Patients' silence following healthcare staff's ethical transgressions

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Original Publication:

Jelmer Brüggemann, Barbro Wijma and Katarina Swahnberg, Patients' silence following healthcare staff's ethical transgressions, 2012, Nursing Ethics, (19), 6, 750-763.
http://dx.doi.org/10.1177/0969733011423294

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Introduction

The inclusion of patients in health care quality improvement processes has only during the latest decades been recognized by the health care sector (1). One way to include patients in these processes has been to collect patients' feedback about the care received, e.g., by means of patient satisfaction surveys (1). Such surveys aim to measure patients' overall experiences of their care, including interpersonal aspects (2), which include nursing care characteristics and ethical demands such as humaneness of care (3). These surveys, however, have been criticized on different grounds and their validity has been questioned (4-6). One major critique is that patients' untoward experiences in health care are not adequately captured by patient satisfaction studies (5). A recent concept analysis showed that events of abuse in health care (AHC) are easily missed out in patient satisfaction studies (7). As these events are characterized by patients losing their value as human beings and as uncaring, regardless of staff's intentions (3), this should be seen as a major ethical problem for the health care system. If such events are missed out in patient evaluations, health care staff runs a great risk of losing vital information to improve caring processes. Therefore, in this study we explored patients' silence after health care staff's ethical transgressions.

Abuse in health care

AHC has been operationalized in the Norvold Abuse Questionnaire (NorAQ, box 1), according to which lifetime prevalence of AHC was estimated to range between 13 and 28 percent of female patients in the Nordic countries (8). Some 8 to 20 percent of all women reported that they currently suffered from their experiences (8). Corresponding prevalence of AHC among Swedish women and men was 20 and 7 percent respectively, and 13 and 4 percent respectively reported current suffering from AHC (8, 9). In qualitative interview studies, female patients described AHC as the feeling of "being nullified" (10), and male patients as "being mentally pinioned" (11). Currently it is not known why AHC takes place and can prevail (7).

	Abuse in health care (AHC)
Mild abuse	Have you ever felt offended or grossly degraded while visiting health care services, felt that someone exercised blackmail against you or did not show respect for your opinion – in such a way that you were later disturbed by or suffered from the experience?
Moderate abuse	Have you ever experienced that a "normal" event, while visiting health care services, suddenly became a really terrible and insulting experience, without you fully knowing how this could happen?
Severe abuse	Have you ever experienced anybody in health service purposely – as you understood – hurting you physically or mentally, grossly violating you or using your body and your subordinated position to your disadvantage for his/her own purpose?
	Answer alternatives (same for all questions)
	1 = No, 2 = Yes, as a child (<18 years), 3 = Yes, as an adult (≥ 18 years), 4 = Yes, as a child and as an adult.
	AHC was operationalized as at least one Yes to one of the three questions.

Box 1: Questions about abuse in health care in the Norvold Abuse Questionnaire (NorAQ)

Theory

Johan Galtung's theory of violence helps depict the complex environment in which AHC exists (12, 13). Galtung pictures direct, structural, and cultural violence as corners on a triangle, thereby portraying the complex but fundamental relationships between these three types of violence. His main idea is that direct events of violence, i.e., mostly face-to-face incidents, never exist in isolation; they are fed by structures and legitimized by cultural norms and taboos. We have applied Galtung's theory to understand and explain cases of AHC on several occasions (14, 15). One example of a "violent" structure in health care is the structural disempowerment of patients, through, e.g., the use of a medical language or the silencing of patients' voice (15). Such a structure enables, or even legitimizes direct events of violence to take place. Galtung's theory makes clear that as long as violent structures exist, it is very hard to prevent direct events of violence. But how to change structures?
Giddens' theory of structuration helps to understand how structural change is possible (16). Structures can be seen as the rules that enable, limit, and organize an individual's behavior. Recognizing the action-guiding power of structures, Giddens also attributes structure-shaping power to individual action: actions reproduce the rules by which they are enabled and limited at the same time. However, this reproduction is not "robotic" but can be done in slightly different ways; acting in a slightly different way may change the rules by which we act as these rules are continuously monitored and altered by means of feedback loops (16). Acting in a way that deviates from the initial rules therefore has the possibility to slightly change those rules through feedback to all agents involved in the social situation. Patients

acting in a different way in AHC situations and giving feedback to staff can as a result lead to structural changes in health care encounters

