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Nøgleord

Electronic patient records
Medical history taking/methods
Patient-generated health data
Patient involvement

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Investigating the possibilities of using patient-generated health data in emergency care: an explorative study

Resume

Background: It is well known that emergency departments (EDs) are exposed to human errors and unintended events due to large patient flow, high work pressure and overload of information. Strategies for providing efficient and effective health care are therefore imperative, and health information technologies are suggested to be one of the solutions. This study sought to investigate if the use of patient-generated health data gathered through a digital patient questionnaire and visualised as a patient-generated journal (PGJ v.1.0) has the potential to improve the care delivered in EDs.

Methods: Using a mixed-method approach, the PGJ (v.1.0) was investigated from key stakeholders' perspectives. First, we examined the PGJ from a patient perspective via participant observation (n = 18) and interviews (n = 18), supported by statistical data from the PGJ (n = 56). Second, we used questionnaires to explore the physicians' perspectives (n = 9). Lastly, two interviews were conducted with healthcare leaders from the ED. The data were compared and analysed using descriptive statistics and hermeneutic analysis.

Results: From the findings, it appears that patients in need of urgent care accept the use of patient-generated data, and patients highly favoured being active in their patient pathway. However, the system needed some adjustments to fit the patients' abilities in urgent situations. The physicians expressed mixed attitudes towards the PGJ: the majority agreed that the system needed some adjustments in order for the full benefits to be gained, but thought that it had potential to improve their work processes when fully developed.

Conclusions: This study concludes that the use of patient-generated data is well accepted by patients in an urgent setting, and that the PGJ has the potential to improve quality of care in patient pathways by adding value to patient flows as well as clinical workflows. The concept of utilising patient-generated health data in emergency care should therefore be further developed and investigated.

What have we learned?

What was known before the study

An integrated electronic patient record (EPR) is thought to be essential for the future of healthcare services, and a potential resource for the content of the EPR are the patients themselves.

What the study has added

The use of patient-generated health data is well accepted by stable patients in an urgent setting and, when further developed and adjusted to the clinic, a patient-generated journal has the potential to improve quality in patient pathways and clinical workflows in EDs.

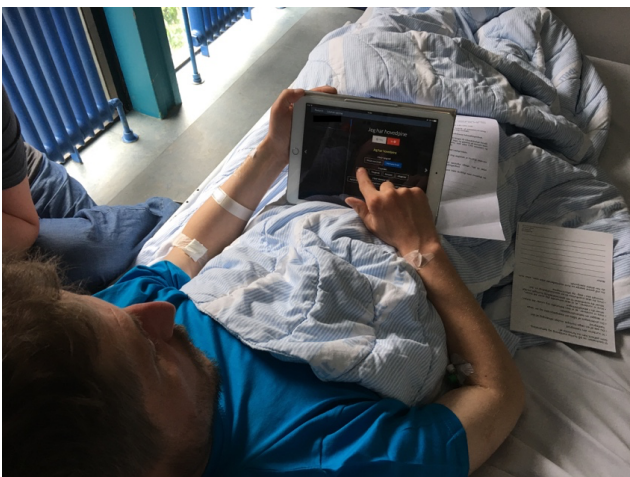
Perspectives

This article can inspire further development of the concept of utilising patient-reported data in an urgent setting.

Introduction

It is well known and documented in medical scientific studies that emergency departments (EDs) are more exposed to human errors and unintended events than other health departments. Several reasons can help explain this: large patient flow, high work pressure and overload of information (1).

To mitigate some of these challenges, triage procedures have been implemented in EDs. In Denmark, the Danish Emergency Process Triage is most widely used, and has become an integrated part of hospitals' health-information systems, enabling faster documentation and initiation of treatment. Despite this, patients in Denmark still experience waiting time and misdiagnosis (2). Several studies have shown positive results when involving patients in the treatment process using health-information technologies that collect health data through computerised patient questionnaires. Such systems have been proven to capture more relevant information than traditional methods, and also have the added benefit of freeing up time for physicians and other healthcare professionals (HCPs) to perform other tasks (3–7). This study explores the use of a digital patient questionnaire in an emergency setting to gain insights into if and how the system adds



Picture 1: A patient entering data into the PGJ at the ED

perceived value for patients and HCPs in diagnostics and treatment processes. The interactive computer system tested in this study is the patient-generated journal (PGJ v.1.0).

