

Navigating Risk Communication Amidst Clinical Uncertainty: Physician Perspectives of Patient Interactions

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Received date: February 22, 2014, Accepted date: February 23, 2014, Publication date: March 1, 2014

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Abstract

Objective:

Communicating risk to patients can be a rather complex process given how subjective and variable its application can be by individual physicians. This is further complicated when the nature of the evidence characterizing the situation is conflicting, unknown, or evolving. This project explored how physicians conceptualize risk communication in the field of cancer care and how they attempt to effectively convey risks to their patients under situations of uncertainty.

Materials and Methods:

Family physicians (n=6) and oncologists (n=8) were interviewed using a series of qualitative semi-structured interviews guided by a process of convergent interviewing to facilitate the exploration of key concepts. Data were analyzed using NVivo9TM. Conclusions were generated based on an examination of areas where participants converged and diverged, and exploring the implications of these within the small sample.

Results:

Ideal risk communication included involving the patient in the decision making process, educating the patient, ensuring patient understanding, having the patient accept any uncertainty present and thus accepting the possible associated risks, and allowing the patient time to process the information. There was discordance regarding whether physicians should participate in shared decision making with their patients, or inform patients and then allow them to come to their own decision. Most physicians also expressed apprehensions about the process, largely in terms of whether or not patients could understand and interpret the information being presented competently enough to be truly informed about the decisions being made.

Conclusions:

Physicians utilized similar techniques when discussing clinical risks with their patients, yet there was a lack of standardized approaches and the process was highly individualized. In these high uncertainty situations, physicians expressed significant unease regarding the efficacy of these discussions.

Keywords: Qualitative; Convergent interviewing; Uncertainty; Risk communication; Risk; Physicians-patient interaction; Cancer

Introduction

The physician-patient relationship continues to evolve, accompanied by a lack of understanding regarding how subtle differences in these interactions can affect patient care. Historically, the physician-patient interaction had been a paternalistic one. Paternalism describes the classic scenario of a physician making clinical decisions without involvement or input from the patient [1-3]. This level of paternalism is not dissimilar to how experts, involved in the production of risk assessments, have been criticized over the evolution of risk communication as a field of inquiry [4,5]. Nowadays

assuming a paternalistic approach is seen pejoratively, implying a lack of acknowledgement of patient autonomy and often assumed lower levels of patient satisfaction [6-9]. The recent trend for clinical decision making now falls along a spectrum between informed decision making and shared decision making, both implying varying degrees of involvement of the patient in the process [1,10], or at least acknowledging that patient preferences in how decisions get made is important [11-14]. With this evolution in the way clinical decisions are getting made, the area of health risk communication has also become increasingly complicated. Cancer care provides a unique context for discussing these risks due to the magnitude of the decisions which get made and the overwhelming lack of scientific evidence which can be applied to the decision making process [15,16].

Informed consent, the concept of requiring the patient to agree to the actions being suggested by the physician, evolved as a way of protecting patient autonomy. Intrinsic to this process is an exchange of information between the physician and the patient, including a discussion of associated risks (or harms) against potential benefits [17]. This process can be seen as relatively straightforward when the physician has clear, acknowledged risks and benefits to convey to the patient, though many would argue that these conversations may be complex in terms of the intrinsic and extrinsic factors which might influence patients in making these decisions [18-20]. While physicians in training are taught the tenants of informed consent, there is a still a significant degree of variability that exists in clinical practice [20-23]. If we expand these concepts to include situations with high degrees of clinical uncertainty, requiring the physician to communicate significant risk in the context of uncertain benefits, the process becomes even more complex.

The aim of this research was initially to address how physicians make clinical decisions despite encountering situations where evidence regarding outcomes is uncertain. Through discussions with physicians in this study, the complexity of risk communication in these situations became evident and this topic proved to be on the minds of many of the participants. Exchange of information with patients, including risk, ultimately affects the entire decision making process; thus having these conversations in an appropriate manner proved to be a significant concern for participants. As such, the way in which physicians address these conversations and perceive patients to understand them became an additional point of focus.

