Seen through the patients’ eyes: Safety of chronic illness care

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Abstract

Objective: Due to the increasing burden of chronic diseases, a considerable part of care delivery will continue to shift from secondary to primary care, and home care settings. Despite the growing importance of primary care, concerns about the safety of patients in hospitals have thus far driven most research in the field. Therefore, the present study sought to explore patients’ perceptions and experiences of the safety of primary chronic care.

Design: An observational, cross-sectional study design was applied.

Participants: Participants were recruited from the Flemish Patients’ Platform, an independent organization that defends patients’ rights and strives for more care quality.

Main Outcome Measure(s): An online questionnaire was designed to assess: socio-demographic characteristics, medical consumption and patients’ perspectives of the quality and safety of chronic care.

Results: Respondents (n = 339) had positive perceptions of the safety of primary chronic care as they indicated to receive safe care at home (68.1%), receive enough care support at home (70.8%) and experience good communication between their healthcare professionals (51.6%). Almost one quarter of respondents experienced an incident, mainly related to self-reported fall incidents (50.4%), wrong diagnoses or treatments (37.8%) and adverse drug events (11.8%). Also, more than half of respondents who experienced an incident (64.9%) indicated that poor communication between their healthcare professionals was the main cause.

Conclusions: Information on patients’ experiences is critical to identify patient safety incidents and to ultimately reduce patient harm. More research is needed to fully understand patient safety in primary chronic care to further improve patient safety.

Key words: chronic care, patient safety, quality of care, quality improvement, patient preference

Introduction

Healthcare systems around the globe are facing the increasing burden of chronic conditions [1]. In practice, the care for chronic patients is mainly provided in primary care. At the same time, the demand for home and community services is increasing substantially to reduce the number of hospital beds, facilitate earlier hospital
discharge, improve quality of care and decrease healthcare-associated costs [2, 3]. Consequently, a considerable part of care delivery will continue to shift from secondary to primary care, and home care settings [4].

In accordance with the publication of the Institute of Medicine’s 2000 report ‘To Err is Human: Building a Safer Health System’, patient safety is widely acknowledged as an important health issue and it is considered indistinguishable from the delivery of high-quality care [5]. Despite the growing importance of primary care, concerns about the safety of patients in hospital settings have thus far driven most research in the field. As a result, the knowledge base about patient safety in primary care is still scarce (especially regarding contributory factors and improvement strategies), although numerous studies have revealed that patient safety incidents in primary care do occur [6, 7]. The median incident rate—derived from population-based record review studies—was 2–3 incidents for every 100 consultations of which 4% of these incidents may be associated with severe patient harm [8]. Although, the incidence rate in primary care seems lower than the frequently reported 10% in hospitals [9], the high utilization rates of primary care may result in a large burden of iatrogenic harm in this setting. Studies documenting the type of safety incidents in primary care identified prescribing and medication management incidents or diagnostic failures as the most common types, which are often caused by administrative issues (e.g. incomplete, unavailable, unclear or incorrect documentation) or inefficient communication between healthcare professionals or between providers and patients [8, 10].

Patient safety data can be collected with information from several methods, such as retrospective medical records review, incident reports by healthcare professionals and patient-reported information. Medical records review and incident reports by healthcare professionals are the most utilized information sources, but can be unreliable as they might suffer from under-reporting or incomplete documentation. At the same time, there has been insufficient recognition of patients’ experiences of safety incidents. Nevertheless, patients and their caregivers can provide useful information, correct inaccurate data and identify inefficiencies in their care, which may be the missing evidence to fully understand patient safety incidents and their impact on patients’ health and welfare [10–12]. In a number of studies, patients have been shown to report medical incidents and adverse events accurately and to provide additional information, specifically regarding breakdowns in the continuity of care, medication incidents, and communication inefficiencies (e.g. incomplete or delayed referral and discharge letters) [10, 13].

Given that the already mentioned potential shift of care delivery from secondary to primary care and given the fact that research concerning primary care patient safety is limited, the present study sought to explore perceptions of the safety of primary chronic care among patients living in Belgium (Flanders).

METHODS

The current study is part of CORTEXS (Care Organization: a Re-Thinking EXpedition in search for Sustainability), an extensive multidisciplinary research project in Flanders (Belgium) that studies integrated care [14].

