the trained volunteer provides the patient with understanding, support, and hope (American Cancer Society, 2009). Although some programs provide refined matching based on the type of treatment, this thesis illustrates a number of additional factors to consider for producing effective matches, such as demographics, lifestyle, and transparency.

In addition to insights for creating highly specific peer matches, this thesis contributes insights for extending community-based services to support a wider breadth of patients' personal health needs. For example, new gatekeeping programs could establish volunteers who serve as 'conduits' or 'contact brokers' for particular domains, such as insurance or organic diet. Although traditional peer mentors who share the same diagnosis and treatment can share a wealth of knowledge, they might not be knowledgeable about every need that arises for the patient they have been matched to for mentoring. In these situations, gatekeeping programs could provide patients with an additional route to obtain patient expertise that is not necessarily tied to a specific cancer diagnosis or treatment. Although patient navigator programs

often serve the function of contact brokers by linking patients to local services, these programs are often staffed by health professionals. Without collaboration with experienced patients, such programs could miss referrals to resources that are often outside the purview of the health-care system, such as housecleaning, helping with tax deductions for medical expenses, or scrapbooking memoirs. Peer mentoring programs that limit matching to diagnosis and treatment alone and patient navigator programs that exclude patient leadership could be missing these opportunities to meet the broad range of patients' highly specific expertise sharing needs.

Community-based support can also be found online through health-related use of social software, such as online health communities. This thesis offers technology designers specific insights for extending health-related social software to facilitate patient expertise sharing, such as how to incorporate expertise locator functionality into a discussion forum. In Chapter 5, I propose design recommendations for enhancing forums, wikis, blogs, and social networking tools with support for expertise location, expertise provision, triangulation of expertise, and management of unsolicited offers of advice. Feedback obtained through my user-centered design effort indicated that a patient expertise locator is a useful extension to health-related social software (see Chapter 6). Focus group participants also offered design ideas for improving this prototype, including the expansion of identification methods (e.g., queries), enriching profiles, and organizing the presentation of results returned by the locator. Concurrently, participants raised important issues that technology designers should consider, such as the questionable utility of consensus-based ratings for highly situated patient expertise and the trade-off between disclosing highly personal information to locate patient expertise and preserving personal privacy (also see Terveen & McDonald, 2005). Patients need help from peers, and this work points to specific enhancements necessary for social software to support this critical need for patient expertise.

### **7.3 Limitations**

The characteristics of patient expertise and patient expertise sharing practices I present in this thesis are derived from qualitative investigations in the breast cancer context. Although the implications of my work could extend to other patient populations (e.g., other types of cancer) or to health consumers more generally, claims of transferability are unwarranted without further research.

A critique of prior work is that it often focuses on one aspect of expertise sharing and fails to consider other related activities in the broad range of knowledge sharing activities (Huysman & de Wit, 2003). This thesis approaches patient expertise sharing from different angles, which provided the opportunity to explore convergent validation of findings between studies and to gain insights for understanding and supporting a range patients' expertise sharing needs and practices. The methodologies I selected were geared towards deep exploration of content from select discussion forums and books (i.e., content analysis) and the experiences and perspectives of a select set of participants (i.e., field study and focus group). Although these in-depth efforts were necessarily restricted to small samples, the work yielded rich descriptions that provide a solid basis for a deep understanding of patient expertise sharing.

Given the experiential nature of patient expertise, it is plausible that the characteristics I ascribe to this specialized form of knowledge are also reflected by the experiential knowledge individuals develop from personally managing health situations other than breast cancer, such as diabetes, heart disease, or pregnancy. Future research could explore whether the characteristics of patient expertise I describe do in fact show transferability to other contexts. In contrast, it is plausible that the transferability of the patient expertise sharing practices I describe could be

more nuanced. In particular, triangulation of expertise and unsolicited offers of advice appear related to the high stakes nature of some problems cancer patients face. Such acute problems can have dire consequences for health (e.g., treatment decisions), family dynamics (e.g., communicating health situation to relatives), and livelihood (e.g., work-related issues). Although it seems plausible that similar practices could take shape when acute issues arise in other health situations (e.g., heart attack, hypoglycemia), it remains an open question whether practices like triangulation also play out in the context of less acute personal health issues. However, even for chronic personal health issues in which there could be more room for experimenting with hit or miss solutions (e.g., stress management), it seems plausible that other fundamental expertise sharing behaviors, such as expertise identification and selection, could play out similarly.

My research on patient expertise sharing generated findings that provide a solid foundation for future research projects that aim to understand and meet patients' information needs. Next, I discuss specific issues raised by this work that point to future research that can extend our understanding of patients' expertise sharing needs and inform the design of tools to meet those needs.

## **7.4 Future Work**

Based on the implications carried by the findings from this research, I propose future research along two fronts: extending our understanding of patient expertise sharing and supporting those practices through innovative design that meet patients' expertise sharing needs.