Patients' silence to the health care system

Structures within the health care system touch upon many actors. If our aim is to improve structures, it is of importance to engage all agents, including patients. However, the active role that the patient has in health care encounters is seldom recognized (17). For comparison, in the large field of the prevention of medical errors, only few have made attempts to include patients in quality processes (18). Being the agent who experiences and defines the event, the patient is a rich source of information. However, regarding the character of the events and the subordinated position the patient is put in from the beginning, the inclusion of patients in improvement processes should primarily not build on patient responsibility. Instead, the health care system should create an environment in which patients' voice is fostered (19).

Therefore, in the present study we aimed to examine patients' silence to the health care system after they had experienced abusive events, operationalized in the Transgressions of Ethical Principles in Health Care Questionnaire (TEP). Patients remaining silent can result in not only a false form of complacency in health care but also a loss of both valuable information and possibilities for structural change.

Three research aims were used during the study: (i) to study to what extent patients experienced staff's wrongful or abusive transgressions and remained silent about it, (ii) to

examine what events patients remained silent about, and, (iii) to test TEP's convergent validity as well as to judge its face validity, as no validated instruments were available.

Methods

Participants and procedure

TEP, which covered patients' experiences of staff's transgressions of ethical principles, was sent to 891 female patients between September 2009 and May 2010. Patients were recruited through a women's clinic at a county hospital in the south of Sweden. The choice of hospital was based on convenience, as we had fruitfully collaborated in earlier research projects. Also, the hospital explicitly expressed their ambition to stimulate point-of-care research projects. The women's clinic was chosen because of ongoing research collaborations and for the fact that the clinic covers a wide range of patients, including healthy patients who visit for screening tests or regular check-ups. The clinic's high number of outpatient visits and staff's engagement in the project contributed to a structured and efficient sampling procedure. The choice for a female patient sample was based on the fact that prevalence of AHC is twice as high in female patients compared to male patients (9). Selection criteria for the sample were: 1. consecutive female patients coming for an outpatient appointment, 2. $\geq$18 years old, 3. speaking and understanding the Swedish language, and 4. having a known address. At the clinic, patients received a first information

letter and had an option to decline participation. After that, patients who had not declined received a second information letter and TEP by post within the next month. Two reminders were sent out with a two-week interval and completed questionnaires were returned in prepaid envelopes. We considered that we had obtained informed consent when we received the completed questionnaires. The study was approved by the regional ethical review board (reg. no. M116-09). The approval included the construction of TEP and the use and modification of instruments earlier developed within our research group (NorAQ and ViolEP, see below).

Measurements

TEP is partly based on the Violations of Ethical Principles Questionnaire (ViolEP) (20). Violations of ethical principles or disobediences have a negative connotation *per se*, so "transgressions" was used instead. Different from violating an ethical principle, transgressing refers to "breaking" a principle but does not automatically imply wrongful behavior, as following one principle can be outweighed by following another more important principle in that situation. TEP describes 23 events that operationalize transgressions of ethical principles in health care based on theory, policy documents, ethical codes and clinical experience. The events were distributed between the ethical principles as follows: autonomy [5]; justice [2]; physical nonmaleficence [4]; integrity [4]; sexual nonmaleficence [8]. Central to TEP is the patients' silence, defined as patients refraining from giving feedback to the health care system, despite having moral reasons to act or speak up. This silence was

seen as a process, which is why we took the starting point of Rest's four component model of moral behavior (21). TEP allows us to study individual patients' feedback to the health care system, although details about what this feedback looked like are beyond the scope of TEP. According to Giddens such feedback is quintessential in processes of structural change. Studying this feedback allows us to gain some first insights in the conditions and latitude for such structural change.