Design and Recruitment

An observational, cross-sectional study design was applied by using an online questionnaire. Participants were recruited from the Flemish Patients’ Platform, an independent organization founded in 1999 which unites more than 100 patient associations. The main goal of the organization is to defend patients’ rights and to strive for more care quality and an active role for patients in health policy. Sampling was opportunistic, based on opting-in and within the constraints of the following inclusion criteria: all participants were over 18 years of age, were able and willing to provide informed consent to participate, and could fully understand and express themselves in Dutch. Several steps were taken to mitigate the risk of common method bias, both ex ante remedies as well as statistical controls after the questionnaires were returned (e.g. during the design and administration stage of the survey, respondents were assured of confidentiality of the study and that there were no right or wrong answers) [15]. The questionnaires were distributed through an online platform (Qualtrics) between April and September 2016 using the mailing list of the Flemish Patients’ Platform. A general reminder was sent 4 weeks after the initial announcement.

Questionnaire Development

To safeguard the relevance of the questions and maintain understandable language, the questionnaire was developed in conjunction with two staff members of the Flemish Patients’ Platform.

The final questionnaire consisted of five parts. The first part contained items exploring socio-demographic characteristics of the respondents, including gender, age, educational level and type plus number of chronic conditions. The second part contained items exploring participants’ medical consumption. Respondents were asked to indicate the number of consultations with a general practitioner, medical specialist, allied healthcare professional, family caregiver and/or informal caregiver during the last 6 months. The next part assessed respondents’ perceptions of the quality of chronic illness care by using the ‘Patient Assessment of Chronic Illness Care’ (PACIC) survey. The PACIC instrument is a 20-item validated questionnaire, assessing the alignment of chronic care with the Chronic Care Model [16, 17]. The fourth part contained three items exploring chronic patients’ perceptions of the safety of primary chronic care. Each item was phrased as a statement: (i) ‘I receive safe care at home’, (ii) ‘I receive enough care support at home’ and (iii) ‘There is good communication between my healthcare professionals about my care’. Participants responded by using a five-point Likert scale ranging from strongly disagree to strongly agree with a neutral midpoint. Data were coded from one to five (1 = ‘strongly disagree’ and 5 = ‘strongly agree’). The final part explored participants’ experiences of safety incidents in primary chronic care. Respondents were asked to indicate whether they experienced an incident (yes or no), which type of incident occurred (open-ended question), and whether or not the incident was caused by poor communication between their healthcare professionals (yes or no). The following definition of a patient safety incident was used: ‘an unintended event during the care process that resulted, could have resulted, or still might result in harm to the patient’ [18].

Statistical Analyses

Analyses were performed using SPSS software version 23. The significance level α was set at 0.05 and all P-values were two-sided. The analyses and descriptions follow the ‘Strengthening the Reporting of Observational Studies in Epidemiology’ (STROBE) guidelines for cross-sectional studies [19]. Univariate analyses were conducted to describe respondents’ socio-demographic characteristics, medical consumption, perceptions of the quality (PACIC) and
safety of chronic care, and their experiences of safety incidents in primary chronic care. Bivariate correlations of covariates (see Appendix 1 and 2) with the perceptions of the safety of primary chronic care and the experiences of incidents were tested using the Chi-squared test. To assess predictive factors, logistic regression models (see Appendix 3 and 4) were utilized. The covariates included: gender, age, level of education, number of chronic conditions, number of consultations with the healthcare team, hours of family and/or informal care received, number of professionals in the healthcare team, duration of home care, and mean PACIC score. The healthcare team was ex post defined when the patient received care from at least two different healthcare professionals.

Ethical Consideration
Participants were informed that the collected information would be kept confidential and that the questionnaire was anonymous. There were no incentives provided for completing the questionnaire. The institutional ethics committees of Hasselt University and Ghent University reviewed and approved the study (ref. CME2016/0122).

Results
Respondents’ Characteristics
A total of 339 questionnaires were returned. Sample characteristics are presented in Table 1. The mean age for the entire sample was 55.80 years (SD ± 11.76) and the majority of respondents were female (n = 221, 65.2%). The median number of chronic conditions was 2, ranging from 1 to 9 chronic conditions. The top five most prevalent chronic conditions were chronic back pain (n = 106, 31.3%), multiple sclerosis (n = 91, 26.8%), chronic neck pain (n = 79, 23.3%), osteoarthritis (n = 77, 22.7%) and hypertension (n = 53, 15.6%).