### **7.4.1 Extending Our Understanding of Patient Expertise Sharing**

My characterization of patient expertise results from thematic analysis of content from a small sample of breast cancer discussion forums and books. My characterization could be expanded by investigating the kinds of knowledge shared by patients affected by other health issues, such as heart disease or asthma. Like the growing number of cancer survivors, individuals who manage chronic conditions develop personal health strategies and tips (Paterson & Thorne, 2000), which they could share with other patients. How might patient expertise vary in terms of topic, form, or style in other contexts? Do certain forms of recommendations surface more or less prominently for other health conditions or through other media than breast cancer discussion forums and books?

My description of patient expertise sharing practice results from a field study with 15 breast cancer patients. Although the makeup of this sample of cases was remarkably diverse, my description of patient expertise sharing practice does not reflect exhaustive details for every possible type of practice or issue. For example, the field study provided much detail about how participants located expertise in the physical world. Perhaps this emphasis on finding expertise resulted from recruiting individuals who were undergoing cancer treatment. Had cancer survivors or expertise sharing in virtual environments been the focus, we might have instead learned more about expertise provision or gained more insights into important issues, such as privacy. Future research could target investigations to gain deeper insights into other aspects of patient expertise sharing that my work only began to uncover.

## **7.4.2 Designing Tools to Meet Patients' Expertise Sharing Needs**

The purpose of my user-centered design was to initiate design work that future work can build upon. I obtained early feedback from enthusiastic target users on the potential usefulness of a scoped direction for facilitating patient expertise locating. Thus, this design effort focused on a small subset of the design recommendations I proposed. We evaluated the usefulness of our design choices, such as the 'knowledge cloud' serving as a surrogate for patient expertise, in a simulated environment. Given that participants concurred that the patient expertise locator could provide a useful extension to health-related social software, this thesis provides insights to stimulate focused design efforts in which researchers, in collaboration with target users, explore the design space for a range of patient expertise sharing support in real-life contexts. In particular, future design work could build upon this thesis by exploring each of the patient expertise sharing design recommendations, focusing attention on information fit, and incorporating support for patient expertise sharing in clinical systems.

### **7.4.2.1 Exploring a Range of Patient Expertise Sharing Designs**

Future work could enhance the design of patient expertise locators by exploring additional techniques for representing the knowledge and experiences of users, leveraging users' personal connections, and organizing results with visual displays. In our initial design of the patient expertise locator, we assumed that if a user discusses a topic in a discussion forum frequently, then there is a good chance they know something about that topic or know other users who do. Leveraging existing artifacts, such as forum posts, also provides an economical strategy for capturing expertise without requiring explicit entry by the user. However, this surrogate for expertise could be problematic if it only represents users' interests rather than their

knowledge (Zhang & Ackerman, 2005). Future research could investigate whether such surrogates are sufficient for representing what users know, and whether this requirement varies by the significance of different expertise sharing situations (i.e., finding a good wig shop versus a high stakes decision between cancer treatments).

Patient expertise locators could also be enhanced by leveraging users' personal networks. Rather than using patients' existing social networks, we chose the simpler route of using a simulated environment with fictitious network connections. In our focus group, the participants did not find our display of users' connections to other users helpful without further enhancements. However, it is unclear whether this result was an artifact of our simulated environment. Future work could incorporate the real social connections of participants who evaluate patient expertise locators for clearer feedback on how to leverage social networks for expertise locating in social software.

Lastly, this thesis points to the potential utility of organizing results from patient expertise locators in meaningful ways (Pratt, 1999; Civan & Pratt, 2007b). Because most prior work presents expertise recommendations as ordered lists, visualizations are an interesting focus for future work (Terveen & Hill, 2001).

In addition to designing patient expertise locators, future work could also explore the other design recommendations I propose, including support for gatekeeping, targeted provision of expertise, and triangulation of expertise. Creating supportive designs for new expertise sharing practices that surfaced during the field study provides the opportunity to inform work conducted by CSCW researchers in other informal expertise sharing contexts. It could also provide the opportunity to investigate the connection between informatics support for patient expertise sharing and for other forms of social support that patients need (Skeels, Unruh, Powell, & Pratt, under

review). By extending such design efforts to incorporate aspects of real-world use, researchers can gain clearer insights into how issues, such as privacy trade-offs and social networks, influence the design of patient expertise sharing tools.