Methods

Design

The present explorative study was conducted as a part of a master's thesis. It was conducted in the ED at Horsens Regional Hospital (HRH), Denmark, in May 2019, and utilised a mixed-method approach to investigate the PGJ from the perspectives of key stakeholders. The PGJ is an interactive web application that gathers and structures patient health data in a uniformed text format and graphics to aid HCPs and patients in the ED. An illustration of the PGJ data and how it is presented can be seen in Appendix 1.

First, we examined the PGJ from a patient perspective using participant observation and interviews. Data were collected prospectively for one week during day hours at the ED, and 18 patients (Table 1) who were presented to the PGJ upon arrival were included. The patients were purposely chosen for their variance in age, gender, patient type and triage level to ensure a representative sample. As a supplement, statistical data describing the number of symptoms reported and time taken for data entry were extracted retrospectively from 56 PGJs (Table 1). The study included adult patients (>18 years of age) that were evaluated as clinically stable by the HCP's and the DEPT Triage system (e.g. patients with triage category red were excluded). Patients arriving at the ED with an ambulance were included in the study if evaluated as clinically stable. Ineligible patients and patients incapable of entering data into the PGJ were excluded.

Second, via a questionnaire, we examined if and how the PGJ created perceived value for physicians. Data were collected prospectively for one week, and nine physicians were included (response rate 82%; Table 1). Lastly, two interviews were conducted with healthcare leaders from the ED (Table 1) to gain insights into the possibilities and challenges of using patient-generated data in emergency care.

The collected data were mainly analysed using a hermeneutic approach. For the statistical data, frequencies and means were calculated, and graphs were created to visualise the distribution. Additionally, standard deviations (SD) were calculated for the statistical data extracted from the PGJ.

Ethics

The study was conducted in collaboration between the ED at HRH and Copenhagen Business School, Denmark. Approvals were obtained from Central

Denmark Region (1-16-02-793-17), and written and oral consent were obtained from eligible patients.

Results

The majority of patients were positive in their assessment of the PGJ. Patients expressed that the system was easy to use (94.4%), that it made sense for them to use it while waiting (94.5%), and that they found it meaningful to report information that the physician could use when assessing them (94.4%). Some patients (66.7%) also agreed that the PGJ gave them an improved overview of their condition which benefited the consultation with the physician (Figure 1). The patients expanded their ratings by describing the PGJ as a tool that gave them comfort, helped physicians to become more prepared and targeted in the consultations, and improved patient involvement. However, they also stated that the data entry was too extensive for their abilities and the urgent setting, and that some questions were difficult to understand due to lack of proper framing and delimitation. This was also evident from the observations, where 94.4% of patients needed support during data entry. Similar

	Type of data	Respondents	Characteristics respondents
1	Participant observation and interviews	<ul style="list-style-type: none"> 18 clinically stable adult patients (>18 years of age) receiving care at the ED at HRH in May 2019 	<ul style="list-style-type: none"> Gender: 9/18 (50%) females, 9/18 (50%) males Age: range from 18–76 years, mean age of 53.7 years Patient type: 10/18 (56%) medical patients, 8/18 (44%) surgical patients Triage level (DEPT): 1/18 (5%) green level, 14/18 (78%) yellow level, 3/18 (17%) orange level
2	Statistical data extracted from the patient-generated journal	<ul style="list-style-type: none"> Information from 56 clinically stable adult patients (>18 years of age) receiving care at the ED at HRH from January–May 2019 	<ul style="list-style-type: none"> Gender: 54% females, 46% males Age: range from 18–79 years, mean age 46.6 years Patient type: 70% medical patients, 30% surgical patients
3	Self-completion questionnaire	<ul style="list-style-type: none"> 9 physicians working at the ED at HRH, that had used the PGJ to some degree in the ED at HRH. 	<ul style="list-style-type: none"> Gender: 6/9 (67%) females, 3/9 (33%) males Age: Range from 20–40 years, 8/9 (89 %) in the age group 20–30 years Years of experience in the field of emergency medicine: 9/9 (100%) 0–1 year Years of experience as a trained physician: 6/9 (67%) 0–1 year, 2/9 (22%) 2–4 years, 1/9 (11%) 5–10 years To what extent tested the PGJ concept: 7/9 (78%) 1–4 patients, 2/9 (22%) 5–9 patients
4	Qualitative interviews	<ul style="list-style-type: none"> 3 healthcare leaders from the ED at HRH 	<ul style="list-style-type: none"> One consultant and two nurses that had leader functions within the department

