

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

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Seen Through the Patients' Eyes: Safety of Chronic Illness Care

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 organisation that defends patients' rights and strives for more care quality.

Main outcome measures: 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.

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INTRODUCTION

One of the biggest challenges most healthcare systems globally are facing is the increasing burden of chronic conditions (Institute for Health Metrics, 2015). 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 (Farfan-Portret et al., 2015; Van Den Bosch et al., 2011). Consequently, a considerable part of care delivery will continue to shift from secondary to primary care, and home care settings (Coulter, 1995).

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 (Institute of Medicine, 1999b). 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 (Marchon & Mendes, 2014; Verstappen et al., 2015). The median incident rate - derived from population-based record review studies - was 2 to 3 incidents for every 100 consultations of which 4% of these incidents may be associated with severe patient harm (Panesar et al., 2016). Although the incidence rate in primary care seems lower than the frequently reported 10% in hospitals (Institute of Medicine, 1999a), the high utilisation 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 (Harrison et al., 2015; Panesar et al., 2016).

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 utilised information sources, but can be unreliable as they might suffer from underreporting 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 (Harrison et al., 2015; Vincent & Davis, 2012; Ward & Armitage, 2012). 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) (Harrison et al., 2015; Vermeir et al., 2015).

Given 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 Organisation: a Re-Thinking EXpedition in search for Sustainability), an extensive multidisciplinary research project in Flanders (Belgium) that studies integrated care (Dessers et al., 2014).

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 organisation founded in 1999 which unites more than 100 patient associations. The main goal of the organisation 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) (Podsakoff et al., 2003). 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 four 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 six 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 (Glasgow et al., 2005; Vrijhoef et al., 2009). The fourth part contained three items exploring chronic patients' perceptions of the safety of primary chronic care. Each item was phrased as a statement: (1) '*I receive safe care at home*', (2) '*I receive enough care support at home*', and (3) '*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*' (C. Wagner & Van Der Wal, 2005).

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 (Elm et al., 2007). 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 utilised. 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 ($SD \pm 11.76$) 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 ($n=53, 15.6\%$).

Table 1 Respondents' Characteristics (n=339)

Characteristics	Mean (SD)
	Median (range)
	N (%)
Age (yrs), mean (SD)	55.80 (11.76)
Gender, n (%)	
Female	221 (65.2%)
Male	118 (34.8%)
Educational level, n (%)	
Less than high school	22 (6.5%)
High school	134 (39.5%)
College	134 (39.5%)
University	49 (14.5%)
Number of chronic conditions, median (range)	2.00 (1-9)
Five most prevalent chronic conditions, n (%)	
Chronic back pain	106 (31.3%)
Multiple sclerosis	91 (26.8%)
Chronic neck pain	79 (23.3%)
Osteoarthritis	77 (22.7%)
Hypertension	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 to 95) during the last six months. Monthly visits to a general practitioner (median=1, range=0 to 12) and a medical specialist (median=1, range=0 to 12) were most prevalent. Respondents often had two professionals (range=0 to 8) in their healthcare team. The majority of patients received home care for more than one 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 hours 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 (Balbale et al., 2016; Boulton et al., 2008; Boyd et al., 2010).

Table 2 Respondents' Medical Consumption and Mean PACIC Score (n=339)

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

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*'.

Table 3 Respondents' Perceptions of the Safety of Primary Chronic Care (n=339)

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

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.

Table 4 Respondents' Experiences of Safety Incidents in Primary Chronic Care (n=339)

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

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 less than one 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).

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 (Wilson et al., 2001). 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 (Coulter, 1995). Nevertheless, major gaps remain in the understanding of patient safety in primary chronic care (Verstappen et al., 2015). 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 recognise inefficiencies in healthcare (Vincent & Coulter, 2002). 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 abovementioned statements, which may indicate that continuity of care among healthcare professionals is perceived as not consistent or coherent (Haggerty et al., 2013). 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 (Lang et al., 2016). 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 organisations 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 organisations or settings; that is the so-called *patient journey* (Amalberti, 2001; Coulter, 2014). 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 (Desmedt et al., n.d.; Hopman et al., 2016; Tsai et al., 2005). 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* (FOD Volksgezondheid, 2016). Within this programme, 20 pilot projects were selected for further conceptualisation. 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 (Hejink et al., 2014; NHS England, 2016; NSW Government Health, 2015).

The results of the present study have to be interpreted carefully. First, respondents consisted largely of members of patients' organisations, 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 (Harrison et al., 2015; Ricci-Cabello et al., 2016). 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*' (Michel, 2003). 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 (Harrison et al., 2015; Wetzels et al., 2008). Finally, the degree to which patients can play an active role in their care depends on patients' willingness and ability (Vincent & Coulter, 2002).

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.

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