Medical Consumption and Mean PACIC Score
Table 2 displays respondents’ medical consumption and mean PACIC score. Aggregated for general practitioners, medical specialists, allied healthcare professionals and home care nurses, respondents had five monthly contacts (range = 0–95) during the last 6 months. Monthly visits to a general practitioner (median = 1, range = 0–12) and a medical specialist (median = 1, range = 0–12) were most prevalent. Respondents often had two professionals (range = 0–8) in their healthcare team. The majority of patients received home care for more than 1 year (n = 95, 28.0%). Furthermore, a wide hour range for family and/or informal care was found, ranging from no care to receiving 672 h per month of care. Finally, the mean PACIC score was 2.87 (SD ± 0.93) on a maximum score of 5, indicating low to moderate quality of care from the patients’ perspectives [20–22].

Perceptions of the Safety of Primary Chronic Care
Table 3 shows respondents’ perceptions of the safety of chronic care delivery in the home environment. The majority of respondents (n = 231, 68.1%) reported to either ‘strongly agree’ (n = 131, 38.6%) or ‘agree’ (n = 100, 29.5%) to the statement ‘I receive safe care at home’. In line with this positive perception of safe chronic care, 70.8% (n = 240) reported to either ‘strongly agree’ (n = 142, 41.9%) or ‘agree’ (n = 98, 28.9%) to the statement ‘I receive enough care support at home’. Only half of respondents (n = 175, 51.6%) reported to either ‘strongly agree’ (n = 74, 21.8%) or ‘agree’ (n = 101, 29.8%) to the statement ‘There is good communication between my healthcare professionals about my care’. Multivariate ordinal logistic regressions show that older age, mean PACIC score, more contact moments with the healthcare team, more hours of family and/or informal care, and receiving home care for more than one year made respondents more likely to agree with the statement ‘I receive safe care at home’. However, respondents with multiple chronic conditions and more professionals in the healthcare team were less likely to agree with the same statement. As for the statement ‘I receive enough care support at home’, respondents with a higher mean PACIC score were more likely to agree. Once again, having multiple chronic conditions and more professionals in the healthcare team made respondents less likely to agree. Finally, respondents with a higher mean PACIC score were more likely to agree with the statement ‘There is good communication between my healthcare professionals about my care’. On the contrary, having more professionals in the healthcare team made respondents less likely to agree with the same statement (see Appendix 3).

Respondents’ Experiences of Safety Incidents in Primary Chronic Care
In total, 22.7% (n = 77) experienced a patient safety incident in primary chronic care. The median number of incidents experienced was 1, ranging from 0 to 4 incidents. The most frequently reported incidents were fall-related incidents (n = 132, 50.4%), followed by wrong diagnoses (n = 50, 19.1%), wrong treatments (n = 49, 18.7%) and adverse drug events (n = 31, 11.8%). Of the 77 respondents who experienced an incident, 64.9% (n = 50) indicated that insufficient communication between their healthcare professionals was the main cause of the incident. A detailed overview of these results can be found in Table 4.

Logistic regressions show that respondents with two or more chronic conditions were more likely to experience two or more incidents and were more likely to agree with the statement that the incident was caused by insufficient communication between their healthcare professionals. Furthermore, respondents who receive <1 year of home care were more likely to experience two or more incidents and female respondents were more likely to agree with the statement that the incident was caused by poor communication between their healthcare professionals (see Appendix 4).
Table 2 Respondents’ medical consumption and mean PACIC score (n = 339)

<table>
<thead>
<tr>
<th>Medical consumption</th>
<th>Mean (SD) N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Visits healthcare team aggregated (monthly), median (range)</td>
<td>5.00 (0–95)</td>
</tr>
<tr>
<td>Most prevalent visits to or contacts with, median (range)</td>
<td></td>
</tr>
<tr>
<td>General practitioner (monthly)</td>
<td>1.00 (0–12)</td>
</tr>
<tr>
<td>Specialist (monthly)</td>
<td>1.00 (0–12)</td>
</tr>
<tr>
<td>Neurologist, n (%)</td>
<td>149 (36.2%)</td>
</tr>
<tr>
<td>Rheumatologist, n (%)</td>
<td>55 (13.3%)</td>
</tr>
<tr>
<td>Pulmonologist, n (%)</td>
<td>49 (11.9%)</td>
</tr>
<tr>
<td>Number of professionals in healthcare team, median (range)</td>
<td>2.00 (0–8)</td>
</tr>
<tr>
<td>Duration of home care, n (%)</td>
<td></td>
</tr>
<tr>
<td>No home care</td>
<td>201 (59.4%)</td>
</tr>
<tr>
<td>Less than 6 months</td>
<td>31 (9.1%)</td>
</tr>
<tr>
<td>Between 6 months and 1 year</td>
<td>12 (3.5%)</td>
</tr>
<tr>
<td>More than 1 year</td>
<td>95 (28.0%)</td>
</tr>
<tr>
<td>Hours family/informal care aggregated (monthly), median (range)</td>
<td>0.00 (0–672)</td>
</tr>
<tr>
<td>PACIC score, mean (SD)</td>
<td>2.87 (0.93)</td>
</tr>
</tbody>
</table>