Tabel 1: Description of data

Accepteret til publikation: 08-09-2021

Sode et al., Investigating the possibilities of using patient-generated health data in emergency care

Dansk Tidsskrift for Akutmedicin, 2021, Vol. 1, s. 10-16

PUBLICERET AF DET KGL. BIBLIOTEK FOR DANSK TIDSSKRIFT FOR AKUTMEDICIN

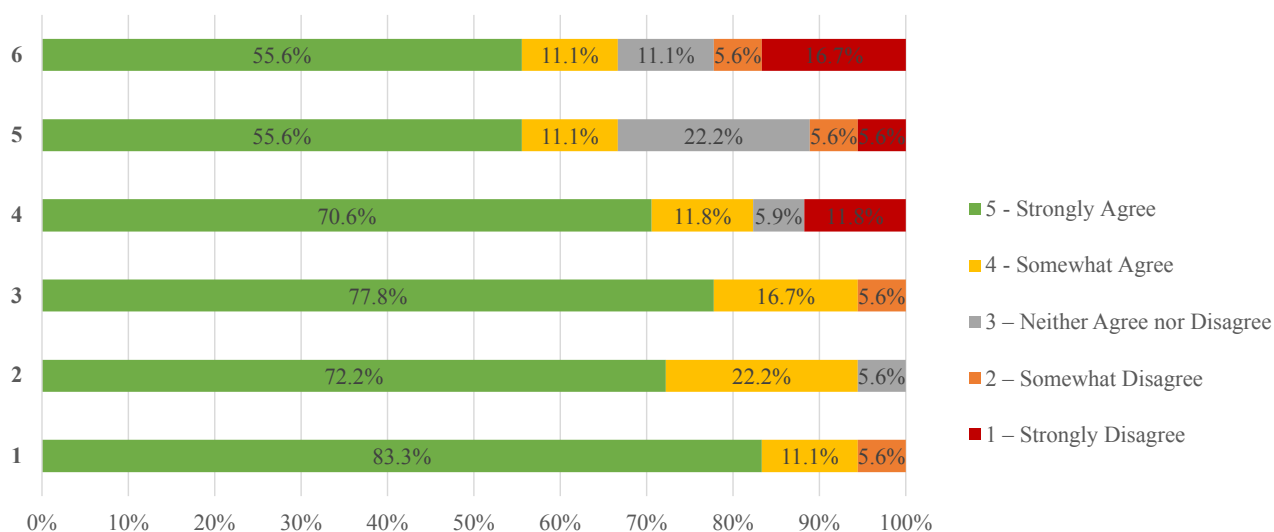
issues were observed in the statistical data extracted from the PGJ which showed that, on average, patients spent 36.7 minutes (SD 13.8) filling in the data, including disturbances occurring during data entry (Table 2). Lastly, the patients were asked if they would have been able to fill in the PGJ at home before arriving at the ED. Slightly more than half agreed to this (66.7%; Figure 1), but the majority stated that they would prefer to do it at the ED due to lack of time and the need for support during data entry.

The physicians expressed mixed experiences and attitudes towards the PGJ. Slightly more than half agreed that the system helped by giving an improved overview of a patient's symptoms, that it was more time-efficient compared to conventional methods, and that patients appeared more prepared and active in the consultation when using the PGJ. However,

most physicians agreed that the system needed improvements to gain these benefits. Their arguments indicated a strong need for integration between the PGJ and the existing electronic health record (EHR) to facilitate improved documentation and workflow. They also stated that they often needed to wait for patients to finish their data entry due to the length of the PGJ, which could lead to delays in patient care. All physicians ended the survey agreeing that the PGJ has the potential to be valuable within emergency medicine in the future when further developed and adjusted to the clinic. See Appendix 2 for examples of citations from the questionnaire.

