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The silent demand in the diagnostic phase

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Abstract

Patients' experience of going through the diagnostic phase in hospital is apt to be overlooked by nurses and physicians; most of their inner preparative work for receiving the diagnosis is hidden due to the vulnerability of the situation. This paper discusses findings from a grounded theory study, of 18 indepth interviews of 15 patients going through medical investigation at a gastric ward in a Norwegian university hospital. The interviews were conducted in 2002-03. The generated "Preparative Waiting Theory", which accounts for how patients in the diagnostic phase work to prepare themselves for receiving a diagnosis, is discussed in relation to the Danish theologian and philosopher Løgstrup's writings about the ethical demand and life utterances of trust, openness, and the untouchable zone. The ethical demand from patients going through medical investigations is silent and radical, and thus challenging for nurses and physicians to judge how to best fulfil. Examples from the interviews are used to illustrate patients' vulnerability as they prepare to face the conclusion about their case. To the extent trust develops between patients and nurses/physicians, patients can reveal what is at stake in their lives without feeling exposed or embarrassed. Due to the power nurses and physicians have in the health care system, and due to laws, morals, and conventions guiding practice, we have a professional responsibility to develop a culture that fosters the ability and willingness to take care of our patients.

Key words – grounded theory, research in practice, ethics, interpersonal communication, nurse-patient interaction, adult nursing

INTRODUCTION

This article voices gastric patients' experience and perspectives of going through the diagnostic phase in hospital. These patients come to the hospital to obtain access to the best equipment and expertise available to investigate their problems and receive a diagnosis. In the hospital the bio-medical and the personal world meet (1, 2), and the outcome of this depends on how health care workers see the individual patient and his situation (3). Nurses are important for quality of care since they are present in the unit 24 hours a day, and are the biggest workforce in the health care system. Physicians are also key personnel for patients in this study since they are responsible for investigations, diagnosis, and decisions related conclusion of investigations and treatment.

Sørli et al. (4) points to the fact that satisfied patients still can be vulnerable patients. This challenges us to be aware of and understand patients' vulnerability and existential considerations related to hospitalisation. Experienced vulnerability is related to degree of exposure to harm and the ability to protect oneself (5), which is related to trust. When patients show trust, they recognise that one can be harmed, but believe that others have a good will towards them and want the best for them (6, 7). Patients want health care professionals that are able to combine knowledge and clinical expertise with relational qualities such as attentiveness, the ability to listen, to be available, and to show support (4, 8-11). Extensive time is not always necessary to form such relationship (9). In nursing there has been a discussion around these professional qualities under labels such as nurse-patient interaction (9), presence (12), advocacy (13), and partnership (14). These combined qualities are reported to enhance mental and physical well-being (12), security (4), ameliorate distress, and induce trust (14).

The study discussed in this article builds on in-depth interviews of patients who shared their experience of undergoing medical investigation. We therefore hold an illness perspective (1-3, 15), which focuses on how patients perceive what is going on and what is at stake in the situation. Our generated grounded theory (GT) named “Preparative waiting theory” (PWT) explains how patients in the diagnostic phase prepare themselves for receiving a diagnosis. PWT can assist nurses and physicians in understanding how the vulnerable time of waiting is experienced and handled by patients. A more detailed presentation of the study and the theory is published elsewhere (17). Patients’ appeal of being cared for, in the midst of uncertainty and vulnerability, might be difficult to uncover in a busy hospital ward (4, 16). This article, however, aims at coming to a deeper understanding of patients’ silent desire, in the diagnostic phase, for trusting relationships with experienced and knowledgeable nurses and physicians, and thereby makes this desire more explicit and easier to acknowledge in a demanding working situation.