*** Figure 1 near here***

Rest's model identifies four necessary components needed for "moral action" (i.e. behavior): 1. moral sensitivity, 2. moral judgment, 3. moral motivation and 4. moral character (21, 22). Within our operationalization, silence can have its roots in Rest's components three or four, which are not measured in TEP. For example, considering component three, the fact that one morally judges the event as wrong does not mean that one prioritizes to undertake moral action, so moral motivation might not come about. Other, *non-moral* reasons are included in the decision-making process and could outweigh the option of moral action; e.g. the patient prioritizes her illness-recovery process. Looking at the fourth component, if moral motivation was established, action still demands moral character, including practical skills, which an individual could lack in a specific situation; e.g., lacking knowledge on how to make a formal complaint or too strong fear of retribution (23). Components one and two, and moral action were transformed into questions for patients concerning staff's transgressions in TEP (figure 1). The main question relates to moral sensitivity; the "actual" experience of an event. Follow-up question A and B separately operationalize moral judgment, and follow-up question C represents moral action. Silence, then, is

operationalized as a “yes” to the main question and “no” to question C; and at least one “yes” to question A or B (box 2).

Have you ever experienced in Swedish health care that…	**A** Did you perceive what happened as abusive?	**B** Did you judge what happened as wrongful?	**C** Have you talked about what happened with the health care staff, complained, or made clear in any other way that you experienced what happened in this way?
Example cases of transgression Yes / No	Yes / No	Yes / No	Yes / No

Box 2: Transgression and silence questions in the Transgressions of Ethical Principles in Health Care Questionnaire

The questionnaire also included questions that covered sociodemographic characteristics, general health, lifetime experiences of emotional, physical, and sexual abuse, knowledge about patient rights, and the AHC questions from NorAQ (box 1) (24). To test for response bias, we included “days to respond” as a continuous variable in our dataset (based on 12 months to 30 days). It has been suggested that non-response can be seen as an extrapolation of late response (25, 26).

Statistics

Descriptive statistical analyses were performed using the Statistical Package of the Social Sciences 17.0 (27). Univariate ANOVA (including Tukey’s post-hoc) was run to test for response bias using “days to respond”.

Validity

Two aspects of TEP were interesting to validate in this study.

One aspect was the *face validity* of the silence operationalization in TEP, which was based on a qualitative judgment. As silence was defined as patients refraining from giving feedback to the health care system, face validity was good if follow-up question C (box 2) covered all patients' feedback. The follow-up questions were reviewed by one expert on response psychology and three health survey experts. Also, the feedback-actions included in question C were compared to a set of possible actions that patients performed according to a study on patients' expressions of dissatisfaction (28).

A second aspect was the extent to which TEP captures abusive events. With this in mind, we tried to estimate the *convergent validity* of the question whether patients had ever perceived one of the listed events as abusive (follow-up question A, box 2). We did so by looking at how well this question converged with the validated AHC questions in NorAQ (gold standard, box 1) (29). The AHC questions in NorAQ have shown good values for sensitivity and specificity, as well as for positive and negative predictive values, with an interview as gold standard in a sample of Swedish women (n=64). Test-retest reliability was high and kappa values were satisfactory (29). Both the TEP and NorAQ questions were transformed into dichotomous variables that represented any lifetime abusive experiences in health care according to the respective instrument (yes/no). TEP, covering a wider range of events, was expected to capture more positive answers than NorAQ. For the aims of the present study it was important that TEP missed few positive NorAQ answers. Therefore,

satisfactory convergent validity would be reached if TEP had a not too high positive predictive value, but good sensitivity.

Results

Background characteristics

534 out of 891 (60%) patients returned TEP and 530 were included in our final dataset. Four respondents were excluded: one male respondent, one respondent who showed an invalid answering pattern, and two respondents who had more than 50 percent of the answers missing. Background characteristics are shown in table 1.

