

A Shared Interface to Improve Oncologist-Patient Communication

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Abstract—Patients recently diagnosed with cancer require information from their oncologist to further educate themselves about their disease, their course of action, side effects, and possible treatment plans and options. However, disagreements on the information discussed in these meetings indicate that patients and physicians leave with different ideas of the content of their discussions, leading to confusion on the part of the patient, and potentially leading to future problems in the course of treatment. With the increasing use of pervasive technologies in the medical environment, there is great potential to augment communication strategies in facilitating better care. In this paper, we propose a solution utilizing a shared mobile device to supplement patient-physician communication during cancer discussions. In particular, we present an application that personalizes the content presented on the device to the patient’s diagnosis in a easy-to-understand language, rather than hard-to-understand medical terminology, and encourages patient-physician interaction on the main topical areas of a patient’s diagnosis.

I. INTRODUCTION

Patients diagnosed with cancer have important communication needs that require the attention of the physician to provide effective treatment, especially due to the fact that the time period following diagnosis is when the patient is most emotionally vulnerable. While it is assumed that the oncologist will better convey to patients the severity of their illness and course of action for treatment in the first meeting following diagnosis, findings on the information discussed in these meetings show that in dyadic environments, both patients and physicians leave these discussions with a disagreement on the information effectively communicated during the meeting [1]. These meetings have potential implications on the future treatment of the patient. Positive influences, including patient confidence resulting from discussions with physicians, have been shown to have effects on future outcomes (such as the decision making, approach to treatment, and patient-physician trust) especially due to misunderstandings [2], [3]. Typically during such meetings, five topical areas are discussed, including the patient’s diagnosis, prognosis (likely outcome of an illness), metastasis (likelihood of a disease spreading), goals, and potential side effects of treatment [1]. However, due to varying levels of education and emotional state, it is suggested that each respective party may interpret these discussions differently.

While oncologists typically provide patients with support documentation to follow their discussion, much of the information consists of generalized pamphlets that may not be particularly personalized to the treatment of a patient, and may not be helpful in building confidence in the patient as they begin treatment. With the increasing use of technology in the healthcare industry by researchers and practitioners, capable methods to supplement treatment, patient-physician communication, and support options have become much more widespread. In particular, there has been increased interest in how mobile technologies such as shared devices can aid in facilitating patient-physician communication, such as the shared device created by Ni and Karlson [4]. Inspired by this work, we propose a solution utilizing a shared mobile device to aid in facilitating patient-physician communication in a language and format that is easy for the patient to understand, as well as personalized to their treatment plan. This implementation further serves to support patient treatment by guiding patient-physician communication and discussion through a shared display, and generates a take-home document personalized for the patient based on the information discussed.

II. MOTIVATION AND BACKGROUND

Studies show that effective patient-physician communication has a positive correlation with patient outcomes [3]. As such, research in the area of oncological discussion shows potential problems and implications resulting from information disagreements in patient-physician communication. Studies were performed via interviews with patients and oncologists following their second meeting, in which each party was questioned on their understanding of the aforementioned discussion topics. The results of one study showed that in both dyadic and triadic discussions, patients, companions, as well the physician were equally likely to be sources of disagreements [1]. Of the five topical areas typically discussed in the meeting following a patient’s diagnosis (diagnosis, prognosis, metastasis, goal of treatment, and side effects), the topic of diagnosis itself showed higher correlation for agreement, while other areas of discussion such as side effects were much lower. The results found that a patient’s understanding of their discussion diverged largely

from that of the physician's in topics other than diagnosis, indicating potential problems in the oncologist's interpretation of their meeting with the patient. Furthermore, patients and companions rated their understanding of these oncological discussions better than oncologists estimated, potentially having an impact on the information oncologists discussed due to this assumption [1].

Other work focusing on the complexity of oncological discussions reveal difficulties in conveying information to meet patient satisfaction in a manner that is on par with the psychological state of the patient [5], [2]. In some instances, certain individuals require less information than others, particularly in respect to patient prognosis and severity of the disease, which potentially has an impact on the manner that information is presented in oncological discussions. In this work, definitions of "good" and "bad" news were found to be dynamic from patient to patient, with certain individuals having a particular tolerance for "worse" news than others. In either case, however, a significant portion of patients continued to feel that their communication needs were unmet, particularly in relation to treatment related information, prognosis, and adverse side effects [2]. This has a direct impact on the manner information is presented to the patient, which could potentially be improved by personalizing information in particular to the patient's diagnosis and prognosis.

Further research in the area of these discussions reported higher patient satisfaction with oncological discussions as a result of physician attentiveness and empathy. Furthermore, these attributes show a positive impact on patient self-confidence, self-efficacy, as well as aided in improving the emotional state of the individual. In contrast, the study also showed an overall dissatisfaction in patient-physician communication with oncologists who were not able to accurately assess patient satisfaction [5].