After we had developed PWT we found the Danish theologian and philosopher Løgstrup’s writings (18-21) about how the sovereign life utterances, could be promoted or hampered by the norms, rules, and standards in the hospital setting thus providing helpful considerations to aid us in a deeper understanding the silent desire from our patients. The Norwegian nurse-philosopher Martinsen (22-24) has applied Løgstrup’s thoughts in a nursing context, and we will discuss our findings in relation to their writings

THE SETTING OF THE STUDY

This study took place in the Norwegian Health Care system, which is a public health care system. According to the Patients’ Rights Act from 1999 (25), all citizens of Norway have

the right to equal access to good quality health care. The act promotes a relationship of trust between the patient and the health service and safeguards respect for life, integrity, and human dignity. The act states the right of the patients to how, where, and when to have their health condition evaluated. Patients also have the right to choose hospital for treatment, though not the treatment level. Some of the patients in this study were admitted for a second opinion, and some had chosen this particular hospital instead of the one to which they geographically belonged.

In Norway there are five health regions with one regional university hospital per region. Close to the hospital where this study was conducted, there is a hotel where next of kin and patients may stay if health and the examination program permit. Both options are fully covered for the patient by the Social Security System. The Health Regions wish to have client cooperation in their policy-making and standards of treatment and care, and our research can feed into that for patients in the diagnostic phase. The participants in this study were admitted to a 22 bed gastroenterological ward with a separate x-ray and medical investigation unit, which were both bottle necks in the system.

THE STUDY

The aim of the study, which serves as the background for the discussion in this article, was to learn about how hospitalised patients going through the diagnostic phase handled their experience and how health care personnel could assist them in the best way.

Classic GT design was chosen to study patients' experience (26-28), and in-depth interviews were chosen for data collection. A substantive GT gives a conceptual account for how participants solve their main concern, and is abstract of time, place, and people that take

part in the study (26-27). A substantive GT thus can also fit other groups of patients sharing the same main concern. The inclusion criteria for participants were that they should be hospitalised for medical examination in stomach-intestine area, be 35 years or older, be mentally and physically able to take part in the interview, and be willing to sign the informed consent form. Participants were chosen in relation to the development of the theory (26). All the participants were ethnic Norwegians, and their age ranged from 35 to 84 (median = 51). Participants were able to wash and dress themselves, and serve themselves meals from a buffet in the hallway. They had problems such as pain, diarrhoea, nausea, and loss of weight.

The 18 interviews of 15 patients (three patients were interviewed twice) were conducted in the hospital setting over three periods in 2002 – 03, with an average length of 56 minutes. Each interview was coded openly, and as more interviews were conducted and analysed, we moved on to selective coding. Memos were written during the whole process and during theoretical coding, memo-sorting aided the process of validating the core category and fitting the concepts to each other to constitute an integrative substantive theory.

The study was approved by the Region's Medical Research Ethics Committee and welcomed by the medical unit. Patients fitting the inclusion criteria were given oral and written information, in accordance with the Helsinki declaration. Interviews started after the patients had signed the written consent form.

THE “PREPARATIVE WAITING THEORY”

The participants' main concern emerged to be; how to prepare oneself for receiving a diagnosis and life afterwards. The core category, which accounts for the ongoing activities in

the area studied (26), was named “Preparative waiting”. It was hard to unveil the main concern and how they handled it, because enduring uncertainty in the diagnostic phase was so painful for most of the participants. The key to understand how they handled going through this was therefore to understand how vulnerable they felt.. PWT was a process of “Balancing between hope and despair” as they were “Seeking and giving information”, “Interpreting clues”, “handling existential threats”, and “Seeking respite”, as illustrated in Figure 1.

Patients protected themselves from despair by actively looking for reasons to hope. They were kept on hold, which together with bodily problems made them feel weary and vulnerable. Relationships with next of kin, nurses, and physicians combined with the experience of the hospital system affected their work of “Balancing between hope and despair”, and thereby made it easier or harder for the patients to endure the investigation process. Hospital staff could strengthen patients and make them feel cared for and carried through the diagnostic phase by exhibiting their expertise in a sensitive way. Small signs of thoughtfulness such as patting of a cheek or offering a bed in the unit for those staying outside the hospital were appreciated. Put downs such as the feeling of being just a number in the big system made them insecure concerning the quality of the investigations, which increased despair.

