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How do Medical Students Deal with Communication of Uncertainty Surrounding a Patient’s Death?

Kristy Deep, MD, MA, University of Kentucky College of Medicine
Rosemarie L. Conigliaro, MD, Montefiore Medical Center, Albert Einstein College of Medicine

Introduction:
Many trainees have their first exposure to informing family members following a patient’s death as medical students during their third or fourth year. When reflecting on their clinical experiences, students report they are underprepared to discuss terminal illness and death with patients and families. In addition, there is wide variability in formal training in delivering bad news, at both the undergraduate and graduate medical education levels, although training programs and curricular interventions have shown improvements in learners’ ability and comfort with this skill. When evaluating trainees’ death notification skills, the use of appropriate terminology is one important and often rated factor. Despite this increased focus on specific training in delivering bad news, it is unclear how well trainees are able to speak directly to family members about a patient’s death.

Moreover, it may be particularly challenging for clinicians to be direct and honest about a patient’s death when there is clinical uncertainty about the cause of death. Evidence supports that survivors have a better experience when death notification occurs in a caring and direct manner, with adequate clinical explanation of the events surrounding death, and with use of plain and direct language to describe the patient’s death. Such an approach may also reduce the risk of complicated bereavement in the next of kin. However, in cases where cause of death is not immediately known, use of clear and direct language may be difficult.

To determine how medical students describe death and clinical uncertainty to surviving family members we developed a standardized patient exercise in which there is diagnostic uncertainty regarding a patient’s death. We sought to examine how medical students report the death of a patient to a surviving family member when there is clinical uncertainty about the cause of death, for example, an unanticipated death or death in a patient with multiple medical comorbidities, in which no clear definitive etiology is obvious. This study examines both the language used to disclose the death and the clinical uncertainty surrounding the death. We hypothesized that students often do not use direct language to describe death and often do not convey clinical uncertainty.

Methods:
An end-of-year clinical performance exam is required for third year medical students at our institution. In one station, the student assessed a patient simulator (Advanced Human Simulator) and were told by the nurse he was found unresponsive at a nursing home and brought to the emergency department. An advance directive indicated that the patient was “Do Not Resuscitate” status. During the assessment, the simulator was programmed to develop progressive hypoxia, bradycardia, and die. The history and physical exam findings on the simulator were intentionally vague to generate diagnostic uncertainty and demonstrate no single clear cause of death.

At the next station the student was instructed to inform the patient’s daughter about the condition of the patient who had died. The simulated daughter appeared concerned and slightly tearful. After the medical student disclosed the patient’s death, the simulated daughter was instructed to respond in a standardized manner with sadness and then ask each student “What happened?”. This was designed to elicit the students’ explanation of the cause of death. This question was open-ended to allow for a full range of responses from the students. This encounter featured the same standardized actress for all students to ensure consistency. These encounters were videotaped.

The videotapes were transcribed; the resulting transcripts were analyzed by three independent raters with the analysis focused on 1) the language used to describe the death and 2) the language used to describe the clinical uncertainty as to the cause of death. Within these categories, the constant comparative method was used, where no preconceived categories or codes are employed; instead categories are generated and refined in an iterative process with each subsequent reading of the data. All three raters independently coded the transcripts to identify themes and patterns in the way students communicated about the patient’s death to the daughter.

Analysis focused on 1) the language used to describe the death and 2) the language used to describe the clinical uncertainty as to the cause of death. The transcripts contained no identifying information so coders were blinded to the students’ sex, race and ethnicity. Discrepancies between coders regarding the diagnosis provided and the level of uncertainty were adjudicated by discussion among all three raters.

Results:
Study Participants
Ninety-four students (62% male) participated in the exam. Demographic description of the class is shown in Table 1. Three were not recorded due to equipment malfunction and two encounters were excluded due to significant script deviation by the standardized patient leaving 89 encounters for analysis.

Language Used to Report the Death
Only 8 (9%) participants used direct language to report the patients death (“died”/”is dead”). Sixty five (73%) participants stated the patient “passed away”, 11 (12%) said the patient “didn’t make it”, and 5 (6%) used other indirect language (“no longer with us”). Female students were found more often than male students to use direct language to report the patient’s death (“died”/”is dead”). Sixty five (73%) participants stated the patient “passed away”, 11 (12%) said the patient “didn’t make it”, and 5 (6%) used other indirect language (“no longer with us”). Female students were found more often than male students to use direct language to report the patient’s death.

Language Used to Describe Clinical Uncertainty about Cause of Death
Analysis of the discussion of the cause of death focused on the students’ initial response to the question of “What happened?”. The transcripts revealed that students’ responses clustered into one of three groups:

1. No expression of uncertainty: Student presented one final diagnosis to the daughter indicating this was the actual cause of death.

Example: “The end result and cause of death was ventricular tachycardia. He had a heart attack essentially.”

DEEP, K.
2. Partially expressed uncertainty: Students discussed many possible causes of death.

Example: “It is possible that he could have developed a pneumonia. It is possible that he had some heart failure in combination with his recent infection.”

3. Fully expressed uncertainty: Students provided no specific diagnostic information and explicitly acknowledged the uncertainty of the clinical situation.

Example: “It’s hard to say at this point. Given his previous medical conditions, they probably all caught up with him.”

Students who did not express clinical uncertainty about cause of death spoke authoritatively about their conclusions, using phrases such as “His heart started beating faster and faster—we can’t be sure why, but ultimately he died of a heart attack” or “It looks like the infection just spread. I know he had some heart problems already and the infection was just too much for his body.”

Students who fully expressed clinical uncertainty about cause of death often began with a statement that acknowledged the clinical uncertainty such as “We’re not exactly sure…” Then they shared mechanismic descriptions in an attempt to explain, such as “his oxygen was low so we gave him some oxygen” or “his kidneys weren’t working, he wasn’t making any urine.”

The distribution of response types by student gender is shown in figure 1. Few female students provided an authoritative cause of death with no expression of uncertainty. Sample quotations are shown in table 2. Students who did not express uncertainty and delivered a definite cause of death most often attributed the patient’s death to myocardial infarction ("heart attack") (N=9), other cardiac causes ("heart gave out", "heart problems") (N=10), infection (N=5), and stroke (N=3).