Some of the complications that result from poor patient-physician communication can be improved using information technology. Research assessing information technology in patient-physician communication currently exists that show positive effects in patient understanding with useful implementations of devices, including interfaces for displaying medical images [6], [4]. Other work looking at improving patient-physician participation show that computer devices and workstations designed to facilitate patient participation, such as computers on wheels (computers capable of being moved about the exam room for promoting communication), further engage patients to take a more active role in their interactions with physicians and their health [7].

Similarly, research focused on user experience design convey the added requirement for systems utilized in specific settings, such as hospitals and medical environments, to address the needs of the secondary user experience (i.e., those

not necessarily using the computer, but are affected by it). In particular, people that are impacted by these interfaces (such as patients) need better ways to view images and details that may be pertinent to their understanding [8], [9]. Designers should include aspects such as secondary user feedback and language tailored to the secondary user to better provide feedback and facilitate patient communication. For example, some of these aspects are present in work relating to physical therapy, in which a projection-based handheld device is used to aid in facilitating patient-physician communication [4].

III. CONTEXTUAL INQUIRY

To better understand the current state and process of patient-oncologist discussions, we conducted a contextual inquiry with an oncologist with over 20 years of experience in the field to identify complications realized in the communication process, as well as discover key concepts that may be helpful in facilitating doctor-patient communication. In particular, the oncologist revealed the overall manner of the discussion varied in relation to the type of individual, as well as the severity of their diagnosis. Several factors played a role in how the information was relayed to the individual, including age, level of education, quality of support, and personality of the individual, among others. In the oncologist's experience, elderly patients most often were interested in the nature of their treatment and their recommended plan of action, whereas younger patients tended to be more questioning of various topics relating to their illness.

The severity of a patient's diagnosis also has an impact on the nature of the discussion. During a patient's diagnosis, they are assigned a stage level of one through four, depending on severity. Depending on this stage, the type of cancer, as well as the patient's prognosis and metastasis, a patient may either be assigned a curative or palliative treatment plan. In respect to each type, curative treatment plans aim to eliminate a disease or illness, while palliative treatments focus more on alleviating or preventing discomfort or suffering of patients. In certain types of cancer, even in later stages, treatment plans may be very standardized (such as colon cancer), whereas others may have various manifestations (such as multiple myeloma, a cancer of plasma cells). Plans may be further complicated by a patient's current health status and history. Thus, each conversation must be tailored to meet each particular patient's needs, perhaps even during the meeting depending on a patient's reaction to news or handling of the discussion.

In such cases, the presentation of the material must be carefully described or issued such that it does not overwhelm the patient. One example the oncologist described was referencing an image or informational poster of cancer of a particular part of the body. For some cases, patients may find this information helpful and beneficial to understanding more about their illness, while others may view it as too much

information. Thus, these considerations need to be taken into account based on the emotional state and level of comfort interpreted by the oncologist during the discussion. As an augmentation, the oncologist believed these images could be even more beneficial as a visual aid if they were able to be personalized to the individual (such as their x-rays, mammograms, etc.) depending on the type of individual and the state of their condition. The main reason these items were not currently used during these consultations were due to technological constraints.

Furthermore, when questioned regarding items patients usually leave with from the discussion, the oncologist personally felt generic pamphlets were not particularly useful in-relation to the patient's understanding. The oncologist instead typically writes personalized notes, which include items such as the scientific name of the disease and trusted cancer information websites (such as the National Cancer Institute and the American Society of Clinical Oncology), which the patient can take home for reference.

IV. SYSTEM DESCRIPTION

Based on this discussion and the aforementioned literature reviews, we developed the concept of a personalized check list implemented in a shared display. Such a list allows for both parties to follow along during their discussion and provide personalized information that could then be given to the patient in printed format as their take-away. In this manner, patients would easily be able to reference topics as discussed in the meeting in an easy to understand language that is suited to their diagnosis and needs. The tablet interface will offer a view of their personalized list of discussion topics tailored to the diagnosis of the patient in the patient's language. Thus, the doctor and patient will be capable of proactively discussing topics of interest as they progress through their interaction, with the interfaces serving as a guide for their discussion.

In addition, the patient's secondary view will enable the physician to show images and highlight specifics relating to the treatment of the patient. The five main topical areas will be provided as requirements of the discussion including: diagnosis, prognosis, metastasis, goals of treatment, and side effects. Other topics, including treatment options and specifics relating to the individual may also be included. As both patients and physicians advance in their discussion, both physicians and patients will be capable of "checking off" topics covered in their discussion, and patients can choose to refrain from "checking off" topics they feel do not satisfy their expectations. This is advantageous in allowing patients the opportunity to gather as much information as possible on the course of action and treatment plan provided by the doctor, as well as provide a guide for the main topical areas of their discussion.

The content of the discussion will be tailored by the oncologist prior to the meeting with information most pertinent to the patient. As such, the application will provide areas doctors can upload images relating to the type of cancer and status of the patient (such as scans), as well as alter items based on the patient's diagnosis and prognosis. This is beneficial to the oncologist in the fact that personalized information based on the patient's diagnosis and will provide better information to the patient as well as promote confidence and trust in patient-physician interaction. Furthermore, data presented in this manner will help satisfy the information needs of patients in an easy-to-understand language that may promote improved confidence in their treatment plan and decision making process.