The ability to seek, give, and process information was related to how strong the patients felt. Adjusted information could reduce uncertainty and give them some control related to the stay; grasping the routines of the unit and being provided with an overview of the content of the day were important, as were preparations, carrying out, and receiving the results of investigations. The participants expressed a clear wish for having one main contact person during their stay, a nurse or a physician who knew their situation and was responsible

for the investigation process. The request for information was the most clearly expressed aspect of the patients' needs, even though it could be hard to fulfil.

The more internal activity of "Interpreting clues" dealt with how patients worked to judge their situation by considering their own symptoms, former experiences in own and others' lives, tests and investigations they went through, and the priority they were given in the system. They observed and evaluated nurses and physicians, and how they spoke and behaved in relation to them. All this was done to possibly develop a frame of interpretation about what was at stake in their lives so they could prepare themselves for the conclusion about their case and what was waiting for them in the future.

Going through the investigation process in the hospital made questions related to their future more pressing, which caused them to be more aware of what was important in their life. Possible threats of life-threatening outcomes of the investigation caused them, to a various degree, to consider the existential threat in the situation. This struggle was to a great extent invisible and awkward for them to talk about. They sought to disconnect themselves from the constant tension of uncertainty by "Seeking respite". Such transfer was improved or hampered by health conditions and medical examinations, as did where they slept; in the hallway, four-bedded room, in the patient hotel or at home.

Figure 1. A model of Preparative Waiting Theory

LØGSTRUP; THE ETHICAL DEMAND

In the next paragraphs we first briefly present Løgstrup's (1905 – 1981) considerations about how we can fulfil the ethical demand of taking care of one another in the best way, since his writing fits well with the vulnerability patients in the diagnostic phase may experience. We also draw on Martinsen's interpretation of Løgstrup's writing in a health care context.

Løgstrup (18-21) considers man to be put in the world in such a way that we are mutually dependant on each other to the extent that we constitute one another's life and destiny. In so being, mutual trust becomes the basis of all communication and relation between us. The ethical demand is a one-sided appeal about being cared for which is directed towards the other. This demand is radical in its claim; we must take care of the other without considering our own reciprocation, even though it might be unpleasant and intrude on our existence. The demand is also silent in that we are not given how we best can fulfil it. Løgstrup states that the ethical demand is impossible to fulfil (21). However, it is up to us to use insight, imagination, and understanding to judge how best to take care of the person placed in our hands. By attitudes and actions we take part in deciding how the other's world is experienced; larger or smaller, bright or drab, rich or dull, threatening or secure (21, p.18).

Løgstrup writes about spontaneous life utterances; phenomena that are so basic to our lives that we do not pay attention to them before they fail. They are mutual, carries our lives, and a hidden desire drives the tendency (19) to redeem and fulfil the ethical demand. He also writes about trust, openness of speech, compassion, mercy, indignation, hope, and respect for the other's zone of untouchability (20). In this article we discuss three of these: trust, openness, and the zone of untouchability, since they in particular shed light over challenges in the diagnostic phase. The zone of untouchability is related to integrity of life, to consistently dealing with facts on the matter at hand, and to look after the other's

strangeness. It appeals to protection of what is vulnerable in life, and if not respected, the person feels insulted. Openness brings us closer to our motives, the personal and emotional elements of a relationship. The zone of untouchability and openness are unified oppositions that keep each other true, flexible, and alive and prevent our lives from stiffness and simplifications (19, 22-23). Without the opposite, the tension between them flattens out and they become a caricature of themselves.

Trust is necessary for human coexistence, and to show trust means to expect to be met. In trusting we open ourselves for exposure, and by revealing ourselves and what is at stake in our lives we become vulnerable. In this way we have power over each other, which can be used to serve and show care, or to insult and make the other feel disappointed, exposed or embarrassed whenever vulnerability is not protected (21).