Discussion and Conclusion:

In this study, third year medical students faced a clinically ambiguous scenario and were asked in a simulated situation to discuss a patient’s death with a family member. The majority of students used indirect language to inform the patient’s next of kin. Euphemisms such as “passed away” or “no longer with us” may be perceived as easier to accept and negate the need for the student to directly say “the d word” – “dying”, “died”, or “dead”. We also found variability in the manner in which students handled the uncertainty in this scenario. Some students were willing to acknowledge the clinical uncertainty to the family member while others provided a more definitive cause of death than facts of the situation would support.

This tendency to present definitive information may lead to inaccurate perceptions among patients and family members. In the context of death notification, Stewart (7) notes that this represents a significant life event for the survivor, and that memories of the notification are impacted by the words used, the person notifying and the physical setting. Death notifications that involve limited or erroneous information may worsen the grief and distress of the survivors.

Discussions about a patient’s death may be particularly challenging when there is clinical uncertainty surrounding the cause of death. Clinical uncertainty may derive from lack of information, contradictory information, or unobtainable information (10). Politi found that clinicians often do not convey clinical uncertainty with patients and/or families faced with health decisions (11). Clinicians’ reluctance to express uncertainty may be due to their perception of a negative impact on the family (12), as well as a negative reflection on themselves and their competence. This may be heightened in students and younger trainees, who are more likely to perceive this as a personal deficit, rather than a general paucity of available information (13). Difficulty coping with clinical uncertainty may emerge during the preclinical years, when students learn that most questions have one best answer. Although learners are taught not to falsify information and to admit when they do not know something, they may not be specifically taught how to manage their uncertainty and its consequences in clinical situations. A challenge to students in this exercise may have been the mismatch between the high level of uncertainty in the facts of the case and the level of certainty they felt necessary to provide when communicating with the family member. Schor identifies three types of uncertainty in medical students: uncertainty related to one’s own inadequate personal medical knowledge; uncertainty due to a limitation of all available medical knowledge; and the inability to distinguish the two (10). By design, the case was too ambiguous to ascertain a cause of death - exemplifying uncertainty in available medical knowledge. Some students recognized this ambiguity and acknowledged it while others felt compelled to arrive at a diagnosis, perhaps confusing lack of available knowledge with limitations in their own personal knowledge. In both cases, students resorted to mechanistic descriptions of the case, perhaps in an effort to satisfy the daughter’s request for an explanation or as a way to revert to known pathophysiologic principles. We observed that in their quest to satisfy the request for information, many students did not identify overtly either their personal limitations or the limitations of the available information in the case.

It is interesting to note how, when faced with an uncertain clinical scenario, students who felt compelled to provide a diagnosis to the daughter were more likely to invoke familiar and common diagnoses. The vast majority of students who spoke with no expression of uncertainty invoked a cardiac cause for the patient’s death—either myocardial infarction, heart failure or simply that the heart “gave out.” This is consistent with other studies which have found that cardiovascular causes are often overstated as the cause of death on death certificates (14).

Our study found that the responses of female students about the patient’s cause of death clustered in the category of partially expressed uncertainty, meaning that they discussed multiple possible causes of death. This pattern differed from the male students who were more evenly distributed—with higher numbers in both extremes. While the numbers in this study are small, other researchers have found similar gender differences. Blanch analyzed students’ expressions of uncertainty in several scripted SP scenarios and their ratings by analogue patients (12). Their findings revealed significantly more expressions of uncertainty from female students, but this difference disappeared when controlling for the length of the visit. The trained raters in that study identified that students with more uncertainty statements seemed more anxious, less interested and less engaged, which may impact on the patient’s experience. Similarly, Politi showed that communication of uncertainty might undermine the positive effects of shared decision making, and increase patient dissatisfaction (11).
These findings have implications for medical education. In studying how medical students, residents and instructors solved medical problems, Simpson found an increasing degree of acceptance of medical uncertainty with increasing experience (15), perhaps indicating that only experience and not teaching of specific skills allows trainees to admit uncertainty. However, many practicing physicians are reluctant to express uncertainty themselves, as they may see this as a threat to their credibility with either their patients or their learners. In the context of oral presentations on rounds, Lingard et al. describe implicit lessons about the acceptability of different amounts of and types of uncertainty (16). The authors identify that some types of uncertainty are more acceptable than others and may, in fact, be considered useful in the appropriate situations. For students, as long as they maintained a degree of confidence, patients were not less satisfied with students who acknowledged limitations in their knowledge (12).

This study has several limitations. The students were observed during a simulated discussion in which the students thought they were being graded; thus the students may have reacted differently in this setting versus a real situation with an actual family member. Students may have felt that they needed to formulate a final diagnosis to tell the simulated family member in order to satisfy the exam station although they were not specifically told to do so. In addition, clinical uncertainty has been shown to be a source of stress for students (10), and thus their performance in this structured observation may have been adversely affected. Additionally, requiring the standardized family member to ask the question “What happened?” may have skewed the students’ responses toward identifying a specific biomedical explanation for which they had insufficient data. The requirement for the standardized family member to ask the question “What happened?” may have skewed the students toward responding in a way that indicated that they were supposed to have an explanation, even in the face of insufficient data. This query, though, was open-ended, allowing students to answer specifically or generally, with no requirement for students to identify a cause of death. This may indicate that the students themselves were more concerned with arriving at a discrete diagnosis, rather than acknowledging the uncertainty in the situation. Finally, this study was performed at a single institution with a single cohort class. However, the results do allow some insight into the way students at this level of training handle clinical uncertainty when asked specific questions by a patient or family member.

In conclusion, this study found that, when faced with diagnostic uncertainty surrounding a patient’s death, a significant proportion of medical students do not use specific and direct language to describe death, and many provide a definite cause of death despite clinical ambiguity. Students are more likely to attribute death to familiar diagnoses such as cardiac conditions. It may be that students should be taught that some degree of uncertainty is inevitable in most clinical encounters, and then coached on how to express uncertainty and limitations in the medical sphere including diagnosis, treatment or management choices. Students should be taught how to do this in a manner that still allows a display of competence. We believe that additional training for students in these areas is necessary and will contribute to helping them manage the uncertainty they will inevitably face in clinical practice.