	Study sample (n=530)*	
	n	**%**
Age		
≤ 34	153	29.1
35-49	182	34.7
≥ 50	190	36.2
Education (years)		
<10	92	17.5
10-12	218	41.5
>12	215	41.0
Country of birth		
Sweden	466	89.6
Other Nordic country	8	1.5
Other European country	20	3.8
Outside Europe	26	5.0
Occupation (latest 12 months)		
(Self) employed	345	65.3
Studied	36	6.8
Unemployed	12	2.3
Parental leave	36	6.8
Sick leave / retired / social welfare	97	18.4
Homemaker	2	0.4
Household income (SEK/month before taxes)		
<7 000	17	3.3
7 - 14 900	61	11.8
15 - 24 900	92	17.8
25 - 34 900	87	16.8
35 - 44 900	98	18.9
45 - 54 900	86	16.6
55 - 65000	48	9.3
>65 000	29	5.6
Any lifetime emotional abuse**		
Yes	135	25.9
Any lifetime physical abuse**		
Yes (mild abuse excluded)	104	19.8
Any lifetime sexual abuse**		
Yes	94	17.8
Any lifetime abuse in health care**		
Yes	130	24.9
Self-rated health		
7 (very good)	58	11.1
6	132	25.3
5	119	22.8
4	100	19.2
3	73	14.0
2	31	5.9
1 (very bad)	9	1.7

* deviations in percentages exist due to item non-response

** according to questions from the Norvold Abuse Questionnaire

Table 1: Background characteristics of the participants

Remaining silent about staff's transgressions

Table 2 shows descriptive data considering patients' reported experiences of staff's transgressions of ethical principles in health care, and their subsequent actions. The vast majority had experienced staff transgressing ethical principles (63.6%). High proportions of experienced events were found within the principle of autonomy, while transgressions within the principle of sexual nonmaleficence were least experienced. Transgressions perceived as abusive were mostly found within the principles of physical and sexual nonmaleficence, and integrity. For most events, more than 90 percent of the patients who experienced an event judged it as wrong. Considering silence, the highest proportions were found for the principles of physical and sexual nonmaleficence, and integrity. For some transgressions, more than 80 percent of the patients had kept silent, despite perceiving the event as abusive or wrongful. The event about which patients remained least silent was that another patient was allowed to pass in the queue without having a reason (48.0%). Of all patients who perceived a transgression as abusive or wrongful, 70.3 percent had ever remained silent about at least one event. No general differences in remaining silent (relative to the amount of events) were found depending on whether the transgression was perceived as abusive or as merely wrongful (data not shown).

	Experienced event n (%) of all women (n=530)*	Perceived as abusive n (%) of women who experienced event*	Judged as wrongful n (%) of women who experienced event*	Silence n (%) of women who perceived event as abusive AND/OR judged event as wrongful*
Have you ever experienced in Swedish health care that…				
Autonomy principle				
you were not adequatly informed?	241 (46.3)	38 (17.6)	185 (88.5)	94/185 (50.8)
you did not get enough time to consider (e.g. options)	77 (14.9)	20 (30.3)	49 (75.4)	31/51 (60.8)
your opinion was not taken notice of?	148 (28.7)	87 (64.4)	124 (96.9)	68/126 (54.0)
you were not listened to?	188 (36.3)	109 (64.1)	165 (95.9)	92/164 (56.1)
you felt forced to accept a treatment or a sampling against your will because of fear for maltreatment if you did not?	33 (6.4)	22 (78.6)	27 (90.0)	20/27 (74.1)
Justice principle				
another patient was allowed to pass you in the queue without having a reason?	43 (8.2)	17 (53.1)	27 (84.4)	12/25 (48.0)
you did not get the care you think you have the right to get?	107 (20.7)	49 (55.7)	87 (96.7)	54/86 (62.8)
Have you ever experienced in Swedish health care that staff…				
Physical nonmaleficence principle				
held you firmly against your will?	19 (3.6)	13 (72.2)	12 (75.0)	8/12 (66.7)
performed an examination/treatment in a too rough way?	86 (16.6)	48 (62.3)	71 (94.7)	51/71 (71.8)
continued an examination in spite of your protests?	26 (5.0)	17 (85.0)	21 (95.5)	12/19 (63.2)
hit you or threatened to hit you?	2 (0.4)	1 (100.0)	1 (100.0)	1/1 (100.0)
Integrity principle				
exposed you to mockery?	46 (8.8)	38 (95.0)	37 (97.4)	26/38 (68.4)
humiliated you?	58 (11.1)	48 (96.0)	50 (100.0)	29/48 (60.4)
made you feel forgotten or neglected?	108 (20.8)	62 (63.3)	90 (97.8)	53/88 (60.2)
violated his/her professional secrecy concerning you?	15 (2.9)	8 (80.0)	12 (92.3)	8/12 (66.7)
Sexual nonmaleficence principle				
watched you undress or dress instead of offering you to do it in private?	39 (7.5)	12 (35.3)	21 (67.7)	18/20 (90.0)
commented or criticized with a sexual undertone, your underwear or your body?	4 (0.8)	3 (100.0)	4 (100.0)	1/2 (50.0)
flirted or talked to you in a seductive way?	9 (1.7)	3 (33.3)	5 (62.5)	3/5 (60.0)
told you about his/her own sexual preferences, problems or fantasies?	3 (0.6)	2 (66.7)	3 (100.0)	3/3 (100.0)
performed an examination in a way that you perceived as having an undertone of sex?	8 (1.5)	5 (100.0)	7 (100.0)	6/7 (85.7)
touched in a sexual way your breasts, external genitals or other parts of your body?	8 (1.5)	6 (85.7)	7 (100.0)	6/7 (85.7)
encourages you to masturbate or made you watch him/her masturbate?	-	-	-	-
wished to start a sexual relationship with you?	-	-	-	-