In addition to life utterances, our lives take shape in accordance to laws, morals, and conventions in our culture. These protect us by instructing us in how to relate to each other, thereby limiting exposure and exploitation. The radical demand offers no help in how to act, whereas norms, rules, and standards are cultural mediations that serve as more or less concrete guidelines for action (21, 23). In many situations we will still need to use our judgement, as the fulfilment of norms also depends on our motives. We also must be alert to the fact that conventions can both promote and hamper us in meeting the ethical demand. Accepted practices may lead to violence and scientific investigations might call into question accepted norms and suggest new and better practices. Therefore we should critique our tradition, judge, criticize, and constantly correct it (21, 23-24).

DISCUSSION

In this section we draw on Løgstrup's and Martinsen's writing and discuss how the appeal to be taken care of can be displayed by patients in the diagnostic phase and how it can be met. We also discuss how the power nurses and physicians have in hospitals, and how laws, moral and conventions can promote or hamper a trusting and caring relationship to develop in the hospital context.

To the degree patients experience troublesome symptoms, they became weary and tired. Patients' weariness gave them little strength to stand up for themselves; most of them kept a low profile and protected themselves from situations where they thought that they could be overwhelmed, become hurt or disappointed. Therefore they were careful to whom they opened up and when it was done, to prevent their trust from not being accepted and returned. In this way trust and vulnerability were closely linked together. Uncertainty related to what their illness meant for them, consequences concerning life, death, and wellbeing, and that they were in a situation with a lack of overview about what to expect during necessary investigations, all added to their experience of vulnerability. Patients were the most unprotected and exposed part due to be the ones coming with their problems to the hospital to get help.

They were dependant on staff and the system and hoped that the investigation process would be done in the most efficient manner. The staff possesses a position of power in hospital due to their knowledge, experience, and responsibility for planning, deciding on, and carrying out undertakings necessary for concluding patient cases (6, 9). How patients and staff sensed each other, how their tone of language was perceived, and how gestures and expressions were taken laid the groundwork for building a trusting relationship.

Since the participants in this study were rather self-sufficient, there were few natural meeting-points between patients and nurses. Since patients seldom openly expressed how they experienced uncertainty and waiting, it was awkward for staff to grasp their vulnerability and appeal, which made it demanding for nurses and physicians to know how to act. This challenge is also discussed by others (4, 13-14). Patients' information-seeking activity was the most clearly expressed part of their preparative work. The more hidden part of interpretation of self and others, their need for respite, and the most concealed part; struggling with existential threat were not easily seen by staff in a busy ward.

Two clinical examples

The challenge in meeting the silent and radical ethical demand can be exemplified by a patient returning to the unit late Sunday night after a leave of absence over the weekend. The patient had found refuge in her home, which had given her a welcome respite in her preparative work. She was nervous about returning to the hospital and had probably hoped that someone would recognise her vulnerability and attempt to make the arrival easier. Therefore she had encouraged herself considerably for coming back to the unit. But her expectations of being met in her vulnerability did not come through. Standing in the hallway with her bag, looking for her bed in the corridor, the nurse asked her: "What are you doing here?" The patient felt neither recognised nor waited by the nurse. She was disappointed, feeling exposed and rejected, which resulted in not being able to handle the situation. She became overwhelmed by emotions and burst into tears. Løgstrup writes about how refused trust can show itself morally. Some patients might have accused the nurse; this patient accused herself for not being able to keep her composure in this situation, and she called

herself silly. Personal weakness might be easier to admit and can cover up refused exposures (4, 21).

Thinking along the unified oppositions between openness and the untouchable zone can aid us in judging how to keep a good balance between inviting openness and respectful distance. Sensitivity to the patients' body language and tones of voice can assist health care workers in awareness of the patients' balancing work; this keeps the patients unharmed and thus makes vulnerability and pain more bearable. Health care personnel carry a major responsibility in this due to their power (9), and patients expect to be welcomed in the environment (29). The nurse in the given example did not know the patient and her expectations, and she probably acted in good faith in the beginning. It is also possible that the nurse intended to keep a respectful distance and not be intrusive when the patient broke down. However, a careful invitation to talk about how she felt could perhaps have made her feel better understood and accepted, and it could have rebuilt mutual trust and courage in their relationship.