References:
9. Sofaer S. Qualitative methods: what are they and why use them? Health Serv Res 1999; 34;1101-1118.
Figure 1. Numbers of students expressing levels of uncertainty regarding cause of death (N=89)

Table 1. Demographic characteristics of students

<table>
<thead>
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<tr>
<td>In-State</td>
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<tr>
<td>Out-of-State</td>
<td>5</td>
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<tr>
<td>Gender</td>
<td></td>
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<tr>
<td>Men</td>
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<tr>
<td>Women</td>
<td>38</td>
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<tr>
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<tr>
<td>Black</td>
<td>4</td>
</tr>
<tr>
<td>Asian</td>
<td>5</td>
</tr>
<tr>
<td>Other/Not Specified</td>
<td>2</td>
</tr>
</tbody>
</table>

Table 2. Categories of responses regarding cause of patient's death

<table>
<thead>
<tr>
<th>Category</th>
<th>Number of Students</th>
<th>Representative quotations</th>
</tr>
</thead>
<tbody>
<tr>
<td>No expression of uncertainty</td>
<td>27</td>
<td>“The end result and cause of death was ventricular tachycardia. He had a heart attack essentially.”</td>
</tr>
<tr>
<td>Partially expressed uncertainty</td>
<td>36</td>
<td>“Right now I don’t know what caused his death. It could have been a blood infection from the kidney infection. Could have been a kidney infection, another stroke, an MI—a heart attack. It could have been pneumonia because he was having difficulty breathing.”</td>
</tr>
<tr>
<td>Fully expressed certainty</td>
<td>26</td>
<td>“I don’t know. All that I know is that he was found this morning unresponsive and they brought him. We were doing the best we could to take care of him here. We knew he had an order not to do any life saving interventions, so we just did whatever we could to make him comfortable.”</td>
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VOLUNTEER FOR MEDICAL ENCOUNTER!

We are looking for interested and energetic individuals to serve on the Editorial Board as associate editors of Medical Encounter. Currently, we have openings for folks to lead the Research and Assessment columns, and we are always looking for ideas for new columns. If you are interested in one of the open positions, or have an idea for a new column, please contact Paul Haidet at phaidet@hmc.psu.edu.
On a cold Saturday in December I co-hosted an interprofessional educational session for graduate medical, nursing, pharmacy, and physician assistant students enrolled in an elective course on rural health care. After a series of interactive lectures, the day culminated in an unfolding case study. The students were placed in the position of a rural provider for a child who had not been immunized for religious reasons and then presented to the emergency department with a preventable life threatening condition. Students were expected to apply principles from the earlier lectures to their decision making. The study was rife with clinical and ethical dilemmas. The discussion was lively and impassioned. At the height of an impassioned debate on the ethics of how to tell the father what caused the condition, I collapsed unconscious to the floor and was taken by ambulance to the emergency room. After I recovered, I was deeply troubled by what I had just done. I had been taught the importance of prevention in my medical training, but somehow I had failed to apply it to this case.

Dear Class,

There’s nothing like teaching by example. In one sense I apologize for the example I provided in class Saturday. Going “down” in the middle of a lecture isn’t the best way to get the point of the lecture across. Leaves no chance for follow up.

However, in this case, it was an extreme example of the exact point of the lecture: know the culture of those who seek medical help from you. Honor patients’ beliefs both in the way you approach them and in how you artfully interpret and apply the science of health care provision. In another sense, I do not apologize for my example Saturday. The morning’s lectures dealt with the geographical and cultural aspects of rural living and how those impact persons’ health beliefs. They also highlighted some of the challenges and rewards of being a health care provider in rural areas.

Maybe this is true for many communities, but I know from experience that rural dwellers often believe in a functional model of health: the ability to do work and meaningful activities defines health. When they seek care it’s often the result of an inability to work productively or to fulfill their perceived roles. I don’t know the current state of the science on this next statement, but it is what I learned many years ago: a person’s Gemeinschaft vs Gesellschaft orientation impacts their health beliefs, reflecting the culture in which they lived at and before age 16. If that’s the case, it’s reasonable to expect that persons who are urban dwellers but grew up in rural areas may (unconsciously) subscribe to their originally conceived functional health model. Case in point: I may look, dress, and act like an urbanite. But I was raised and lived on a farm until age 17. And yes, I believe that if there’s work to be done, then you just need to get out there and do it. If you’re physically able to perform the tasks at hand, then your own needs can wait until the harvest season (or end of the semester) provides a break. Then you can go see your health care provider.

What does this mean to you as an aspiring rural practitioner? Your office volume is likely lower during heavy work times and heavier during seasonal breaks. Rural dwellers tend to have a strong work ethic, and when they come to see you during heavy work times the reason is likely to be substantial. If it’s not an obvious injury or disability, then look for an underlying cause. Ask: “What’s going on that brings them in for “just a checkup” during planting or harvest season? How are things going at home? How’s your energy? Are you sleeping as well as you used to? Been in any scrapes with friends, family or the law lately? What would your spouse or sibling say about how you’ve been acting? How’s work (or planting, harvesting, etc.) going?” These questions are all easily asked while performing your routine exam. By listening carefully to not only what is said but how it’s said, you can learn more than you will from the exam itself. Listen to tone and observe body language to try to discern when you can take “fine” or “ok” as an acceptable answer. Asking yourself and your patient what “fine” really means can open the door to the “real” point of the visit.

How many times during the month before my collapse did I say “fine” when asked how I was doing? “Fine” is a stock answer that satisfies the inquirer and deflects further inquiry. But it doesn’t really get at how you’re doing or promote self-reflection in terms of health or well-being. “You really need to slow down” I’d be told. My next stock answer would be “but I love what I’m doing,” which securely locks the door that I’d shut with “fine.”