Materials and Methods

Participants were contacted from two separate medical disciplines. Family physicians were recruited by contacting all lead physicians associated with the Uniting Primary Care and Oncology (UPCON) Network of Cancer Care Manitoba (CCMB); a network of 53 primary care clinics within the province of Manitoba, Canada. Oncologists were recruited by contacting all medical oncologists, malignant hematologists, and radiation oncologists working at both Cancer Care Manitoba sites. Consent was obtained prior to beginning the interviews, which were audio recorded. Efforts to maintain physician anonymity were made by referring to the participants only as either "oncologist" or "family physician".

The physicians were asked ahead of time to reflect on a scenario which they had recently faced, or which particularly stood out to them, where they had felt a great deal of uncertainty while making a clinical decision. The domain of cancer care was preferentially requested as it provides a rich source of discussion regarding uncertainty and involves complex decision making processes, often with patients closely involved in coming to the final decision [15,16], as well as being part of a larger funded program of research [24]. A semi-structured interview guide had been prepared, yet the discussions were primarily driven by the material raised by the participants. In an attempt to provide additional material for discussion if time permitted and to collect a variety of opinions in the same clinical context, standardized scenarios were prepared in conjunction with a specialist from each field who did not participate in the interview process. Research ethics approval was obtained by the Health Research Ethics Board at the University of Manitoba (HREB#: H2010:194).

The project was designed using a convergent interviewing framework such that flexibility was permitted at the end of the natural

conversation with a participant to explore ideas raised by previous participants for comment/reflection [25,26]. This allowed participants to agree or disagree with issues raised during previous interviews, better characterizing multiple viewpoints while maintaining a manageable sample size. As data was collected and evaluated, the themes and key issues that arose from discussing participant viewpoints and behavior in this context became the focus of both the remaining interviews and the final qualitative analysis. NVivo9™, a qualitative data analysis program, enabled easier management of large data sets yet all analysis activities were researcher driven and directed. Responses were categorized into thematic ideas and queried (using advanced functionalities within the software of researcher-driven categories) against differences and similarities in responses between clinicians. In as many ways as possible best-practice protocols outlined elsewhere in the field of qualitative research to establish rigour in qualitative interviewing were followed [27,28].

Results and Discussion

Health risk communication, as a process, was not initially an explicit study aim. Nonetheless, it was fundamentally important to participants regarding how decisions are made when there are high levels of clinical uncertainty. The physicians who specifically addressed risk communication expressed some basic concepts for how it should be approached, as well as concerns they had with this exchange of information.

The pervasive theme while discussing risk communication was the involvement of the patient in the decision making process. Participants were unanimous that the patient should be involved, showing a preference for utilizing an informed or shared decision making process in situations with significant clinical uncertainty. They also identified the need to clearly communicate to the patient, at least within the bounds of available information, the risks associated with the different clinical options that may be available as a part of this process. However, there was little standardization in the ways in which physicians described approaching these consultations with their patients. Several core concepts were presented by the participants as ways to appropriately communicate risk and to hopefully ensure that these conversations are efficacious in informing their patients.

Education of the patient

The first key concept in communicating risk to a patient was educating the patient in terms of their health condition in the context of the decision to be made.

"You have to kind of allow the patient to understand that as well. You have to educate to a point. You can't educate with four years of medical school and these years of experience but you have to educate with what you know about things. That is where the knowledge of the literature is actually a really good thing." (Oncologist)

As implied by the physician above, medicine is a highly specialized and overwhelming body of knowledge which is taught over a series of years, and then continuously evolving throughout one's clinical practice. A physician's duty in the context of involving a patient in their own care is to be able to translate the important aspects of this vast body of knowledge into terms which can be communicated to a non-medical professional. Education of the patient is the cornerstone of providing informed consent or having patient involvement in the decision making process. Further, it aids in setting the stage for them to be able to understand the risks and benefits of any given

intervention. At a minimum, physicians must disclose enough information to satisfy “what a reasonable person would want to know before making a decision” [17].