* deviations in percentages exist due to item non-response

Table 2: Descriptive statistics of patients' reports of staff's transgressions in TEP

Non-response

Univariate ANOVA tests showed that there were no differences between the number of days it took to respond in relation to whether respondents experienced transgressions or reported any silence. This may suggest that non-response rates did not significantly influence prevalence numbers of these main variables.

Considering item non-response, we could see a clear difference in our data set, as follow-up questions (A-C) showed a higher non-response than the main questions ("Have you ever experienced…"), which explains deviations in percentages in table 1.

Validity of TEP

Measures of TEP's performance as a screening instrument for experiences of AHC (according to NorAQ) were used to test convergent validity (table 3). Sensitivity and positive predictive value were found to be 82 and 58 percent respectively. Considering face validity, the experts reviewed our follow-up questions and appropriate changes were made according to their comments. Follow-up question C seemed to cover all of the patients' possible actions considering direct feedback to the health care system, but it did not cover actions within the patients' informal networks, political action nor changes in health care seeking behavior.

		Abuse in health care (NorAQ)	
		Yes	No
Perceived events as abusive (>0) in TEP	Yes	107	79
	No	23	313

Sensitivity	82.3%
Specificity	79.8%
Pre-test probability	24.9%
Pos. predictive value	57.5%
Neg. predictive value	93.2%
Likelihood ratio for positive test	4.1

Table 3: Reporting abusive events in TEP as screening instrument for experiences of abuse in health care (according to NorAQ; gold standard)

Discussion

The present study aimed to map patients' experiences of staff's transgressions of ethical principles in health care and patients' silence to the health care about these experiences. The vast majority of the female patients had experienced transgressions, and many patients perceived these events as abusive or wrongful. Of these patients, more than two-thirds had ever remained silent about at least one event. For some transgressions, more than 80 percent of the patients had kept silent, despite perceiving the event as abusive or wrongful. As expected, TEP captured more abusive experiences than NorAQ, and missed a few. This resulted in a high sensitivity and a rather low positive predictive value, as we expected, which is why we consider the convergent validity of TEP for the aims of this study to be satisfactory. It should be noted that this validity is relative considering sample used and prevalences found (30). Where it concerned face validity, it was suggested that TEP should

cover all of the patients' possible actions that related to direct feedback to the health care system. The patient actions that were excluded were actions within the patients' informal networks (e.g., talking about their experiences with acquaintances) as well as political actions and changes in health care seeking behavior. Seen from the definitions and aims of the present study, however, it is doubtful whether talking with acquaintances and switching health care provider has any direct effect on the structures in the health care system, even if such actions are important for patients. There are many reasons why a change of health care provider does not have a direct effect on underperforming providers, e.g. an excess of demand or a lack of feedback on what to improve, since leaving a health care provider does not give the provider specific enough information to improve practice (19, 31). As silence was defined as patients refraining from giving feedback to the health care system (see Measurements), it was concluded that these limitations of question C do not reduce the face validity of our silence operationalization. On top of that, one of the strengths of our operationalization is that it captures more than formal complaining, as it has been shown that formal complaints are only a part of patients' actions, and that only 41% of patients classified their complaint as a complaint (28). Overall, the face validity of our silence operationalization was judged to be good.