Maybe many other health care providers and educators experience this. My previous month had been brutal, both physically and psychologically. There was no break between “normal” work and travel out of state for a family crisis, two conferences, and a holiday trip. The travel consistently overlapped on the weekends, which I am usually able to use for recharging my energy. “Normal” work was at a seasonal peak. I was behind on grading with the semester coming to a close, simmering student issues tend to emerge then also, and the last of the clinical site visits must be completed. State and national program reports had been due. My clinical case load of persons with severe, chronic, and persistent mental health diagnoses had been increased. Within the past week my car was struck from behind, while I was driving it. I pulled a large filling out of a molar with holiday candy. And I had only slept six hours Friday night after preparing Saturday’s lectures. I well know the seasonality and rhythm of my current job position. “Fine” meant I still had all the balls in the air and I anticipated that I could keep juggling for two more weeks until the holiday break.
Now, recall another point from Saturday’s lecture series: a person may be able to compartmentalize their life, rationalize their actions, and feel as if they are in control. . . but the body has a memory and will tell the whole truth. After arriving at the ED by ambulance, I received a battery of tests including UA, CBC, CMP (including TSH), EKG, head CT, cardiac echo, and overnight telemetry. All results were normal/negative. On Sunday morning my discharge diagnosis was Exhaustion.

Exhaustion. Apparently my body needed a rest and told me so by shutting down. Even at discharge my body felt deeply and utterly exhausted and my brain felt bruised but I was relieved to know there was nothing more functionally severe.

I talked to my paramedic/nurse daughter from my bed on Sunday. She wasn’t surprised. I expected a daughter-mother lecture on slowing down and realizing new limits with aging. But she “got it.” “I know you love what you do, Mom,” she said, “I’m going to send you a picture with Charles Bukowski’s saying: ‘Find what you love and let it kill you’ (see Figure 1). But, mom, maybe you shouldn’t let it kill you.” We had a good laugh.”

She got it. She realized that she wasn’t going to change who I am, what my work ethic is, how I view health promotion, or what I do to find meaning in life. Rather, she was there to acknowledge my situation and help me consider how I might benefit from changing certain attitudes and/or behaviors so that I could continue to do the work in which I find so much meaning.

We have all experienced or seen instances in which one person aims to “fix” another with advice, admonishments, shame or whatever. This often emerges from that person’s own needs or agenda: a child who can’t bear for the parent to die, a health care provider who wants his patients to do exactly as (s)he says because (s)he practices from an evidence base that indicates that doing x yields y. As practitioners, we need to ask ourselves if our agenda is aligned with the patient’s beliefs and agenda. And if it is not, can we couch our evidence-based advice in such a way that the patient may still pursue their preferred lifestyle . . . but not so far that it will kill them?

So, yes. Behaviors have meanings, and if you don’t find the meaning in the health history or interview, look for it in the voice and the body. How people offer up their stock answers—intended consciously or unconsciously to look the other way. If you are unable to find a functional cause for the presenting problem, then look to find out what secrets may be found in the manner of speech, expression and posture. If health-related change is to be successful it must be within the context of the patient’s cultural beliefs. Cultures like the rural culture and the over-working health professional culture should be acknowledged and honored in the same way we acknowledge and honor ethnic cultures and beliefs. That was the point which I so graphically illustrated by fainting during the case study.

In that case study, the mother’s rural/religious beliefs about health care must be honored even if you don’t agree with them. Otherwise you risk alienating your intended audience, which gets you nowhere. Just before I fainted I asked the question, “When the father asks how his daughter got epiglottitis, what would you say?”
The Potential of Narrative Medicine: A Snapshot of a Parkinson’s Support Group

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Melissa Nicolas Ph.D., University of Nevada

Background
Rita Charon, the leading conceptual voice of narrative medicine, states that narrative medicine is a philosophy and practice that “allows physicians to reach and join their patients in illness, recognize their own journeys through medicine, acknowledge kinship and duties toward other healthcare professionals, and inaugurate consequential discourse with the public about health care” (1). Charon suggests that clinicians must listen for stories patients tell because within those stories lie not only the facts of illness but also the revelations about self that influence wellness and illness. Charon, a physician and educator at Columbia University College of Physicians and Surgeons, imbues her medical practice with close reading of literary texts, reflective practice, and narrative writing, connecting texts to patients and clinicians. In her work and that of her followers, the joint construction of story encourages multiple voices of illness to give expression to concurrently universal and unique experiences of illness.

Likewise, neurologist Oliver Sacks acknowledges the power of narrative: (2)

If we wish to know a man, we ask ‘what is his story—his real, innermost story?’ for each of us is a biography, a story. Each of us is a singular narrative, which is constructed, continually, unconsciously, by, through, and in us—through our perceptions, our feelings, our thoughts, our actions; and not least, our discourse, our spoken narrations. Biologically, physiologically, we are not so different from each other; historically, as narratives—we are each of us unique.

Narrative medicine is a vehicle for bringing patients, families, and clinicians together, supporting a joint construction of illness, giving voice to all participants in illness. As health care institutions across the country create programs strengthening humanistic and patient centered care, clinicians, patients, and families join together in new ways attempting to improve patient satisfaction and providing a richer understanding of how illness is experienced.

At The Atlantic Health Neuroscience Institute, a neurologist with expertise in movement disorders wanted to investigate how to support his Parkinson’s disease patients with modalities other than those offered by the biomedical model. In collaboration with a narrative medicine practitioner, they designed a seven-month medicine narrative program for people living with Parkinson’s disease, their care partners, and multidisciplinary clinicians. The neurologist’s intention was to explore whether or not a narrative medicine approach would render a deeper expression of non-medical needs than more typical, standard means of needs assessment. The insights from the narrative work coupled with data from standardized instruments would inform the offerings of a Wellness and Support program.

The narrative sessions were two hours. The participants were introduced to narrative medicine practice in an introductory meeting. At subsequent sessions, participants came having read a piece of literature that illuminated some aspect of the illness experience. Of the seven narrative sessions, five featured a text that was explicitly related to Parkinson’s disease and two were more generic in nature. The literary pieces included poetry, short story, memoir and essay. Participants read from the text, elaborating on sections that moved them. After a reflective discussion, all participants wrote short narratives, which they were then invited to share. A responsive discussion ensued. Participants were very verbal during the discussion except for one care partner who never spoke but who wrote deeply revealing narratives that contrasted the care partner experience and the patient experience.

While the original intention of the program was to focus on a better articulation of patient/care partner needs, what we found during discourse analysis of our corpus of narratives is that the narrative approach enabled clinicians, patients, and care partners to find common ground as human beings. Our study suggests that a narrative approach to illness allows participants to step outside of their socially and institutionally prescribed roles and relate to each other as individuals.