Educating the patient regarding the decision being made was often seen by participants as the first step in a process of patient involvement. However, there is no specific requirement that patient involvement extends past this point in clinical practice for most types of decisions.

“You explain that to the patient and the risks that you’ve come up with are reasonable, then I think it’s okay.” (Oncologist)

In the context of clinical consultations, with an oncologist or a family doctor for example, there is no formal process requiring informed consent regarding the transfer of information every time a decision is made. It appears to be more of an ethical imperative for the physicians involved to ensure that patients understand their health care, also often with the hopes of this leading to greater patient satisfaction as an outcome [29,30]. When there is little clinical evidence to guide the decision making process, informing the patients of the risks and benefits and ensuring understanding as one would with a formal informed consent process seems to be more ethically appealing than simply making the decision for the patient.

Checking for patient understanding

As mentioned above, checking for patient understanding is a second core concept in what is believed to be effective communication of medical information, including risks to which the patient may be exposed.

“We said to her again do you--and it’s part of this kind of consent process--do you understand [...] and she appeared to be competent.” (Oncologist)

“I went through everything again [...] making it about the patient and reaffirming that it’s about her [...] and these are real risks.” (Oncologist)

Checking for patient understanding is a very common, likely universal, part of physician-patient communication. In quotes from participants in this study, they explicitly mention this method of ensuring appropriate patient involvement in the medical consultation. It was in these high uncertainty scenarios which physicians were most likely to make this practice of checking for understanding a part of the process. Often in clinical practice when patient involvement or approval is not openly needed, physicians will simply convey information to patients and expect them to understand it unless they state otherwise. As already mentioned, with increasing risks and unclear benefits, the ethical imperative is to ensure patients are involved and appropriately understand the complexities associated with their care. This once again mirrors the process of obtaining informed consent for decisions which carry tangible risk to the patient.

Explaining the uncertainty

Addressing the uncertainty itself, the source of the evidence regarding clinical risks and benefits as well as the strength of the evidence, was an additional approach that some physicians used to help communicate risks to patients when clinical uncertainty was particularly high.

“I have had that happen once where talking with everybody it wasn’t clear what to do and I said to the patient, ‘Okay, it’s not clear

what we want to do here.’ I’ve talked to all sorts of people and I’ve got twenty doctors, twenty-one different opinions.” (Oncologist)

With increasing uncertainty, physicians appeared to be more willing to admit to the patient that the uncertainty was present and the finer details of why they could not provide a better answer for the patient. Being honest with the patient and having them understand what the limitations were on the evidence for each possible option was seen as a positive approach. It allowed the physician to inform the patient the limits of how far they could go in advising them about the best course of option.

“And then, as a punch line, tell the patient you don’t know what the right answer is.” (Family physician)

As the above quote implies, some physicians may not be completely comfortable with the idea of explaining the uncertainty to patients, as some might feel they are putting the burden of the choice on the patient in a situation where they could not provide greater insight into the decision. However, this opinion was the minority and was brought up more in the context of situations where there is no correct answer, but where the risks and benefits were seen as being of similar significance (i.e. PSA testing). When the possible risks were significant and the benefits were uncertain, as with many cancer care treatment decisions, many physicians opted to explain why they could not further recommend a specific course of action. These efforts helped the patients to understand that the lack of clear-cut decision was not attributable to the physicians, but rather the unfortunate truth regarding the current body of medical evidence.

Allowing time to Process the Information.

Another method of ensuring patients understood the risks was to allow the patient time to consider the information they had been told. Though not ideal in terms of efficiency in treating patients, physicians believed it to be important for some patients to work through the risks and benefits in coming to the decision which might be best for them.

“If the patient says to me, ‘I really can’t make a decision right now,’ ‘Okay, that’s good. Here is the information. Think about it and then we will come back and we will talk again.’” (Oncologist)

Once again, when patient understanding is seen to be important to the communication process, physicians do their best to check if patients are truly informed. Allowing time for them to process the information they are being given is a simple solution in terms of assisting in decision making.