Table 3 Respondents’ perceptions of the safety of primary chronic care (n = 339)

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly disagree n (%)</th>
<th>Disagree n (%)</th>
<th>Neither agree or disagree n (%)</th>
<th>Agree n (%)</th>
<th>Strongly agree n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>‘I receive safe care at home’</td>
<td>37 (10.9%)</td>
<td>25 (7.4%)</td>
<td>46 (13.6%)</td>
<td>100 (29.5%)</td>
<td>131 (38.6%)</td>
</tr>
<tr>
<td>‘I receive enough care support at home’</td>
<td>32 (9.4%)</td>
<td>23 (6.8%)</td>
<td>44 (13.0%)</td>
<td>98 (28.9%)</td>
<td>142 (41.9%)</td>
</tr>
<tr>
<td>‘There is good communication between my healthcare professionals about my care’</td>
<td>49 (14.5%)</td>
<td>44 (13.0%)</td>
<td>71 (20.9%)</td>
<td>101 (29.8%)</td>
<td>74 (21.8%)</td>
</tr>
</tbody>
</table>

Table 4 Respondents’ experiences of safety incidents in primary chronic care (n = 339)

<table>
<thead>
<tr>
<th>Experiences</th>
<th>Median (range) n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Experienced an incident, n (%)</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>77 (22.7%)</td>
</tr>
<tr>
<td>No</td>
<td>262 (77.3%)</td>
</tr>
<tr>
<td>Number of incidents experienced</td>
<td>1 (0–4)</td>
</tr>
<tr>
<td>Most prevalent incidents, n (%)</td>
<td></td>
</tr>
<tr>
<td>Fall-related incident</td>
<td>132 (50.4%)</td>
</tr>
<tr>
<td>Wrong diagnosis</td>
<td>50 (19.1%)</td>
</tr>
<tr>
<td>Wrong treatment</td>
<td>49 (18.7%)</td>
</tr>
<tr>
<td>Adverse drug event</td>
<td>31 (11.8%)</td>
</tr>
<tr>
<td>Caused by poor communication, n (%)</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>50 (64.9%)</td>
</tr>
<tr>
<td>No</td>
<td>27 (35.1%)</td>
</tr>
</tbody>
</table>

Discussion

Primary care entails a greater likelihood of causing unintentional harm to patients due to early discharge from hospitals, the pressure of short consultations, and the fragmented nature of care services [23]. In addition, the increasing prevalence of chronic patients tends to shift the balance of care delivery from secondary to primary care, and home care settings [4]. Nevertheless, major gaps remain in the understanding of patient safety in primary chronic care [6]. Indeed, a better understanding is needed on the epidemiology and contributory factors of safety incidents and the possible safety improvement strategies in this setting. A growing body of evidence suggests that patients and their caregivers can recognize inefficiencies in healthcare [24]. Therefore, the current study explored the perceptions and experiences of chronic patients on the safety of primary chronic care.

In general, the findings of this study suggest that patients with chronic diseases have positive perceptions of the safety of primary chronic care in their own home environment. The majority of respondents indicated that they received safe care at home, received enough care support at home, and experienced good communication between their healthcare professionals. It is, however, remarkable that patients with more than two healthcare professionals involved in their care delivery were less likely to agree with the above-mentioned statements, which may indicate that continuity of care among healthcare professionals is perceived as not consistent or coherent [25]. One might expect that patients would feel more supported when they are surrounded by multiple healthcare professionals, but findings of the present study thus indicate otherwise. Furthermore, almost one-quarter of respondents experienced an incident in primary chronic care. These incidents are mainly related to self-reported fall incidents, wrong diagnoses or treatments, and adverse drug events (i.e. wrong type of medication or wrong dose). These incidents do not only have a physical impact on patients, but also on their families (e.g. emotional impact), healthcare professionals (i.e. second victims) and the healthcare system (e.g. financial impact). Additionally, insufficient communication between healthcare professionals was perceived as the main cause in more than half of the incidents. Aforementioned findings are noteworthy in light of previous research. Recently, Lang et al. conducted a systematic review to provide a comprehensive summary of the published literature assessing patients’ views on adverse events in primary care [26].
The authors concluded that most of the problems identified were concerns about communication and limitations in coordination or access to healthcare, which is consistent with the findings of the present study.

