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Stiftung für Patientensicherheit
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'Trust rather than blind faith' – Chemotherapy patients' perspectives on medication safety

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Background:
Medical errors pose a serious health threat to patients with cancer undergoing chemotherapy. Research suggests that patients with cancer often work hard to ensure safe care and to prevent errors that could cause harm. Worldwide, many cancer centers now try to engage patients with cancer as vigilant partners. Yet, there is limited evidence about chemotherapy patients' perspectives on safety. The main aim of this study was therefore to explore chemotherapy patients' experiences and perceptions of drug administration safety, risk and error, and to investigate predictors for their participation in error prevention.

Methods:
A mixed methods design combining qualitative and quantitative methods was appropriate for this study:

- Semi-structured interviews with chemotherapy patients at two occasions (n=30 patients; 60 interviews). The qualitative data were transcribed, coded and analyzed using content analysis.
- Quantitative self-administered survey of chemotherapy patients (n=479). The survey included measures of risk, error, and error prevention strategies. Based on the theory of planned behavior, scales were developed to assess instrumental attitudes (Cronbach's α=0.86), affective attitudes (α=0.86), perceived behavioral control (α=0.80), subjective norms relating to staff (α=0.87), norms relating to relatives (α=0.84), and intentions to engage in error prevention behaviors (α=0.92).Confirmatory factor analysis and structural equation modeling were used to model patients' safety related behaviors.

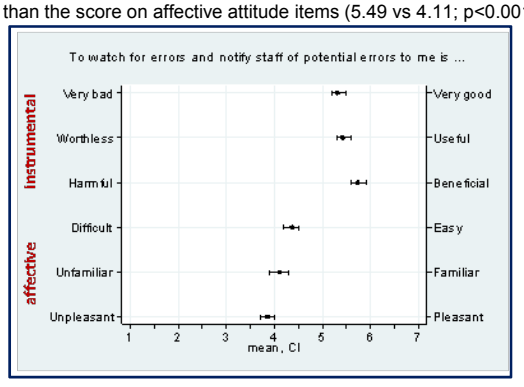
The study was conducted at the oncology/hematology department of a large regional hospital in Switzerland.

Key results:
Interviews with patients: Many patients reported experiences of errors or safety slips during their chemotherapy treatment (example cit., box 1). Patients described engaging in their safety as a learning process and highlighted the importance of being proactive, asking questions and communicating any deviations from routines. Instruction by nurses was central for patients, but the underlying reasons varied. There was no indication that patients perceive participation in safety actions as eroding trust in their providers (box 2).

Box 1
Once, the nurse came in with only one IV bag. I asked him why I should only have one. I always had two bags, you know. He left the room… and came back only after a minute, smiling, and with the second bag.

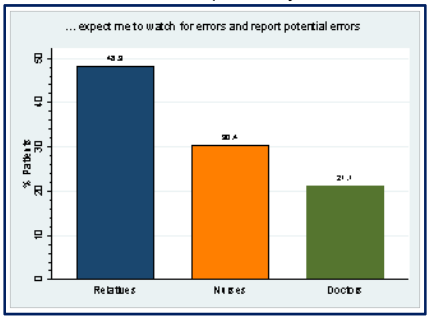
Now, when I check the drugs, it is a good feeling of trust. Because, now I know that I can have trust, that my trust is justified. Before that it was simply 'blind faith.'
Box 2

Quantitative survey among chemotherapy patients: 16% of chemotherapy patients reported having experienced error in their care, and 11% were currently very concerned about errors. Relative to other errors, patients systematically underestimated the harm associated with drug overdosing. 77% of responders agreed that patients can help to prevent errors. In general, patients shared positive attitudes towards involvement in safety. The mean response to instrumental attitude items was significantly higher than the score on affective attitude items (5.49 vs 4.11; p<0.001; figure).



This clearly indicates that patients valued the outcome expectations of error monitoring more positively than the process of performing this behavior.

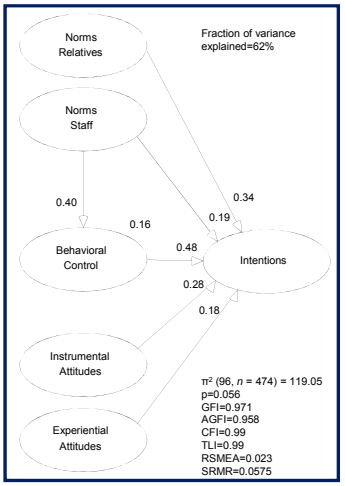
Although patients perceived staff as being committed to providing safe care, ratings related to patient involvement in safety were considerably lower. 27% strongly disagreed that staff instructed them to report potential errors. These experiences are also reflected in subjective norms, i.e., patients' perceptions of behaviors that are requested by them.



Only 21% of the responders agreed that doctors expected them to watch for and report errors, whereas 30% attributed this to oncology nurses (p<0.001, figure). Perceived subjective norms associated with patients' private environment were significantly higher than expectations attributed to hospital staff (p<0.001).

Patients in fact engaged in a variety of safety behaviors, particularly in those behaviors that are compatible with traditional patient-provider relations compared to more proactive behaviors. For example, 19% frequently asked nurses questions relating to treatment or medications whereas only 5% asked nurses to show or explain the chemotherapy scheme.

The structural equation model indicates that patients' engagement in safety behaviors is strongly determined by perceived behavioral control and norms. Standardized factor loadings were generally high (>0.7) and all paths were significant (p<0.001). The fit indices suggest that the six-factor model fit the data very well. Predictors explained 62% of the variance in intentions to engage in safety (figure). Perceived behavioral control (β=0.476) and norms relating to relatives (β=0.343) were the strongest (direct) predictors of intentions. Subjective norms relating to expectations attributed to oncology staff had substantial direct and indirect effects on patients' intentions (total effect =0.382).



Conclusions:
Patients acknowledge the benefit of error monitoring and reporting and anticipate positive *outcomes* of involvement, but their valuations of the *process* of engaging in error prevention are less positive. Behavioral control and perceptions of staff approval are central for patients. Involvement of cancer patients in safety processes requires clinicians to address their patients' normative and control beliefs through education and proactive approval of patient engagement. Based on these results, staff trainings and communication guidelines have been developed that are currently being tested. These may also be easily adapted to other conditions and settings involving intense patient-provider relations (e.g., chronic care).

Publications:
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3. Schwappach DLB, Wernli M: Barriers and facilitators to chemotherapy patients' engagement in medical error prevention. A vignette study. Annals of Oncology 2010: DOI 10.1093/annonc/mdq346
4. Schwappach DLB, Wernli M: Predictors of chemotherapy patients' intentions to engage in medical error prevention. The Oncologist 2010; 15: 903-912
5. Schwappach DLB, Wernli M: Chemotherapy patients' perceptions of drug administration safety. Journal of Clinical Oncology 2010; 28: 2896-2901