“We were able to come to an agreement between the two of us that we would watch and wait for a while and see what happened...” (Oncologist)

“So [the] patient understands, you know what’s your goal, and have a very strict parameter when you’re going to quit if it doesn’t work. Set up all those goals prior and start. I think that’s ethically and morally right” (Oncologist)

A similar technique mentioned by the some participants was to emphasize that a decision was not necessarily a static endpoint. Decisions could be re-visited later on at the discretion of either the patient or the physician. This led them to sometimes provide patients with clear parameters for when a decision should be reassessed, almost as if they were trialing a certain option, in cases where this was possible.

Contextualizing uncertainty

Along with educating about the medical aspects of their care, it is also the physician's responsibility to contextualize the clinical risks and benefits to their individual patients. In light of clinical uncertainty this is often a challenge, yet is necessary for appropriate risk communication to occur. In practice, many participants expressed the importance of how the final decision must fit into the preferences of the patient.

"If it's acceptable for the patient and it's not getting in the way of anything that the patient wants to do..." (Oncologist)

"That comes down, I think, to the patient a lot of the time; what the patient wants to do" (Oncologist)

"So there is a certain amount of uncertainty as I go in to talk to the patient, what are they wanting to do? How do they want to approach this?" (Oncologist)

Degree of patient involvement

Not uncommonly in situations with high clinical uncertainty, the physicians tended to put more of the responsibility on patients in terms of coming to the final decision. There was an unclear division between physicians making the decision after exploring the preferences of their individual patients, and trying to fully inform their patients then allowing them to come to a decision on their own. The practical difference is between allowing the patient a role in the decision versus having the patient accept full responsibility for the decision being made.

"Where there are questions that aren't fully settled, yeah, I think you do well to have a reasonably nuanced discussion and make a point of allowing the patient some role in the decision" (Oncologist)

"I think that's part of why I have a definite preference that the patient make an informed decision on the matter rather than me simply telling them what to do [...] especially when there are those gray zones, those areas of uncertainty" (Family physician)

"I wouldn't say leaving it up to the patient. I would say that I have informed the patient and we would discuss what would be the best for them" (Oncologist)

There was variability in the way each physician approached the decision making process in terms of where they placed the responsibility for the final decision. Some physicians made a point of saying they would prefer to assist the patient in making a decision together, whereas others indicated they preferred to inform the patient as best they could and then let the patient make the final decision themselves. Complicating matters, the degree of uncertainty and the phenotype of the patient prompts many physicians to tailor their strategy depending on the context. The patient's personality/phenotype, though not explicitly discussed here, is known to affect the amount of information shared with the patients and their involvement in the decision making process. The majority of patients, at least within the context of these individual physician experiences, wanted involvement in the decision making process as opposed to having their physician decide for them. That said, many of these same patients, as reflected by study participants, do ask upfront what their physicians would recommend for them to do at some point in the process. Unfortunately, how best to involve each patient individually is not yet known [5,13,31,32]. The physicians in this study presented their scenarios in a way which already assumed patient involvement in the

process, likely due to beliefs that this is more appropriate in the context of situations with high degrees of clinical uncertainty [5,20,31].

Allowing the patient to accept the risks

As discussed above, some physicians preferred to have their patients make the final decision in the presence of clinical uncertainty, often with the implication that it should be the patient who is ultimately responsible for accepting all of the possible clinical risks. It was not that physicians did not want to do their best for their patients, but they wanted the patients to be aware of their inability to suggest a clearly superior option where the benefits were sure to outweigh the risks.