#### **7.4.2.2 Designs that Improve Information Fit**

Much Consumer Health Informatics research has probed medical misinformation in online health communities. Although many studies suggest that inaccurate information is minimal or quickly corrected by online correspondents (Kelly et al., 2002; Eysenbach, Powell, Englesakis, Rizo, & Stern, 2004, Esquivel, Meric-Bernstam & Bernstam, 2006; van Uden-Kraan et al., 2008), the democratic nature of the Internet prevents us from mitigating this concern completely. Perhaps because patient expertise sharing involves interaction among patients as experts in their own right, rather than among patients acting as amateur doctors (see Chapter 3), the appearance of biomedical information that can carry inaccuracies in patient interactions is less frequent than the appearance of highly personal advice that colors many shades of grey. Nevertheless, my research suggests that encouraging the kinds of misinformation safeguarding strategies that patients already use could be useful. For example, designers should consider whether public or group-level venues for peer exchange, in which onlookers can catch and correct potential inaccuracies, outweigh risks to personal privacy.

Moreover, my findings suggest we refocus our attention to accommodate work that mitigates potential disadvantages associated with poorly fitting or conflicting information. For example, this thesis provides significant insight into creating suitable matches between expertise seekers and providers. Good matches certainly result from finding ‘someone like me’. However, patients have a range of specific expertise needs, and some of those needs are best met by someone who can offer

information or a perspective that they, and people like them, don't already have. The selection criteria used by patients to locate patient expertise indicate the types of contextual factors that are important for making a solid match between a patient's need for expertise and the context from which that expertise is drawn. Thus, designers should use this knowledge to create tools that can make the fit of information between users, as well as the potential for conflicting information, highly visible.

#### **7.4.2.3 Making Room for Patient Expertise Sharing in Clinical Systems**

Although my research is motivated by a desire to design personal health tools for patients in community-based settings, insights from this thesis can inform the design of tools that encourage information sharing between patients and health professionals, such as integrating a broad range of personal factors into health-care planning in the context of shared decision making (Ruland, 1999; Berry, Ellis, Woods, Schwien, Mullen, & Yang, 2003), or designing tools that bridge the expertise of patients and health professionals (e.g., <http://www.wegohealth.com>). Furthermore, my findings contribute insights for designing physical spaces in clinical environments that can support patients (Unruh, Skeels, Civan, & Pratt, under review). For example, the field study demonstrated that patients can identify expertise by coming into contact with other patients in local clinics. However, these 'information grounds' (Fisher & Naumer, 2006) are not designed to help patients connect or share through sustained interaction. Cancer treatment centers could add simple and low-cost amenities, such as message boards in waiting rooms or phone-based chat systems in infusion rooms, to facilitate expertise sharing among their patients. More sophisticated support could come from leveraging social networking tools to help the patients of a particular cancer treatment center connect and interact in their local communities.

## 7.5 Concluding Remarks

Coping with a new health issue requires acquiring knowledge and skills to manage personal health. Rather than relying on trial and error alone, individuals can leverage patient expertise by learning from the personal stories of peers who have experienced similar situations. Scaffolding the learning of others, by offering the knowledge they have gained through their own health experiences, provides peers with a fulfilling outlet to give back. This dissertation contributes foundational knowledge about *what* patient expertise is and *how* patients share this valuable resource. This in-depth understanding provides substantial guidance on new ways to think about the design of supportive tools for patients. Patients need help from peers and this thesis provides the understanding and guidance necessary to empower patients by facilitating patient expertise sharing.

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## *Appendix A*

# **Codebook for Content Analysis**

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This code book describes (1) the coding categories that evolved from the content analysis conducted to meet Aim 1 of this thesis, (2) the design of the inter-observer reliability testing of the coding procedure, and (3) coding instructions.

## **Coding Categories**

### **I. Topics**

A topic reflects the overarching theme of a content unit, such as a personal health issue or problem discussed. Each content unit is assigned one topic. There are two overlapping categories of topics: medical, personal, or both medical and personal.

#### **Medical (T.M)**

Code T.M applies to content units in which the main topic is mostly medical in nature because it involves problems or concerns around constructs or processes that are tied closely to the health-care delivery system, clinical care, and health professionals' work. Features that suggest a content unit is mostly medical in nature include a topic that relates to:

1. Activity that occurs at a health-care facility
2. The goals of health-care professionals more than the goals of the patient
3. Fitting oneself into the ongoing work and processes of the health-care delivery system

Examples of medical topics include:

- Deciding on health-care teams, treatments and procedures, and research trial enrollment
- Understanding biomedical and clinical concepts and processes (e.g., clinical procedures, treatments, side effects, test results, cancer risks and prognosis, clinical terminology) or research purposes and processes
- Managing interactions with health-care professionals
- Managing information to collaborate with clinicians and understand biomedical issues

### **Personal (T.P)**

Code T.P applies to content units in which the main topic is mostly personal in nature because it involves problems or concerns around constructs or processes that are tied closely to one's home life, work life, social life, emotional world, and health-related behavior that occurs outside of the health-care delivery system. Features that suggest a content unit is mostly personal in nature include a topic that relates to:

1. Patient activity that occurs outside of the health-care system (e.g., in the home, at work, with the social network)
2. The goals of the patient more than the goals of health-care professionals
3. Fitting health into the ongoing work and processes of one's life