Retrospectively, in performing a discourse analysis of nearly 100 narratives, we came to understand that our writing prompts did not necessarily focus writers upon discrete information about patient/care partner needs. However, our study:

...found that the narrative medicine approach allowed healthcare professionals to engage in imperative discussions about healthcare with patients and their care partners, to deepen understanding of their needs in a patient-centered fashion and to better align support services with those needs. Although time consuming, narrative medicine methods allowed participants to contemplate their needs and to articulate their thoughts about those needs. In addition to providing a context for engagement and for support in an emotionally and intellectually challenging way, the narrative medicine approach yielded important insights that were not identified by other, briefer and more commonly used approaches such as questionnaires and assessment instruments. In particular, we learned about the important need for additional support services directed not only to patients with PD but also to their care partners and focused on their interpersonal relationships and stresses and their need for ongoing hope in dealing with the illness. (3)

Snapshot of Narrative Themes
As previously mentioned, because the narrative writing prompts were not necessarily conceived with discourse analysis in mind, it is difficult to make general claims from our sample. However, within our set of doctor, patient, and care partner narratives from November and December some interesting themes emerge. We are able to see these themes because the writing prompts for these months were broad enough to allow the three groups to write outside of their prescribed roles in the healthcare system (i.e. patient, care

1 Gemeinschaft: social relations between individuals, based on close personal and family ties; community. [Retrieved on February 25 2015 at https://www.google.com/search?q=gemeinschaft+definition&ie=utf-8&oe=utf-8].

2 Gesellschaft: social relations based on impersonal ties, as duty to a society or organization. [Retrieved on February 25, 2015 at https://www.google.com/search?q=gessellschaft+definition&ie=utf-8&oe=utf-8.]
partner, clinician). Our observations about the narratives point to the potential of narrative programs to improve relationships among clinicians, patients, and care partners by revealing overlapping needs and desires.

In November, patients and care partners were asked to write about what they wanted and/or needed from their clinicians. Clinicians were asked what they wanted from their patients. Both patients and their care partners, not surprisingly, had similar responses. From their written responses, we learn that patients/care partners want clinicians who are, as John notes, caring, knowledgeable, patient, and truthful. (4) Truthfulness, for patients/care partners encompasses things like sincerity, “giving all the facts, not just those he thinks I can handle;” sharing “observations and conclusions at each visit” and having someone who is willing to have the “and now what?” discussion. (5-6) Sadie and Mary also want doctors who remember them and their specific situations from visit to visit. (8, 9) Care partners, especially, expressed a need for empathy from their clinicians. Tyler asks for someone who is good at “narrowing the distance” between clinician and patient/care partner. (10) Lynn claims that the “extra human touch” and “empathy” are important. (11)

Interestingly, even though in this same month clinicians were asked to write about what they wanted in their patients, one clinician, Alexandra, wrote about her experience as a care partner for her mother. Her desire for her mother’s physicians is the same as the desires expressed by the patient and care partner groups. Alexandra wants someone who can speak in a way she can understand and who can direct her to the appropriate resources. (12) Fortunately, in this sample, clinicians seem to want to give patients/care partners what they are asking for. Fred talks about the process of “listening deeply” to patients and believes “the telling of one’s story is an intimate moment.” (13) Maya believes it is important that one of her patients reported leaving her office feeling comfortable, “expressing her fears; she felt safe [. . .] she felt understood.” Maya continues: “Patients need to “leave an office visit feeling they have been listened to and understood.” (14) This overlap in patients’ and care partners’ stated needs and clinicians’ desire to provide for those needs is a promising finding for researchers looking for ways into improving doctor-patient-care partner communication. Knowing all three groups share a common goal of empathetic, caring, connected knowing and being, all parties can work towards creating spaces where these types of relationships can flourish.

In December, participants were asked to write about their fears of illness and end-of-life concerns. What we notice in these narratives is there is no discernible difference among clinician, patient, and care partner fears although care partners do seem to have an additional area of concern not expressed by clinicians or patients. For example, participants were afraid of being helpless and burdening their families. (15-19) Some expressed fear they would reach a point of illness where their inability to take care of themselves would take away their free will. (20-23) Once illness takes away their free will, some are afraid “those who care for [them] will be able to deprive [them] of the ability to make the decision to exit life.” (24) also (25, 26) In addition, care partners also expressed fear of the “unknown future” while Tyler is worried that his “spirit [will] no longer sing.” (27, 28) Amy is concerned directly about her “inability to react in advanced Parkinson’s when realistic danger requires immediate forceful physical reaction or request for helpful action on the part of others.” (29)

Our cursory analysis of just some of the narratives we collected during this seven-month narrative medicine group suggests that patients, care partners, and clinicians want and worry about similar things. Acknowledging these overlapping desires and concerns can go a long way towards bridging what is too often perceived as a divide between doctors and patients/care partners. One of the most important benefits of narrative work, like the work done in this group, is that it flattens communication. Clinicians in this study were not considered any more knowledgeable or expert than the patients or care partners as the purpose of the group was to respond to universal human concerns such as joy, fear, and illness. This non-hierarchical forum allowed people to step-out of their socially prescribed roles and interact with each other without the limitations of role expectations. In so doing, this pilot study suggests that narrative work as a complementary supportive modality has the potential to improve doctor-patient/care partner communication because of its ability to help each group identify key similarities and differences in their attitudes, approaches, and beliefs about health and wellness, in particular, and human interactions in general.

1 The sample of narratives discussed in this essay include: 5 clinician authors, 4 care partner authors, and 4 patient authors. We discuss a total of 7 care partner narratives, 6 clinician narratives, and 7 patient narratives. Each unique author may have more than one of his/her narratives discussed in this essay.

2 Names have been changed and genders have been randomized to protect confidentiality. All participants have given informed, written consent to quote from their written narratives. Names have been changed and genders have been randomized to protect confidentiality. All participants have given informed, written consent to quote from their written narratives.

3 Admittedly, this is a sample of clinicians who are invested enough in their patients and their practice to participate in this form of alternative therapy. It is not surprising, therefore, that this particular group would display such a concern for and dedication to empathetic relationships and treatment.

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7 Mary (patient). Narrative. 2010 Nov 17.
10 Tyler (care partner). Narrative. 2010 Nov 17.
14 Maya (clinician). Narrative. 2010 Nov 17.
Coaching as a Micro-Teaching Skill: Defining a Concept

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Introduction
Teachers of clinical skills, especially communication skills, generally begin by demonstrating the skill, allow the learner time to practice, and finally, provide feedback. There is another essential step, however, that is less understood and quite frequently left out of the sequence when clinical skills are taught to learners. We call this coaching as a micro-teaching skill.