"And then when you see the next patient you can tell them, 'Well, you know, I had a patient with a disease similar to yours and we gave him chemo and they're still here', even though the guidelines don't say anything. 'It worked out for that guy; do you want to take that chance?'" (Oncologist)

"If you want to experiment and your patients know that you're experimenting and they trust you..." (Oncologist)

"So at the end of the first meeting she was willing to accept the risk" (Oncologist)

In theory, allowing the patients to make an informed decision and accept the clinical risks of a medical intervention is an ethical ideal. Unfortunately however, the degree to which patients can fully be informed has been questioned, including by the participants in this study, as will be discussed.

Delivery impacts comprehension

Framing clinical risks in certain ways can affect the way patients understand what is being communicated to them, yet not all physicians commented on the delivery of the information as being important.

"He called it my oncology voice, right, where suddenly you're in this zone and it kind of comes out in this kind of lovely way [...] and you speak slower [...] And again, is it my delivery" (Oncologist)

"I was biased when I was presenting my idea to her, [...] the way the conversation took place, the way I presented the idea to her" (Oncologist)

"I think when we present an idea, options, [...] I think it's a very fine balance between patients' choices, complete patient choices versus how a patient perceives you and how a patient trusts you sometimes" (Oncologist)

There is a great deal of research focused on the particulars of how information is conceptualized and framed to patients, and though it may not have explicitly been addressed by most participants in this study, these considerations appear to be essential to how patients understand what they are being told [27,32-38].

Evaluating the risk communication process

All participants agreed that clinical risks should be communicated and that the patient should be involved in coming to the final decision to some extent, reflecting the trend found in current clinical practice [39]. However, there was discordance regarding whether the physician should share the responsibility for making the clinical decision, or whether in some cases the patient should be informed of the clinical risks and then decide for themselves what to do. In these scenarios

with high clinical uncertainty, a significant proportion of physicians took the approach that if they had attempted to effectively communicate risk, they would allow the patient to “accept” that risk and thus be responsible for the final decision.

Overall, there was very little standardization regarding how risk communication should be approached. Physicians interviewed in this study tended to employ similar methods when communicating risk, yet their methods were still strikingly subjective and individualized. To complicate matters, there are many ways in which patients interpret the information being conveyed to them, and many internal and external factors which affect the way they approach decision making [19]. Recognizing that while communication is, in itself, subjective and individual, insufficient attention has been paid towards evaluating best practices within the medical sciences literature.

Almost all of the conversations regarding risk communication between physicians and their patients became centered on the worries that most physicians had regarding their ability to do so effectively. Participants expressed discomfort with the current manner in which clinical information, including risk, is communicated. One significant challenge was seen as bridging the gap of knowledge and experience that exists between physicians and their patients.

“How to bridge that knowledge gap in a short time so that people can be on board and in the right place to make the decisions about what to do for treatment. That’s something that I find really, really challenging and I don’t really know what the best way is at this point in my training.” (Oncologist)

“It’s just a huge amount of information to go through emotionally and then actually understanding stuff. I’ve seen patients where you ask them, they’ve had this and they’ve had cancer for like five years and they’re just about dead and you ask them, ‘So what is cancer, how does it work?’ They don’t know; they’ve no idea.” (Oncologist)

“How do you give that information to a patient in a meaningful way that’s not just a statistic [...] it’s not descriptive enough and we don’t have more time, or I think the vocabulary or the culture to convey that information to patients.” (Oncologist)

“How do we present the evidence in science best to patients. So that itself is not really well understood. There’s lots of guidelines. But how the guidelines transferred to a layperson or a level one and all that...” (Oncologist)

Some physicians questioned the appropriateness of putting such challenging choices on their patients amidst such high levels of uncertainty. The discussion mirrored the ethically focused discussion of how to appropriately obtain informed consent and whether current manners in obtaining consent are truly “informed” [21,34,40].