Examples of personal topics include:

- Managing life at home, such as recovering from medical treatments and procedures, household responsibilities, caring for children/parents, legal issues, financial issues, insurance issues
- Managing work life, such as interacting with coworkers, colleagues, or clients about one's health situation, managing one's workload during treatment, deciding whether to work during treatment

- Managing one's emotional response to illness, such as dealing with feelings, facing fears, or depression
- Managing interactions with one's social network, such as telling (or not telling) friends or family members about your health situation, keeping others up to date on your situation, getting help from others, such as a ride to treatment or help with household chores
- Managing personal tasks and projects, such as hobbies, lifestyle activities, diet, self-care, taking vitamins, massage, finding a wig
- Managing advocacy and volunteer work, such as fundraising

### **Both Medical and Personal (T.B)**

Code T.B applies to content units that have a main topic that is shared pretty equally between issues that are medical and personal in nature as described above. Features that suggest a content unit is both medical and personal in nature include a topic that relates to:

1. Patient activity that occurs both inside and outside of the health-care system
2. The goals of the patient and health-care professionals equally

Examples of topics that are both medical and personal include:

- Managing insurance paperwork with health-care providers, such as referrals
- Coordinating treatment scheduling with schedule of work or personal activities
- Communicating medical concepts to social network

## **II. Recommendations**

A recommendation is a piece of advice that acts as a suggestion for dealing with a personal health issue, such as solving a problem. Every content unit is assigned one or more recommendation. There are four major types of recommendations: action

strategies, recommended knowledge, suggested approaches, and information resources.

### **Action Strategies (R.AC)**

Code R.AC applies to recommendations for action strategies, or ‘things to do’. Action strategies refer to recommended actions (e.g., low-level tasks) that one can take to help deal with a personal health situation. I considered recommendations that offered low-level, specific, and actionable tasks as ‘action strategies’ that can contribute towards solving a problem. Factors suggestive of action strategies include:

1. A physical activity
2. A task to complete
3. Step(s) to take
4. Directions for completing a task
5. A procedure

If an action strategy is in reference to an information resource (e.g., recommendation to read a book), then this recommendation is coded as an Information Resource (R.IN)

Examples of action strategies are:

- Prescriptive: “You should do...”
  - Get a second opinion
  - Talk to your doctor
  - Find a wig shop
  - Ask yourself the following questions...
- Personal story: “Let me tell you about what *I did* when I was in your situation...”
  - I set up a modified work schedule during treatment
  - I brought a list of questions to my appointment
  - I used vitamin B
  - I took an exercise class

### **Knowledge (R.KN)**

Code R.KN applies to recommendations for ‘things to know’. Recommended knowledge refers to informative facts and opinions that one can learn about to help them deal with a personal health situation, such as working through questions about one’s pathology report. Unlike action strategies, I considered recommendations that described concepts or ideas that one can come to learn and understand as ‘recommended knowledge’. Factors suggestive of recommended knowledge are:

1. A ‘factoid’, explanation, or description of a concept or process
2. Something important to know about
3. An opinion
4. Findings from research studies in which the source material is not referenced\*
5. A definition for a term
6. Encyclopedic-like description of a concept

\*If recommended knowledge is associated with two or more bibliographic details that would enable someone to obtain a referencing source (e.g., journal article), then this recommendation is coded as an Information Resource (R.IN).

Examples of recommended knowledge include:

- Prescriptive: “You should know about...”
  - Description of a process, treatment, or procedure (e.g., something found on Wikipedia (<http://www.wikipedia.org>) or MedlinePlus (<http://medlineplus.gov>))
  - A list of side effects or symptoms
  - Results from a research study indicating the risk of recurrence
  - Uncertain knowledge (e.g., “My understanding is that ...”; “You should probably expect the procedure to go something like this...”; “Usually chemo is given after surgery ...”; “I think it happens because...”)
  - Informal ideas about good practices, which might or might not be widely accepted

- Personal story: “Here is what happened to me when I was in your situation...”
  - Sharing a personal story about how a situation was experienced (“This is what happened to me...”)
  - “Every clinic is different, but where I got my therapy the procedure was done like this...”

### **Perspectives (R.AP)**

Code R.AP applies to recommendations that reflect ‘ways of believing or approaching situations’. Perspectives refer to recommended belief systems, attitudes, or philosophies that drive an overarching approach for dealing with a personal health situation, such as coping with emotions. In contrast to action strategies, I considered recommendations that reflected high-level and generalized beliefs or attitudes towards an overarching experience as ‘perspectives’. Factors suggestive of recommended perspectives are:

1. Approaches to life
2. Perspectives on situations
3. Believe systems
4. Attitudes towards situations

Examples of recommended perspectives include:

- Prescriptive: “You should approach it this way...”
  - Think positively
  - Be your own best advocate
  - Be patient
  - Be open to change
  - Slow down
- Personal story: “I approached the situation this way...”
  - I always kept an open mind
  - I allowed myself to process the information fully before deciding