Defining the Concept
Coaching as a micro-teaching skill is different from the “coach” who works with someone over time to observe and provide suggestions on their performance, a type of coaching often confined to high-level executives or even as described by Atul Gawande in honing his surgical skills. (1) Rather, coaching as a micro-teaching skill incorporates one element of deliberate practice, repeatedly guiding a learner through the performance of a skill or art until he or she can demonstrate its correct performance. (2) An analogy can be made to tennis: The coach has the aspiring tennis player demonstrate his or her forehand, observes each demonstration and suggests major or minor corrections until the learner gets it right. The micro-teaching skill of coaching is what ensures mastery of a skill and, therefore, should be indispensable in the sequence of steps involved in initially learning a clinical skill.

In the standard approach to teaching a communication skill, instructors demonstrate and clarify a skill to be learned, such as expressing empathy to a frightened patient. The learner then attempts to do this in a role play, with a standardized patient, or sometimes with a real patient, and, especially if new to the skill, most often fails awkwardly. There then follows feedback. Done successfully, and with some sophistication, the feedback generally allows the learner to identify both strengths and weaknesses in his or her performance and to agree with the teacher’s assessment of ways to improve performance. The session usually ends with the learner receiving feedback on his or her generally inadequate performance.

The micro-skill of coaching is based on the principle that the session cannot end until the learner correctly performs the skill. After the learner has failed to give a good performance, the teacher demonstrates correct variations of the task, asks the learner to identify a variant that feels natural to him or her, and observes while the learner carries out this task. The teacher stays right at the learner’s side until the skill is achieved and continually seeks words and nonverbal behavior that are natural for the learner and improve mastery of the skill. If a standardized patient is employed to help coach, he or she may also provide feedback to the learner (for example, “You would be more convincing if you looked directly at me when saying that.” or, “Your need to speak more slowly and use a softer tone of voice.”) After two or three iterations, coaching generally succeeds in eliciting a good performance. Some final feedback and reflection (for example, “In what ways do you think expressing empathy might be helpful to a patient?”) solidifies the learning.

One of us (WTB) has employed the coaching technique successfully for many years. Settings where this has been successful include teaching end-of-life and other difficult conversations to medical students and residents and numerous faculty development courses addressing communication skills. (3) We have not gathered statistical data, but the technique of coaching is simple and seems obviously important. We suspect many AACH facilitators may employ coaching in micro-teaching sessions without explicitly drawing attention to their use of the technique.

Coaching as a micro-teaching skill allows the teacher to encourage skill development while also exploring the learner’s values and attitudes during the session. This is done by reflective discussion of the issues raised in interactions. As a result, coaching can be a key element in building the doctor-patient relationship.

We advocate incorporating coaching into every micro-teaching encounter. The focused practicing, feedback and reflection are central to deliberate practice. But we cannot call this deliberate practice without a long-term commitment by the coach and learner. (2) Nevertheless, numerous brief teaching interactions could benefit from coaching.

Summary and Future Directions
Simply giving feedback does not lead to mastery. By finding their natural voice, being coached until they perform the skills effectively, receiving constructive comments as well as praise for their performance, and reflecting on the meaning and success of this process, medical students, residents and others can master fairly intricate clinical skills which will undoubtedly positively impact their care of patients. We plan to incorporate coaching into medical students’ communications skills training using standardized-patients. We will compare the skills of these students in future sessions with skills of students who received feedback but no coaching.

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Declarations of Interest: none
BOOK REVIEWS

Frederic Platt, Editor

This is Frederic Platt’s last column as Book Review Editor for Medical Encounter, since Fred is retiring after 20 years at his post. I did some looking back through the Med Encounter archive (an extremely enjoyable experience recommended to all who like history and are AACH members) and found that Fred is only the second editor to hold this post, succeeding Rita Charon. Over the past 20 years, there has been at least one book review in nearly every issue of Medical Encounter, and I personally have bought many books based on Fred’s insightful reading and engaging commentary. Fred has the unique ability of being able to put a work into the larger context in which we all live, and show us just how we can grow by reading (or in some cases, not reading) the reviewed work. We at Medical Encounter will miss that greatly, and can only hope that the next book review editor or editors can channel at least a piece of Fred in this important and ongoing work. Thank you, Fred, for your tireless devotion to Medical Encounter. - Paul Haidet, Editor

Being Mortal: Medicine and What Matters in the End


Those of us who are still young (not yet retirement age, maybe younger still) can pretend we are immortal. I remember feeling strong and able to go on forever, running up hills, bench pressing my weight, making slams at the bridge table. But alas, now I am no longer young, am feeling frail and wobbly, and know for sure that I am indeed mortal. Atul Gawande, a Boston surgeon and writer, has given us a book we all need to read. If we are caring for patients who need understanding more than a quick fix, or if we ourselves have entered the downward spiral of age and debility, we need to read this book.

As humans, what do we all need? Gawande tells us.

As our time winds down, we all seek comfort in simple pleasures - companionship, everyday routines, the taste of good food, the warmth of sunlight on our faces. We become less interested in the rewards of achieving and accumulating, and more interested in the rewards of simply being. Yet, while we may feel less ambitious, we also become concerned for our legacy. And we have a deep need to identify purposes outside ourselves that make living feel meaningful and worthwhile.

Gawande tells us how contemporary medicine, highly technology driven, very “find it and fix it” behavior, simply fails to provide what our aging population needs. I myself have fifteen (more or less) chronic disabilities and nothing that is fixable (unless my trigger finger recurs.) I am not a crock with a chief complaint. I am a crock with fifteen complaints. Gawande wants us to start attending to our patient’s needs and desires. “What are you most afraid of?” “What do you most want to accomplish this year?”—questions he advises us to ask and address.

Gawande spends a lot of time looking into nursing homes (mostly terrible places to end up) and various sorts of assisted living places. My favorite is the story of Chase Memorial Nursing Home that Dr. Bill Thomas transformed mostly by involving children and animals. Gawande recounts a dialogue between Thomas and Lois Greising, the director of nursing, when Thomas urged her to accept two dogs as residents of the nursing home. She hesitantly accepted and Thomas added, “What about cats?” They ended up with two dogs, four cats, and 100 parakeets. The residents/patients soon had a purpose to their lives. And they perked up, became once again human, and even lived longer. That’s a place I want to go to when I need placement.