A response rate of 60% was regarded as acceptable, and this was in line with data collections similar to the one used in this study (20). This, however, does not mean that the data is free from response bias. For this reason we measured respondents' days to respond and found no differences in days to respond for experiences of transgressions or for silence. This may suggest that response bias in our data set has not significantly affected the prevalence numbers of our main variables (25). The main assumption underlying methods based on time to respond is that non-responders have more in common with late responders than

with early responders (32). Time to respond is one of only a few methods for estimating the influence of non-response if data on non-responders is absent. Unfortunately, the method has not received much attention in existing literature, and our application of it should be seen as an attempt rather than a final conclusion concerning a response bias in our data set. Our follow-up questions showed a higher non-response than the main questions, which is a weakness in our data, since our main outcome variables are based on these follow-up questions. One explanation for this may be the structure of the questionnaire, combining multiple follow-up questions with a rather high number of events. Unfortunately, the overall number of responses to each follow-up question was too low to perform strategies such as estimation or imputation of values (33), which is why we chose to exclude missing values in the calculation of percentages in table 2.

Another limitation of the present study is a risk of recall bias, which is a factor in most, if not all, retrospective studies (34). Different from memory failure, a condition for recall bias is that the memory failure is differential, i.e., the failure is not randomly distributed throughout the sample, which affects the accuracy of the results (34). An example in the present study could be that patients' gratitude over the care they received prevented them from reporting abusive transgressions, as this has also been suggested to prevent patients from reporting dissatisfaction (2). The number of transgressions may, for that reason, have been underreported.

TEP builds upon a patient's own moral judgment of transgressions; silence can only occur if the patient herself perceived an event as abusive or judged it as wrong. This prevented us from having to engage in moral absolutism, i.e., assuming that some actions always are wrong, independent of consequences and context. Such absolutism is not in line with how ethical guidelines are structured in Swedish health care, as ethical principles should always

be seen in a context and can be outweighed by other ethical principles (35). One weakness of this way of looking at transgressions is that patients who do not perceive a "clearly wrong" event as abusive or wrongful, are excluded from our operationalization of silence. Such silence through acceptance may be even more serious than the silence we describe, in a sense that these patients somehow got numbed in their moral judgments, possibly caused by their total dependency within the health care. Silence through acceptance seems more harmful, since these patients no longer recognize that certain behavior is wrong. This form of silence, however, goes beyond what we have been able to study here.

The methods used in the present study cannot explain why patients keep silent about events in health care that they perceived as wrongful and abusive, but a few suggestions based on our theories and earlier studies can be made. It has been shown that reasons for patients not to complain include that there can be large, organizational barriers, and only complex complaining procedures are available to patients (28). Factors behind not expressing dissatisfaction (including not complaining) can be fear of retribution, there may be feelings of powerlessness to contribute to change, the issue could be seen as a waste of time, or it can be outweighed by other personal issues or by feelings of gratitude for the care received (5, 28). We can imagine that similar factors are active where it concerns silence on abusive transgressions. The current application of Rest's model shows that patients' silence towards the health care system is rooted in the absence of moral motivation or moral character (21). This model could be helpful to future intervention programs. For example, a mere focus on decreasing organizational barriers to file formal complaints may be not enough to reinforce patients' moral character if feelings of fear and powerlessness are too strong. Also, moral motivation may not come about as a consequence of patients' ill-health. Therefore, more research into the factors that restrain patients from speaking up is needed before

intervention programs are tested. In this respect it should be considered that no general differences in remaining silent were found depending on whether patients perceived a transgression as abusive or wrongful. This is somewhat surprising, knowing that female patients have described AHC as “being nullified” (10), which would have been reason to expect higher silence after abusive transgressions than after wrongful ones. However, as the severity of events is unknown, some abusive transgressions may not imply feelings of being nullified, but emotions which may motivate action more actively, such as anger (cf. 36). This non-difference would be interesting to examine more closely.