**Information Resources (R.IN)**

Code R.IN applies to recommendations that point to ‘things to obtain and use’. Information resources refer to recommendations for obtaining and using specific tools and tangible artifacts to deal with a personal health situation. Factors suggestive of information resources are:

1. A tangible resource
2. An artifact that you obtain, use, and/or share

Examples of information resources include:

- Books
- Contact information (e.g., addresses and phone numbers)
- Magazines & magazine articles
- Multimedia (e.g., figures, pictures, graphs, interactive programs, animation, audio files, videos)
- Newspapers & news articles
- Poems & quotes (e.g., personalized letters, inspirational quotes, quotes from scripture, and songs)
- Academic journals & research articles (e.g., references to articles with at least 2 bibliographic details)
- Templates (e.g., survey, self-tests, fill-in charts, forms, tables, lists, or checklists.
- Web pages
- Miscellaneous publications (e.g., conference papers not published in proceedings, white papers, booklets, pamphlets, catalogs, recipes)

## Reliability Testing

Inter-observer Reliability testing of the coding procedure for Aim 1 of this thesis followed the design for reproducibility described by Krippendorff (2004). The goal of reliability testing was to determine the degree to which the content analysis from Aim 1 can be replicated. A test-test condition compared inter-observer differences from two independent coders who applied the same coding instructions to the same sample of content units (i.e., “reliability data set”). Although an accuracy design is stronger than a reproducibility design, no accuracy (i.e., ‘gold’) standard is available for this content analysis.

Two observers applied codes for reliability testing, including myself (AC) and a second observer (CL) whom I selected based on the following criteria: previous qualitative coding experience, not a member of my immediate research group, and does not specialize in consumer health informatics. Thus, I selected an experienced coder who did not make routine use of nomenclature or constructs that mirror those I use.

Reliability testing was conducted on 10% of the data (i.e., “reliability data set”), which provides a minimal standard to enhance trustworthiness of the content analysis based on degree of reliability (see table 11.2 in Krippendorff, p. 240). I randomly selected content units for inclusion in the reliability data set for representation across the entire corpus. Each possible coding category was represented in the reliability data set.

Kappa scores were calculated to determine the level of inter-coder agreement on the reliability data set. I applied linear weighting (Lowry, 2008) to the Kappa calculations for recommendations to account for the level of agreement between

coders for both types and numbers of recommendations (i.e., coders could assign multiple types and numbers of recommendations to each content unit).

## **Coding Instructions**

The goal of coding is to characterize patient expertise by analyzing and coding individual “content units” (i.e., recording unit of analysis). For message boards, a content unit is defined as a thread. For books, a content unit is defined as a titled subsection within a chapter.

Patient expertise reflects “informational support” that appears in a content unit, which is defined as *the exchange of information or advice used to guide or advise* (Helgeson & Cohen, 1996). More specifically, informational support manifests when one or more recommendations are offered to deal with some situation (e.g., to solve a problem).