Communication and coordination among different healthcare professionals and organizations remain complex issues. Care delivery is often developed in ways that have tended to fragment care: patients with chronic diseases often receive treatment from many healthcare professionals working in different locations and parts of the healthcare system. Coulter and Amalberti recently identified a clear need for further research on capturing patient experiences when transitioning care between different organizations or settings; that is the so-called ‘patient journey’ [27, 28]. Patients may experience harm during an episode of care (e.g. mistaken identity in the hospital) or later, after some time has passed (e.g. adverse drug event at home due to inefficient patient handover after hospital discharge). This will especially become important given the substantial shift of chronic care delivery from secondary to primary care and the resulting focus on transmural care.

Within this context, policy makers are constantly searching for structural alternatives to ensure innovative, qualitative and safe healthcare. Currently, ‘integrated care’ has great potential to redesign care around patients’ needs and it is considered an appropriate answer in potentially reducing the fragmentation of care, improving the quality and safety of care, and controlling healthcare-related costs [29–31]. In response to the emerging challenges posed by chronic diseases, several countries are experimenting with new models of care delivery. In Belgium, a large national programme on integrated care was launched, called ‘Integrated Care for a Better Health’ [32]. Within this programme, 20 pilot projects were selected for further conceptualization. It is advised that these projects pay explicit attention to patient safety as this study indicates that incidents in primary chronic care do occur. Other similar national pilot programmes include: ‘Integrated Care Strategies in Australia, New Care Models and Integrated Care Pioneers in England, and Population Health Management Pilots’ in the Netherlands [33–35].

The results of the present study have to be interpreted carefully. First, respondents consisted largely of members of patients’ organizations, comprising dedicated and committed individuals with a strong involvement in their care. This could result in a more critical attitude towards patient safety. Furthermore, capturing patients’ experiences of incidents is challenging due to the lack of an adequate definition of the term ‘patient safety incident’ and the difficulty to identify and recruit patients who have experienced an incident. Third, no single validated tool currently captures patients’ experiences of incidents [10, 36]. A systematic review of methods to identify incidents in healthcare concluded that ‘the available methods have widely differing purposes, strengths, and weaknesses and must be considered as complementing each other by providing different levels of qualitative and quantitative information’ [37]. Hence, mixed methods approaches or a triangulation of approaches (including healthcare professionals’ perspectives) are needed to identify incidents in primary care and to focus more on the impact of incidents on patients and their caregivers [10, 38]. Finally, the degree to which patients can play an active role in their care depends on patients’ willingness and ability [24].

Conclusions

Information on patients’ experiences is critical to identify safety incidents and to ultimately reduce patient harm. Patients have a key role in their care and must be part of the patient safety discourse. This study showed that the majority of patients with a chronic disease have positive perceptions of the safety of primary chronic care. However, incidents do occur and are mainly related to wrong diagnoses, inappropriate treatments, adverse drug events and insufficient communication between healthcare professionals. Addressing patient safety in primary care requires a rethinking of guiding frameworks that have been used to examine patient safety in institutional healthcare settings.

Authorship

M.D. and D.V. conceptualized and designed the study, collected the data, analysed and interpreted the data, and drafted the manuscript. J.H. and D.V. conceptualized the study, interpreted the data and revised the manuscript for important intellectual content. M.P., J.B., H.V., J.H., P.V., L.C., E.D. and I.W. interpreted the data and revised the manuscript for important intellectual content. All authors had full access to all the data in the study and can take responsibility for the integrity of the data and the accuracy of the data analysis. All authors approved the final version to be published.

Supplementary material

Supplementary material are available at International Journal for Quality in Health Care online.

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Conflicts of interest

None declared.

Ethics approval

Institutional ethics committees of Hasselt University and Ghent University.

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27. Coulter A. Collecting data on patient experience is not enough; they must be used to improve care. *BMJ* 2014;348:g2225.