The leaders at the ED had a positive attitude towards the PGJ, with an expectation of enhanced efficiency in the department when implementing the system. They further identified two main barriers for

Patients' attitude towards the PGJ



Rated statements:

- 1: *I understand why I should contribute by providing information to the physician. I can therefore see the meaning in contributing with information about my health.*
- 2: *I find the patient-generated journal easy to use.*
- 3: *I find the utilisation of the waiting time valuable, as I can contribute by providing information to the physician.*
- 4: *It gives me comfort knowing that I have actively contributed with information regarding my health and that I can make use of this information in the dialogue with the physician when he/she is assessing me.*
- 5: *I have an improved overview of my condition and a greater understanding of the patient pathway when using the patient-generated journal.*
- 6: *I would be able to register the information about my health from home using the application if this was an option. The time before arriving at the emergency clinic would be better utilised if this was possible.*

Figure 1: Patients' attitude towards the PGJ

Variable	Mean	Median	Min	Max	Range	SD
<i>Total number of symptoms reported</i>	25.77	26	7	47	40	9.47
<i>Recently occurred symptoms (experienced the last 3 months)</i>	9.27	9	1	24	23	6.08
<i>Time</i>	36.7 min	33.7 min	7.1 min	73.7 min	66.6 min	13.8 min

Table 2: Statistical overview of data extracted from the PGJ (The number of symptoms may be slightly overestimated due to the inclusion of reported exposures and double reporting of symptoms for validation purposes)

implementation: the need for integration between the PGJ and EHR system, and the change in tasks and interprofessional collaboration needed when implementing a PGJ in an urgent setting. See Appendix 3 for examples of citations from the interviews.

Discussion

The results support that patients in urgent settings who are clinically stable are willing and able to be active and involved in their care by reporting information about their health in the PGJ. The majority of patients were positive about the PGJ and found it beneficial to both them and the physicians, but thought that it needed improvements to fit their capacity in the urgent situation. International studies conducted in EDs have shown similar findings; that is, that the use of a digital device is well accepted by patients in urgent settings, and computer interviews could improve patient pathways in EDs if adjusted to patient abilities (3,8).

Both physicians and leaders had mixed perceptions of the PGJ. The majority agreed that it had the potential to be a valuable tool, but that it would need to be integrated with the EHR system and further developed before being beneficial. Similar challenges have been identified in previous studies, which stated

that integration was essential for computer-based interviews to benefit both patients and clinicians (9).

All data used in this study were collected at one ED by the same investigators, which improves the internal validity of the data. The mixed-method approach, where both quantitative and qualitative data were collected simultaneously, made it possible to expand on findings and allowed for validation of data between methods. This also strengthens the credibility and internal validity of the study.

Fieldwork – Patients

Data saturation was achieved for the fieldwork. The patients were purposely chosen for their variance in age, gender, triage level and patient type, to avoid a homogenous data sample. These choices strengthen the internal and external validity of the data.

Questionnaire – Physicians

The physicians represented a homogeneous group due to similarities in characteristics (Table 1). This has not been valued negatively as this group of physicians is normally represented in an ED. However, only a small number of physicians were able to test the concept on a limited number of patients, which weakens the internal and external validity.

Even though the study supports the concept of utilising patient-reported health data in emergency care, the results cannot be generalised due to the size and composition of the sample. Future studies should systematically select a specific and larger sample, to enable more generalisable results.

Despite these limitations, this study shows that the use of a PGJ in an ED has great potential, but further development and investigation is needed to ensure a valuable and financially viable solution.

Conclusion

Based on this study it can be argued that a fully integrated PGJ may help provide more efficient and effective delivery of care in EDs in Denmark through standardised sharing of data and promotion of patient involvement. This study supports that using patient-generated data is well accepted by stable patients in an urgent setting and that the PGJ has the potential to improve quality in patient pathways by adding value to patient flows as well as clinical workflows.

Acknowledgements

We thank the Innovation Department at New Hospital North Zealand, the primary host of BSS's and FBK's thesis project, for their support in the development of the data-collection methods used in this study. We also thank the Innovation Department, HRH, for their administrative support, the staff at the ED, HRH, for their practical help throughout the data collection, and Nad Husainov (NH), IT specialist, for technical support of the PGJ.

Disclosure

PGJ v.1.0 was developed by MK and NH prior to the initiation of this study. No commercial funding or other form of financial support was received. Additionally, none of the developers was responsible for the data collection or analysis performed.

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