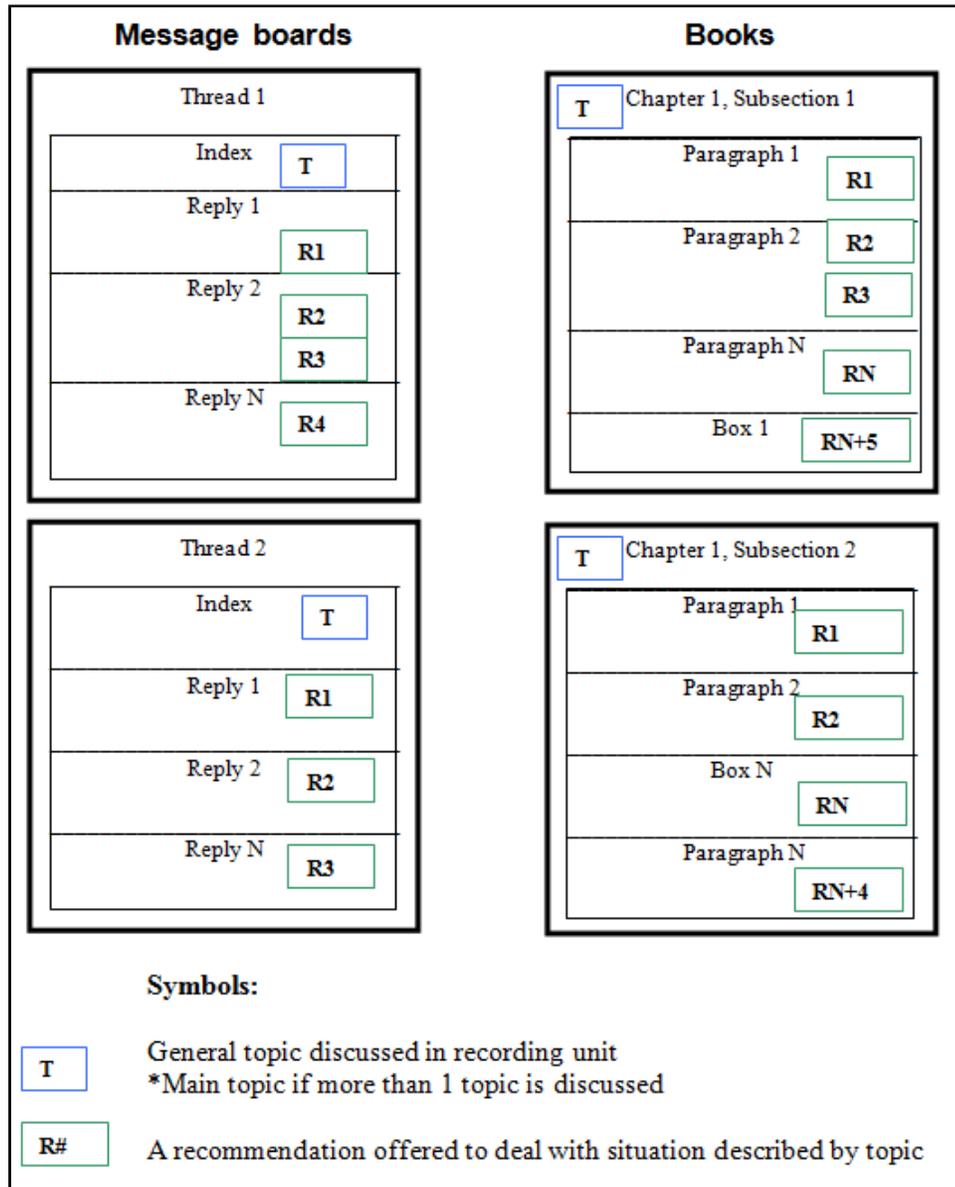
In message board sources, informational support generally manifests when one user initiates a thread by posting a description of the situation they are facing and asks for advice from others for dealing with that situation. The initiating post of a thread is referred to as the thread’s ‘index message’. Then, other users post recommendations in reply to the index message (i.e., ‘reply messages’). Informational support can also manifest when a user posts recommendations for dealing with a particular situation in the index message in the absence of a message from another user who seeks advice. Informational support in book sources follows this latter pattern.

Each content unit is treated as one instance of informational support. Each instance of informational support is associated with 1 topic and 1 or more recommendations. Definitions for topics and recommendations are provided below. A mapping between content units appearing in message board and book sources is shown in Figure A.1 to

illustrate the concepts of content unit, topic, and recommendation, and how they play out in both types of sources.

**Topics:** The topic of the content unit is the predominate phenomenon discussed in a thread (i.e., message boards) or described in a subsection of a book chapter. The topic can be thought of as the essence of the situation discussed or described. Useful clues in message boards for identifying the main topic of the thread include the subject line and the description of the situation in which a user seeks or offers advice in the index message. There are two overlapping categories of topics: medical, personal, or both medical and personal. For every content unit, code one main topic from the coding categories “T.M”, “T.P”, and “T.B”

**Recommendations:** A recommendation is defined as advice, a tip, or a suggestion, that is either explicit (via a prescriptive command) or implicit (via a personal story), for dealing with the situation described by the topic of the content unit. A recommendation does not incorporate emotional support offered by the provider (e.g., ‘I wish you well’, ‘I understand how you feel’). Instead, a recommendation reflects informational support by suggesting action on the part of the receiver (e.g., the receiver should *do*, *know*, *try*, or *obtain* something). There can be one or more recommendation present in every content unit, each of which corresponds to the topic discussed. Recommendations can be thought of as bits of advice that are offered to deal with the situation described by the content unit’s topic. Typically, recommendations are found within reply messages on message boards. There are four major types of recommendations: action strategies, recommended knowledge, suggested perspectives, and information resources. For every content unit, code every recommendation that appears, which can range from 0 to many, from the coding categories “R.AC”, “R.KN”, “R.AP”, and “R.IN”.