The outcome of this situation was probably connected to what happened later that evening. After the patient found her bed in the corridor, she was offered a bed in a one-bedded room. This could be interpreted as a caring offer by the nurse, but the patient kindly refused this without giving any reason to the nurse. "You understand," she explained in the interview the day after, "I knew the room was vacant because the patient had just died. I could not stand the thought of sleeping alone in there, where somebody had just died; I rather preferred to sleep in the corridor". The noise, light, and lack of privacy in the corridor were preferable to the threatening silence in the room. Her struggle with the existential threat and balancing despair could not handle the closeness to death this room represented. In this difficult situation she turned to God and she revealed: "Most of us pray when we are in some

kind of need. I say: God help me now (she cries), I cannot take anymore, now I need your help”.

As demonstrated in this example, the unexpressed ethical demand easily slips away in the clinic. When nurses and physicians have little awareness of these patients’ vulnerability, the silent demand is apt to be overlooked (4, 14). Even though most of the patients’ preparative work is not easily seen, Løgstrup’s poetic expression that we hold some of the other person’s life and destiny in our hands rings true for nurses and physicians working with patients in the diagnostic phase, as do his writings about our responsibility to take care of the other person’s best interest.

The tone and gestures of nurses or physicians are also important when patients evaluate to what extent staff members are sensitive to them so that they dare the risky undertaking of coming forth (12). The following story exemplifies how one participant developed trust with one particular physician. She felt he was committed to her situation; he saw her and cared for her, or to use Austgard’s (16) expressions; saw the need for dignity, integrity, and hope, phenomena our eyes cannot see. At one point he came into the corridor where she was walking, put his arm around her shoulder, and told her that he had come to take her down to the long-awaited investigation. Later on, when she misunderstood a different physician at one of the rounds and thought that she had cancer, she was very upset. She tells: “He (the first physician) knew how worried I was. In the afternoon he came to my room and sat on the bed and talked with me for 20 minutes. I got all the answers I needed. Even though he is so occupied, he gave me a lot of his time.” In this way the physician assisted her preparative work by providing her with accurate information. Her interpretation of clues from her own body and his way of being and talking with her helped her to better understand her case. This improved her sense of hope both related to the final result of the

investigation and in a renewed experience that there was a professional in this hospital who knew and cared about her.

In our study it might be easier for physicians than nurses to see the ethical demand, since physicians have more concrete tasks related to these self-sufficient patients in the diagnostic phase, such as giving information and carrying out investigations. However, the challenge remains the same for all staff; to carry an attitude, interest, and ability to act in the best interest of the patients (12). We find stories in our data of nurses and physicians who were able to practice this and others who did not. The healing balance between closeness and distance, attention and presence that makes vulnerability and pain bearable (19, 23) is also reported in other studies (10-12, 29-30).

Conventions and the ethical demand

Earlier we stated that the ethical demand is radical, silent, and one-sided. The nurse meets the patient with an ethical demand just as the patient does the nurse. They are both dependant on trust, but their power and thereby their vulnerability is different. Løgstrup also argues that in our social lives we do not have the right to make the ethical demand to others, expect from those which are conditioned by social norms, moral, legal, and conventional criteria implied in our lives together (21). How laws, morals, and conventions relevant for our professional practice are set up and informally exerted are therefore of interest to this discussion. They serve as guidelines and give clearer directions to individual professionals, leaders and organisations of what to do and how to relate to each other to protect misuse of trust and exploitation.

The aims of the Patients' Rights Act are, for example, outlined as to promote trust, safeguard respect for life, integrity and human dignity and it states clearly what rights patients have and obligations professionals and their organisations have (25). Patients have rights such as to participate in implementation of care and to obtain necessary information. The Ethical guidelines for professional conduct for nurses state that nursing shall be founded on compassion, care, and respect for basic human needs; it shall safeguard the integrity of the individual patient and protect them from offence (31-32). Both are well in accordance with the ethical demand and place responsibility on professionals to take care of patients in their best interest due to the knowledge and power we have. An important part of taking care of patients in the diagnostic phase is to have skilled staff, sufficient and quality equipment as well as good coordination of required investigations, and accurate exchange of information. This together with compassion and support is highly valued by patients (8).