A neighbor, an ex-patient of mine gave me this book. My wife grabbed it and read it in a day or two. Then I read it. Our responses were different. My dear Constance found her concern for my deterioration growing. The book asked her to face the reality and that was not easy. For me, the book was a great gift; I was led to think more about my goals for the next year and I came up with a couple of great ones. (One is to read all the Shakespeare plays and discuss them with a good friend who taught just that subject for 50 years. He says he will be eager to join me for coffee and literary discussions. Wow!)

OK, this book review is altogether too much about me and too little of Gawande, but that will be the effect of the book when you read it. It will be about you, as a clinician and as a person who is sure to grow old and less agile. I urge you to do just that.

Frederic W. Platt, MD
December 1, 2014

Fields of Blood: Religion and the History of Violence


Do you, perchance, agree with me that religion is the parent of violence, murder, and warfare world wide? But did you notice that the two world wars in the last century were not based on religious differences? If so, do you still hold to the stance of blaming religions, especially the monotheistic ones, for the rest of our terrible behavior to one another? Well, we all need to read Karen Armstrong’s new book. She says I’ve got it backwards. She makes a good case, backed up with hundreds of pages of key references and data, for warfare and violence being a result of an agrarian society that led to cities, art, music, and governing aristocrats who needed an army to stay in place and then needed a mythology to explain how they became powerful and needed to stay in such power.

Armstrong notes:

People rarely go to war for one reason only; rather they are driven by interlocking motivations - material, social and ideological. In Homer’s Iliad, when the Trojan warrior Sarpedon urges his friend Glaukos to make a highly dangerous
assault on the Greek camp, he quite unselfconsciously lists all the material perks of a heroic reputation --- special seating, the best cuts of meat, booty, and “a great piece of the land” - as an integral part of a warrior’s nobility.

What about the mythology that lards religious belief? Armstrong notes that

“A myth is never simply the story of an historical event; rather, it expresses a timeless truth underlying a people’s daily existence. … A myth is always about now. … religion gave supreme sanction to what was essentially organized violence and theft …

Armstrong spends a lot of time with the Sumerians who between 6000 BCE and 1000 BCE developed much of what we now call civilization. Probably “pastoralists” (actually nomadic herdsmen and far from the word we now use to depict nature and softness) living in the mountainous regions about the Fertile Crescent, introduced warfare to Sumer. “The herdsman would have found the cities’ wealth irresistible.”

This book provides an encyclopedic analysis of culture, warfare and other human violence, and history. Religion seems to usually come in after warfare as a scheme to justify our terrible behavior, not the other way around. I think we need to reconsider, at least in part, our puzzlement about Catholic/Protestant conflict in North Ireland, about Sunni/Shiia conflict in the middle east, and about our own political conflicts that otherwise make no sense.

A great book to read in your reading club. It will stimulate LOTS of conversation.

Frederic W. Platt, MD
December 1, 2014

JOURNAL WATCH

Paul Haidet, Editor


In 1998, Catherine Caldicott articulated a notion that, like “entrance music” that plays when operatic characters stroll into a scene, doctors and patients have their own form of entrance music that is playing as they enter the medical encounter (Perspectives in Biology and Medicine 1998;41:549-564). Now, William Ventres adds to this notion by articulating five different presentations of the self, both by patient and physician, that shape the overall arc of the medical encounter. Developing mindfulness around these different presentations can help practitioners to foster presence, equilibrium, and connection in interactions with patients.

2) Lown BA, Muncer SJ, Chadwick R. Can compassionate healthcare be measured? The Schwartz Center Compassionate Care Scale. Patient Education and Counseling 2015; epub ahead of print.

Patient satisfaction. Empathy. Trust. Patient-centeredness. These are all constructs for which validated measures already exist. So, why do we need another measure and another construct, namely, compassion? Perhaps because the nature of human relationships and true human connections is wondrously complex, and there remains much work to be done. In this article, Beth Lown and colleagues present a nicely thought out, thoroughly analyzed scale that shows good initial psychometric properties, is compact (12 items), and should be fast and easy for patients (or simulated patients) to complete. Definitely a tool to check out!


For those of a certain age, I have this question: when did you buy your first CD player? 1983? 1986? 1992? If you are a student of Everett Rogers’ “Diffusion of Innovations” theory (Rogers. Diffusion of Innovations, 5th ed. Free Press, 2003), then you know that CD players were introduced in 1982, adopted by the innovators in 1983, adopted by the early adopters around the mid 80s, and adopted by everyone else starting in the early 90s. Well, as far as Twitter and other social media platforms go, it’s the early 90s, and the CD players are flying off the shelves. This is not only a powerful platform for disseminating one’s work and participating in the conversations of the field, it is a predominant form of community engagement for the digital generation. I was at a meeting a few months ago and realized that if I didn’t want to fade into obscurity as an irrelevant anachronism, I needed to square with this fact. There are a number of resources on how to get started with Twitter on the web, but this nice, tightly written article gives a great primer on how to actually use the platform as a tool to disseminate your work, find those of a similar mind, and engage fruitfully.

4) Jesus TS, Silva IL. Toward an evidence-based patient-provider communication in rehabilitation: Linking communication elements to better rehabilitation outcomes. Clinical Rehabilitation 2015 May 7 (epub ahead of print)

When one looks at the communications literature, a vast majority of it was performed in primary care fields. However, works by Rich Frankel, Mary Catherine Beach and others have suggested that the way communication works, and even the definition of patient-centeredness itself, may not be a fixed constant. Instead, communication may be contextually dependent and situated within the specialty in which the communication occurs. The implication of this notion is that much work is needed in the various specialties and contexts of medical care to better understand the salient factors impacting the quality of communication within them. This rigorous and well thought-out article begins that process for the field of rehabilitation medicine, and provides a model for an initial approach that is both specialty specific AND draws upon the vast amount of existing evidence already in the communications literature. A must read for anyone thinking about studying communication in a specialty where little work exists.
Walk-in homes for people living with cancer and their family members: A new Dutch communication and support approach

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Dutch walk-in homes are a meeting place for people suffering from cancer and for their loved ones. A study was performed in order to assess to what extent the offered complementary activities and the psycho-social support in these houses are, as well as whether or not these homes are present, comparable to initiatives in other countries.