**Figure A.1. Mapping between Informational Support in Content Units from Message boards and Books**



## *Appendix B*

### **Interview Guide for Field Study**

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Alternative questions for coding categories included:

#### **(1) Identifying instances of patient expertise sharing**

- *Tell me about how all of this (breast cancer experience) got started. (the participant volunteers an instance without prompting as they tell their story)*
- *Tell me about a time when you had a question or a problem that you felt that someone who had 'been there before' might be able to help*
- *Tell me about a time when you used advice that you had received from someone who had been through this before*
- *Tell me about a time when you wanted to give someone advice based on your experience with that problem*
- *For which questions/problems have you thought it would be helpful to talk with someone who's been through it?*

#### **(2) Value of Patient Expertise sharing**

- *Why did you look for (or give) help for that problem/question?*
- *Why was it useful to get help for that question/problem from someone who has 'been there'?*
- *Why was it useful for you to give help for that question/problem?*
- *When/how did sharing advice help?*
- *Why/how was the advice you received helpful?*
- *Why was it helpful for you to give that advice?*
- *Why is sharing advice helpful?*
- *How was that information helpful for you?*

**(3) Patient Expertise Location****(a) Expertise identification**

- *How did you come to find out about [source X]?*
- *Have you looked for anyone/anything else for help?*
- *Tell me about the different places you have looked and/or people you have asked for help?*

**(b) Expertise selection**

- *What is it about [source X] that makes it/them a good resource for you?*
- *What is it that makes you trust [source x]?*
- *How did you know to go to [source x]?*
- *How well did the advice fit your own situation?*

**(c) Repairs in expertise locating**

- *Tell me about the advice you received from [source X] (i.e., what is it)*
- *How do you keep that advice? (e.g., in your head, written down, etc)*
- *Tell me about how you remembered to use that advice*
- *How easily were you able to follow that advice?*
- *Were you able to use the advice right away or did you need to make some changes to it or hunt around for more help?*

**(4) Patient Expertise Provision**

- *When has someone asked you for advice because of your experience?*
- *When did you feel that you had important advice you wanted to give to others?*
- *Tell me about some of the ways you give advice to others who are dealing with that problem*

**(5) Barriers to Patient Expertise Sharing**

- *What advice would you like to receive from/give to other people dealing with this experience but don't feel you are able to?*
- *What makes sharing advice with others in your situation hard?*
- *Are there things about sharing advice with others in your situation that aren't so good?*
- *What kinds of things might help make sharing advice easier?*
- *Were there things that made that hard?*



## *Appendix C*

### **Focus Group Protocol**

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**Paperwork:** Consent & demographic survey

~10 min

**Overview:** Motivation and today's goal

~5 min

- People develop personal health expertise through their breast cancer experience
- We are developing technology to help people share this knowledge with each another
- Our initial design helps people connect and share on the Internet
- Are we heading in a useful design direction? How can we enhance our design effort?

**Group Introductions**

~15 min

- Have you ever used an online community? (e.g., support group, discussion forum?)
- Describe a time when you exchanged advice (i.e., sought or provided) with another patient
  - o What was the advice for?
  - o Who did you considered asking/telling?
  - o Did you approach anyone? Why?

**Storyboarding**

~20 min

- Our initial design of the patient expertise locator
- In what situations could this tool be useful given your experience?

<< Break >>

~10 min

**Profile sorting**

~20 min

- Exploring people available for advice through profiles: Who should Lily approach?
- What make someone a good person to approach for advice?

**Designing to “find” other people**

~10 min

- Design options for discovering helpful people
- Other options? What about privacy? Trust? Control?

**Designing to “approach” or “be approached by” others**

~10 min

- Design options for connecting with people to share advice
- Other options? What about privacy? Trust? Control?

**Wrap up**

~5 min

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- 2009** Ph.D. in Biomedical & Health Informatics  
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- 2009** Civan, A., McDonald, D.W., Unruh, K.T., & Pratt, W. (2009).  
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- 2006** Civan, A., & Pratt, W. (2006). Supporting Consumers by Characterizing the Quality of Online Health Information: A Multidimensional Framework. In *Proceedings of the 39th Annual Hawaii International Conference on System Sciences (HICSS)*. January, 2006, Kauai, HI, p. 88a. (Best paper award nomination)
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- Civan, A., Skeels, M.M., Stolyar, A., & Pratt, W. (2006). Exploring Personal Health Information Management. National Library of Medicine Informatics Training Conference 2006, Nashville, TN, p.41.
- 2005** Civan, A., Teller, D.Y., & Palmer, J. (2005). Relations between Spontaneous Preferences, Familiarized Preferences, and Novelty Effects: Measurements with Forced-Choice Techniques. *Infancy*, 7(2), 111-142.
- Civan, A., Doctor, J.N., & Wolf, F.M. (2005). What Makes a Good Format: Frameworks for Evaluating the Effect of Graphic Risk Formats on Consumers' Risk-Related Behavior. In *Proceedings of the AMIA Annual Fall Symposium*. October, 2005, Washington, DC, p. 927.
- 2004** Civan, A., & Pratt, W. (2004). Online Health Information: Multiple Dimensions of Quality. In *Proceedings of the 11<sup>th</sup> World Congress on Medical Informatics (MEDINFO)*. 2004, San Francisco, CA, p.1557.
- Civan, A., & Pratt, W. (2004). Health information on the World Wide Web: A Multidimensional framework of Quality. National Library of Medicine Informatics Training Conference. 2004, Indianapolis, IN, p.58
- Teller, D.Y., Civan, A., & Bronson-Castain, K. (2004). Infants' Spontaneous Hue Preferences are not Due Solely to Adult-like Brightness Variations. *Visual Neuroscience*, 21(3), 397-401.
- 2003** Civan, A.L., Teller, D.Y., & Palmer, J. (2003). Infant Color Vision: Spontaneous Preferences versus Novelty Preferences as Indicators of Chromatic Discrimination among Suprathreshold Stimuli. *Journal of Vision*, 3(9), 712a.
- Teller, D.Y., Pereverzeva M., & Civan, A. (2003). Adult brightness vs. Luminance as Models of Infant Photometry: Variability, Biasability, and Spectral Characteristics for the Two Age Groups Favor the Luminance Model. *Journal of Vision*, 3(5), 333-46.