Concerning factors behind remaining silent it must not be overlooked that our current sample was confined to female patients only, as issues as fear, power and gratitude are likely to be gendered. As an example, a societal pattern of female subordination can be assumed to affect the norms that guide women’s behavior, especially within male dominated hierarchies such as the health care system (37). This has been suggested to be a reason behind why women tend to avoid confrontation with doctors and choose indirect approaches, such as switching health care provider, more so than men (38). It also has been shown, on multiple occasions, that staff’s behavior towards patients is gendered regarding diagnosis, treatment, and care, most often to the disadvantage of women (39, 40). Societal changes, such as a focus on women’s rights and an active patient role, could lead to more female patients speaking up. This, however, has been suggested to be related to staff’s prejudices that female patients are more demanding than male patients (41). Regardless of what future studies in male patient samples will show, the health care system and staff should be aware of such gendered patterns if patients are to be included as sincere active patients in health care processes for structural improvement. Future interventions in the area also need to be gender sensitive.

Galtung explains the importance of structures for the prevalence of direct incidents of violence (12, 13). The high prevalence of patients' silence found in this study suggests that silence is the norm rather than the exception, and it can be seen as a structural factor that prevents a counteraction of direct events of AHC. Especially if silence is interpreted by staff as a form of acceptance or confirmation of correct behavior, then silence does not only hinder counteraction, but it may also unintentionally contribute to the prevalence of structures that have harmful consequences for patients. Even if patients raise their voice, the structural change necessary to improve health care practice upon this feedback is in the hands of health care staff and clinics. According to Giddens, this feedback can lead to change if staff and clinics (i) see other options to act, and (ii) find a desire to pick the option that does not lead to AHC. We believe that the voice of patients can affect both. First, they can do so by giving direct and constructive feedback about abusive events and possible alternative options, as was done, for example, by homosexual patients on how to ask about family life (42). Second, the voice of patients can also explicitly activate the moral resources of staff, by pushing harder on staff's "empathy" button, and function as a moral mirror. This insight may help staff to reflect on the consequences of certain routines and actions seen from the patients' perspective. Being actors within strong hierarchical institutions, with limited options to act, health care staff may be in need of finding alternative ways of acting, and we believe that patients may be one source of such alternatives.

Future studies in the field could explore whether remaining silent is associated with patient characteristics, and to what extent. It would also be of interest to study how patients who act or complain are encountered by staff and the health care system. What happens to them and what happens to their feedback? And not the least, did any change come about?

Conclusion

A vast majority of female patients had experienced staff's transgressions of ethical principles in health care. Many of these patients perceived these events as abusive or judged these events as wrong, but they often remained silent. It was also concluded that TEP is a sufficiently valid instrument to capture patients' abusive experiences in health care, as well as the silence that follows such events.

The high prevalence of patients' silence found in this study suggests that silence is the norm rather than the exception, and this can be seen as a structural factor that prevents the counteraction of direct events of AHC. From the viewpoint of change, this is an alarming result. Patients' silence could be interpreted by health care as a false form of satisfaction, legitimizing present (violent) structures, and it is a loss of essential feedback for the health care system. Interventions to lower this silence will need to be explored, e.g. aiming at opening up alternative ways for patients to speak up, in order to enhance patient – health care interaction and feedback. Even though the health care system bears responsibility for health care processes, this does not mean that patients should be excluded from these processes. Combined with health care providers' willingness to systematically listen to their patients, patients' feedback could lead to structural changes towards preventing AHC.

Acknowledgements

The NorVold Abuse Questionnaire (NorAQ) was developed by NorVold, a research network established in 1997 to explore the prevalence of violence against women and its effects on

women's health. The NorVold research network was supported by grants from the Nordic Council of Ministers.

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Conflict of interest statement

The Authors declare that there is no conflict of interest.

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