In addition to the improved information presentation, our application will also include support for document printing, where upon completion of an oncological discussion, patients and physicians can "check off" their discussion as complete, and oncologists can print documentation of the meeting while providing a copy personalized to the needs of the patient. This is beneficial to the patient in that their take-home information is personalized and relates directly to the information communicated in their cancer discussion rather than generic informational pamphlets. The document is also helpful in ensuring patients understand their treatment plan, potential side effects of treatment, prognosis, as well as provides the overall discussion on record in an easy-to-understand format. Doing so may also impact patient satisfaction with the communication and information discussed in oncological meetings, potentially improving the patient-physician relationship so that better informed healthcare decisions can be discussed and made.

V. CONCLUSION

The increasing pervasive nature of technology in the medical environment has an influence on the way information can be presented to patients, potentially improving communication between patients and physicians if implemented in a useful manner. This influence can be particularly useful in oncological discussions where patient-physician disagreements in communication occur, creating confusion on the part of the patient while potentially having an impact on treatment. In taking secondary user design considerations into account, our mobile device platform can be useful in promoting improved patient-physician discussion and can be beneficial in improving understanding between both parties. Furthermore, we can improve the documentation and language presented to the patient during and following discussions to address their communication needs, improve the patient-physician relationship, and provide easy personalization of healthcare communication.

VI. FUTURE WORK

We plan to design workshops for local oncologists and cancer patients to incorporate stakeholder design considerations while developing our platform in an iterative approach. We also plan to conduct further contextual inquiries with oncologists in different geographical areas to see how variations in discussions may occur, as well as with nurse practitioners who also aid doctors in follow-up discussions with patients. We will use this feedback to improve upon designs as well as determine effective strategies that aid in improving patient-physician communication in oncological discussions. Furthermore, we subsequently intend to develop and begin testing our system in oncology clinics for insight into the effectiveness of our platform in improving clinical communication, taking feedback from use cases to improve upon our overall system as a supplement to these discussions.

REFERENCES

- [1] S. Eggly, L. Penner, N. Hagiwara, R. Gonzalez, F. Harper, E. Heath, and T. Albrecht, "Patient, companion, and oncologist agreement regarding information discussed during triadic oncology clinical interactions," *Psycho-Oncology*, 2012.
- [2] T. F. Hack, L. F. Degner, and P. a. Parker, "The communication goals and needs of cancer patients: a review." *Psycho-oncology*, vol. 14, no. 10, pp. 831–45; discussion 846–7, Oct. 2005.
- [3] M. A. Stewart, "Effective Physician-Patient Communication and Health Outcomes: A Review," *Canadian Medical Association Journal*, vol. 152, no. 9, pp. 1423–1433, 1995.
- [4] T. Ni and A. Karlson, "AnatOnMe: facilitating doctor-patient communication using a projection-based handheld device," *Proceedings of the 2011 annual conference on Human factors in computing systems*, pp. 3333–3342, 2011.
- [5] R. Zachariae, C. G. Pedersen, a. B. Jensen, E. Ehrnrooth, P. B. Rossen, and H. von der Maase, "Association of perceived physician communication style with patient satisfaction, distress, cancer-related self-efficacy, and perceived control over the disease." *British journal of cancer*, vol. 88, no. 5, pp. 658–65, Mar. 2003.
- [6] G.-M. Breen, T. T. H. Wan, N. J. Zhang, S. S. Marathe, B. K. Seblega, and S. C. Paek, "Improving DoctorPatient Communication: Examining Innovative Modalities Vis-à-vis Effective Patient-Centric Care Management Technology," *Journal of Medical Systems*, vol. 33, no. 2, pp. 155–162, Jun. 2008.
- [7] Y. Chen, V. Ngo, S. Harrison, and V. Duong, "Unpacking exam-room computing: negotiating computer-use in patient-physician interactions," in *Proceedings of the 2011 annual conference on Human factors in computing systems*. ACM, 2011, pp. 3343–3352.
- [8] O. Alsos and D. Svanæs, "Designing for the secondary user experience," *Human-Computer Interaction, INTERACT 2011*, pp. 84–91, 2011.
- [9] L. Wilcox, D. Morris, D. Tan, and J. Gatewood, "Designing patient-centric information displays for hospitals," in *Proceedings of the 28th international conference on Human factors in computing systems*, ser. CHI '10. New York, NY, USA: ACM, 2010, pp. 2123–2132. [Online]. Available: <http://doi.acm.org/10.1145/1753326.1753650>
- [10] A. Back, R. Arnold, B. Walter, J. Tulsy, and K. Fryer-Edwards, "Oncotalk: Improving your communication skills," Feb 2012, <http://depts.washington.edu/oncotalk/>.
- [11] PCORI, "Patient-centered outcomes research," Apr. 2012. [Online]. Available: <http://www.pcori.org/patient-centered-outcomes-research/>