Patients waiting for a diagnosis vary in their background, experiences and expectations, in patterns of balancing, how they work on making sense of their situation, how they experienced the existential threat, how they seek respite, and what it means to them. There is therefore no easy way to outline how staff should act to follow the norms in relation to patients in the diagnostic phase. We need our judgement, which must be built on the motive of wanting the best for the patient in addition to the use of knowledge, experience, and imagination (21), in acknowledgement that the illness experience relates to man as a whole being, and goes beyond the objective and bodily focus found in the bio-medical model (1-2). This should not be outlined as that in all interactions there should constantly be a focus on all sides of the illness experience; it rather means that nurses and physicians should have the readiness, ability, and willingness to be sensitive to what is of importance to individual patients. Sometimes showing respect for integrity can be to focus on a limited aspect in acknowledgment of the fact that there is more to be said about the

person and the situation. This can help patients to keep their face and endure the waiting time (4).

We mentioned that the nurse, who kept a distance from the patient who broke down crying, probably did so out of respect or fear of being seen as too open and not respecting the patient's untouchable zone. It is also possible that informal norms at the unit affected her evaluation of the situation. Nurses create norms of how to relate to patients to protect both themselves and patients (23, 33), and if the informal norm at the unit, for example, were that nurses too readily become involved in psychological and spiritual aspects of patients, it would hamper the nurse in making an adequate judgement of the actual situation. How well our practice, built on knowledge, experience, formal, and informal norms, is in accordance with the ethical demand is practically tested in our interactions with each other.

A hospital is a complex organisation that serves many purposes, which lead to discussions not about the best possible care and treatment, but about what is good enough; what is professionally justifiable (32). In this reality it is a professional responsibility for individuals and leaders to develop and maintain a culture where conventions, procedures, and guidelines are practiced so that life utterances can come alive and patients feel taken care of while in our hands (6). To the extent leaders pay attention to how trust, openness, and untouchability are practiced, they are of great importance as attitude reminders for their staff (14). Such attention can be shown in activities such as teaching, discussions, requests, giving feedback, and report-giving in the system.

Since cultures, norms, and science work as authority for what professionals evaluate as good, we need to constantly evaluate if they are in accordance with the ethical demand. Martinsen recommends that we should be both committed to norms and at the same time keep enough distance from them to give adequate room and space to make good judgements

in the best interest of the other and thereby prevent abuses such as assault and rejection (23-24).

CONCLUSION AND IMPLICATION

If it matters to us how patients experience going through the diagnostic phase in hospitals, a central question becomes: How can nurses help them make the situation more bearable? Patients that need little physical care can easily disappear from nurses attention in a busy ward; however they too need to be followed up with information, coordination, and to be cared about. These patients see and evaluate how nurses and physicians appear, and to what extent they can be trusted and thereby be someone they can lean on for strength and hope in a very painful time of their life. Patients' ethical demand can never fully be understood nor met by nurses and physicians, but to the extent we are knowledgeable with a well equipped and coordinated hospital, we can make good judgements on how to meet the individual patient. Trusting relationships and communication protect vulnerability and strengthen patients; thereby making the time of uncertainty easier to endure.

The discussion in this article focuses on qualities in personal relationships and in professional cultures which are so basic that we often forget to acknowledge them. They might therefore be easy to overlook and not be given enough attention in the evaluation and development of norms, rules, and standards in clinical practice. If that happens, these qualities are handed over to the individual health care worker to perform and foster, and not looked after as an integrated part of professional accountability. Leadership at units and in the organisation is responsible for assisting the individuals and groups of professionals to keep up good practice.

PWT has implication for nursing education; to teach about and foster the ability and willingness to focus on the interpersonal relationship between patient and health care personnel. Further research can help us learn more about how we better can unveil and recognise the silent demand in the diagnostic phase without letting the patient feel exposed or embarrassed.

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Figure 1. A model of Preparative Waiting Theory