Teller, D.Y., Civan, A., & Bronson-Castain, K. (2003). Are Infants' Spontaneous Hue Preferences Determined by Saturation Differences? 17th Symposium of the International Color Vision Society, Seattle, WA.

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**1997** Lia, B., Dobkins, K.R., Hartzler, A., Palmer, J., & Teller, D.Y. (1997). Three-month-old Infants Respond to Quadrature Motion of Isoluminant Gratings. *Perception*, 26(6), 760.

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Peterzell, D.M., Chang, S.K., Kelly, J.P., Hartzler, A.L., & Teller, D.Y. (1997). The Development of Spatial Frequency Covariance Channels for Colour and Luminance: Psychophysical (FPL) and Electrophysiological (sweep VEP) studies. *Perception*, 26(6), 759.

## AWARDS & HONORS

**2008** Biomedical & Health Informatics Research Training Travel Award  
**2007** Nomination for Distinguished Paper Award at AMIA:  
 Civan, A., & Pratt, W. (2007). Threading Together Patient Expertise, In *Proceedings of the AMIA Annual Fall Symposium*. November, 2007, Chicago, IL, p. 140-144.  
**2007** University of Washington GSFEI Graduate Student Travel Award  
**2006** Nomination for Best Paper Award at HICSS:  
 Civan, A., & Pratt, W. (2006). Supporting Consumers by Characterizing the Quality of Online Health Information: A Multidimensional Framework. In *Proceedings of the 39th Annual Hawaii International Conference on System Sciences (HICSS)*. January, 2006, Kauai, HI, p. 88a.  
**2006** University of Washington GSFEI Graduate Student Travel Award  
**2003-2006** National Library of Medicine Predoctoral Training Fellowship  
**1996** Elected to Phi Beta Kappa National Honor Society  
**1995** Golden Key National Honors Society

- 1995** National Dean's List  
**1995** Psi Chi National Honor Society  
**1992-1996** Dean's List, University of Washington, Seattle, WA.

## **EDITORIAL EXPERIENCE**

- 2008-2009** JAMIA Student Editorial Board

### **Ad Hoc Reviewer for the Journals:**

- 2008** Communications of the ACM (CAIS)  
**2007** Journal of the American Society for Information Science and Technology (JASIST)  
**2007** Transactions on Information System, Special Issue on Personal Information Management  
**2007** Methods of Information in Medicine  
**2007** European Journal of Information Systems (EJIS), Special Issue on "Healthcare Information Systems Research, Revelations and Visions"  
**2006** e-Service Journal, Special Issue on "e-Health"

### **Reviewer for the Conferences:**

- 2009** International Workshop on Personal Information Management (PIM)  
**2007-2009** American Medical Informatics Association (AMIA) Fall Symposium  
**2006-2009** Hawaii International Conferences on System Sciences (HICSS)

## **PROFESIONAL MEMBERSHIPS**

- 2008-present** American Society for Information Science and Technology (ASIS&T)  
**2003-present** American Medical Informatics Association (AMIA)

## **TEACHING RESPONSIBILITIES**

- 2008** Guest lecture, MEBI 498, The Personal Health Approach to Health Informatics, University of Washington  
**2008** Guest lecture, MEBI 537, Qualitative Methods in Biomedical and Health Informatics, University of Washington  
**2007** Instructor, MEBI 591, Personal Health Informatics Seminar, University of Washington

- 2007** Guest lecture, INSC 310, Individual Perspectives on Information Systems, University of Washington
- 2006** Guest lecture, INSC 498, Special Topics in Informatics: Personal Information Management, University of Washington

**VOLUNTEER ACTIVITIES**

NSF IDM Conference, September 14-16, 2003, Seattle, Washington

NSF Invitational Workshop on Personal Information Management, January 27-29, 2005, Seattle, Washington

SIGIR, PIM Workshop, August 10-11, 2006, Seattle, Washington

ASIS&T Annual meeting, October 24-29, 2008, Columbus, Ohio

**STUDENT ADVISING**

- 2005-2006** Amelia Lacenski, undergraduate advisee  
Grace Preyapongpisan, undergraduate advisee