“How do you give someone enough information in a clinic visit so that they can actually make an informed decision? Because it almost seems unfair to put the decision about a treatment, like it’s huge, on a patient.” (Oncologist)

“How do you let the patient know that you’re doing a Hail Mary that isn’t backed up by any guidelines, and it may be to their detriment, but if it pays off then I’ll look like a genius doctor and they’ll still be alive. How do you convey that to them?” (Oncologist)

“How do you put that on a patient, right? Is that even fair to say, ‘Okay, so now you’ve got this cancer, you have to make a decision, what do you want to do? These are all the things that can happen and

we’re just going to tell you about the serious side effects, because there may be more though...” (Oncologist)

“My thoughts aren’t fully formed about what the right thing to do is as far as informed consent. The culture that we do now, although I know it’s legally fair, it doesn’t seem like it’s very compassionate. Do you know what I mean because people are faced with huge decisions and a lot of harm? We kind of wash our hands of it because we say, ‘Well, they signed a consent form.’” (Oncologist)

“It seems like the term “informed consent” - I don’t know how informed... it’s a spectrum, right, because they don’t have any experience, I guess, so how do you get them to take a choice when they don’t have any experience with it?” (Oncologist)

The physician-patient communication in these scenarios was complicated by the magnitude of the decision being made, often entering into treatment decisions fraught with high risks and uncertain benefits. This may account for why the oncology participants were more likely to bring up risk communication in their interviews; the area of cancer care is an evolving one still lacking a robust body of clinical evidence [15,16] In the end, physicians often expressed the sentiment that they were doing ‘the best they could’ in communicating the uncertainty and associated risks to their patients.

Conclusions

Physicians used similar approaches when discussing clinical risks with their patients, largely focused around ensuring that the patient is capable of understanding the risks and accepting the consequences of a given decision. Though physicians shared some similar methods in having these discussions, styles were highly individualized [36]. A large degree of apprehension does exist for physicians regarding the efficacy of these conversations, and there is a desire to be able to do their best in terms of completely informing the patient about their health and health care decisions.

These conversations raised the question of how doctors learn and evolve the ways in which they address risk communication with their patients and whether this topic should be explicitly addressed through physician education and training. In 2004, a study of internal medicine residency training programs in Canada demonstrated a lack of consistency regarding teaching and evaluation of informed consent skills and a deficit of these abilities in participants in these programs [22]. In addition, more research into how the way risk is communicated affects outcomes, such as patient satisfaction, needs to be done as it is currently a highly debated topic [39,41-43]. In some disciplines they have practice guidelines which address informed decision making and the risk communication process around certain specific topics [44].

Possible limitations of this project are the limited sample size, as it consists of fourteen participants from within the province of Manitoba. Fortunately our established network of family physicians (UPCON) and centralized CancerCare Manitoba centers simplified our ability to invite physicians to participate in the study. It was possible to avoid a convenience sample in this manner, though there may have been a volunteer bias in the physicians who agreed to participate. By inviting physicians from two different disciplines to participate we also hoped to increase the variety of opinions in our sample. Though this study was not designed to focus explicitly on risk communication, the strength of qualitative inquiry and the convergent interviewing process is that participants are able to direct

conversations towards those ideas that are most important to them. The process of risk communication played a significant role in physicians' decision making processes, and their raising of the topic without prompting provided plentiful data to explore. Further research focused on better detailing and characterizing the relationships between risk communication in the context of varying clinical uncertainty and patient phenotypes would be greatly beneficial to advancing this area of knowledge.

ACKNOWLEDGEMENTS

The authors wish to thank the study participants for sharing their time, experiences, and insights about managing uncertainty in clinical decision-making. This research was supported by a Canadian Cancer Society Research Institute grant held by author SMD entitled "Advancing quality in cancer control and cancer system performance in the face of uncertainty" (Grant # 700589). It was also supported by an equipment and infrastructure grant from the Canadian Foundation for Innovation and the Manitoba Research and Innovation Fund (Grant #202990) held by SMD and funding from the Government of Canada's Canada Research Chairs program. Lastly, the primary author would like to acknowledge the University of Manitoba's Bachelors in Medicine student summer research program and all who contributed to fund this endeavor.

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This article was originally published in a special issue, entitled: "**Risk Communication Analysis in Medical Sciences**", Edited by Dr. Massimo Cecaro, Corridonia. ITALY.