Introduction
Dutch walk-in homes are a meeting place for people suffering from cancer and for their family members, friends and other loved ones. Walk-in homes are institutions based on private initiatives and funds. They offer several complementary activities as well as psycho-social support by trained volunteers. Walk-in homes generally have a low threshold; an appointment is not necessary. Most activities are free of charge. They are functioning independent of hospitals. In the meanwhile there are more than 80 houses in the Netherlands (1).

Evaluation study
An evaluation study was performed in order to find out to what extent the offered complementary activities and the psycho-social support fulfils the needs of the visitors (2, 3). We interviewed 34 visitors from 20 walk-in homes. Further, 711 visitors of 25 walk-in homes filled in a questionnaire (by post or by e-mail). The walk-in homes participated actively in the study. The coordinators of walk-in houses also filled in a questionnaire about the organization of the offered support in their homes.

We found that the walk-in homes offer a great variation of activities and support. The attitude of the visitors towards the homes is very positive. They are satisfied with the offered activities and support. The people with cancer and their family members are visiting the houses rather often and for a long time (2, 3).

Part of this study was an exploration of what can be learned of walk-in homes outside the Netherlands (4). This study is based on a literature search in Pubmed and Google Scholar using the following terms: psycho-oncologic care, walk-in houses, psychosocial support, evaluation and effects. We could not find much information about comparable initiatives in other countries. Therefore we did a survey among 115 researchers all over the world, working in the field of cancer, based on an authors list of Patient Education and Counseling. From 40 authors we did receive an answer (35%). Again, it did show that there are only a few initiatives applying the concept of walk-in homes as existing in the Netherlands. Below a few examples which we found.

Results
In table 1 we summarize the main results. If a country is not mentioned it means that we did not find information about it in the database and nor in the answers of the letters to the authors. In the reminder to them we stressed that no answer would be indicating that there was nothing like a walk-in home in their country.

Table 1: Information from the databases and the answers on the letters to the authors of PEC

<table>
<thead>
<tr>
<th>Countries (alphabetic order)</th>
<th>Possible comparative initiatives in the country</th>
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<tbody>
<tr>
<td>Australia</td>
<td>Some houses facilitated by the government, offer group activities by trained volunteers and nurses. Further, mainly support by telephone and the internet.</td>
</tr>
<tr>
<td>België</td>
<td>There were two walk-in homes from the Liga Against Cancer, but were closed due to lack of interest (5). Recently two new initiatives were founded. The Erika Thijs Home in Hasselt (Limburge Kankerkoepel (6) and A Touch of Rose in Bornem/Willebroek, Psychosocial Oncological Well-being Center (7). Both initiatives are not officially related to hospitals.</td>
</tr>
<tr>
<td>Canada</td>
<td>Comparable initiatives are part of hospitals. Recently in Edmonton a private house has been founded, independent from hospitals, with emphasis on professional psychosocial support for emotional problems (8).</td>
</tr>
<tr>
<td>Country</td>
<td>Description</td>
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<tr>
<td>-----------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>China</td>
<td>A pathologist in the field of cancer stated that such houses do not exist in China. This was confirmed by an author of a review on communication training in hospitals.</td>
</tr>
<tr>
<td>Denmark</td>
<td>There are some comparable initiatives, but always in cooperation with hospitals, like two houses by the foundation of you go.</td>
</tr>
<tr>
<td>Duitsland</td>
<td>Comparable initiatives are part of hospitals. An example is the foundation on Lebenswert (Life value) at the University of Köln, offering psychosocial and complementary care.</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>Israel</td>
<td>Psychosocial support is part of the treatment in hospitals.</td>
</tr>
<tr>
<td>South Korea</td>
<td>There are no walking-in homes in South Korea, as also based on visits of one of the authors (AV).</td>
</tr>
<tr>
<td>UK</td>
<td>Comparable initiatives are part of hospitals. There are 20 Maggie’s Centers based on a private initiative, with also foundations in Hongkong and Barcelona. Emphasis is on information supply and psychological support. Also the Macmillan Foundation is active in facilitating patient education, self-help- and support groups.</td>
</tr>
<tr>
<td>USA</td>
<td>Comparable initiatives are part of hospitals like the MD Anderson Cancer Center in Houston and the Memorial Sloan Kettering Cancer Center in New York offering support groups in complementary therapies. The independent foundation Little Red Door Cancer Agency offers financial support for less fortunate people with cancer.</td>
</tr>
</tbody>
</table>

So in Belgium, Germany, the UK and USA are a few comparable initiatives. However, it is important to note that these forms of psychosocial support in foreign countries are often functioning in cooperation with hospitals. But that is not the case for the Dutch walk-in homes. Also, support is frequently performed by telephone, e.g. by patient organizations, as also in the Netherlands, but this is not seen as a core task of Dutch walk-in homes. Studies about the effects and evaluation among visitors of comparable organizations like walk-homes are not found.

**Conclusion**

It can be concluded that walk-in homes are rather an exclusive service in the Netherlands. This also means that we did not find information about evaluation and effect studies.

The overview of walk-in homes is a first inventarisation in this field. It was difficult to find fitting search terms for walk-in homes. Although authors of PEC are well-known experts in the field of psycho-oncology, it may be selective group which could have been extended to e.g. authors in Psycho-Oncology. The response of the sent-off reminder emails was restricted, although we stressed that no answer would be interpreted that there is no walk-in homes in that particular country. Websites were sometimes not understandable due to not using the English language.

Why are walk-in-houses so exclusive for the Netherlands? The medical care is concentrated in hospital, while the extensive professional psychosocial care is mainly in specialized outside hospitals. Walk-in homes may fill up the gap between both types of care. Further, walk-in homes provide a more structured and continuing support than patient organizations. Finally, the initiative to found walk-in homes fits in the Dutch culture to take private initiatives in the health care. In the last century that did happen too for founding hospitals with their own denomination, and recently also happening for the founding of hospices. The interviews and questionnaire study will give more insight in the specific character of the Dutch walk-in homes.

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