Abstract
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Feelings of Burden in Palliative Care: A Qualitative Analysis of Medical Records

Milenko Rakic, MSc¹, Monica Escher, MD², Bernice S. Elger, MD, MA¹, Sandra Eckstein, MD³, Nadia Pacurari, PhD¹, Susanne Zwahlen, MD⁴, and Isabelle Wienand, PhD¹

Abstract

Background: Care for palliative care patients is often provided by unpaid caregivers (eg, family members) who take care of the patient’s daily needs (eg, bathing, dressing). Family members of palliative care patients are involved in numerous ways. These tasks and responsibilities can make them feel burdened and even overburdened. Aim: We specifically looked at patients’ medical records to determine what is being reported about burden and overburden and who seems to be mostly affected. Burden was understood as a weight or task that is difficult to accept or carry, whereas overburden indicates that this weight or task cannot be carried anymore. Methods: We looked at 300 medical records of palliative care patients written by health-care professionals. Written notes were analyzed using latent content analysis as it helps to analyze large amounts of textual data qualitatively and to understand the underlying concepts of what was said. Results: Most (73.5%) patients had a cancer diagnosis. Mean age was 67.6 years (range, 22-98 years). Burden and overburden were identified as main categories and further divided into the following subcategories: for patients and families. According to the written notes, patients often felt burdened by their disease, financial problems, situation at home, and families’ reactions to their disease. By and large, patients felt overburdened by their own disease. Families often felt burdened because of issues related to patients’ medical condition, providing home care, or financial and social aspects. Families mentioned home care and the decision-making process as being overburdening. Conclusion: Findings in the palliative care patients’ medical records are inasmuch important, as they point at the health-care staff’s awareness of possible weights and tasks that might be burdensome for patients and their families. Attention should be drawn to the documentation of medical records in order to identify recurrent difficulties and to help discuss these.

Keywords

palliative care, burden, qualitative research, caregivers

Introduction

The Swiss Federal Office for Public Health (FOPH) estimates that 40 000 people are currently in need of palliative care (PC), and this number will increase to 53 000 people by 2032.¹ According to the World Health Organization, PC encompasses an interdisciplinary and holistic approach focusing on several domains of care, such as physical, social, psychological, and spiritual care of patients and their families.² Another important defining principle of PC is the promotion of autonomy.³ Palliative care offers a range of support services to help families cope with the patients’ illness, but also with the families’ own problems.² Care for PC patients is often provided by unpaid caregivers⁴ or someone (eg, family member, friend, neighbor) who takes care of the patient’s daily needs (eg, bathing, dressing).⁵ Family members of PC patients are involved in numerous ways: They care for the patients’ daily needs, are in close contact with health professionals, and sometimes act as the patients’ surrogates. These multiple roles can affect their own health, as Kristjanson and Aoun suggest.⁶ Older caregivers most often provide care to partners, friends, and neighbors, whereas younger caregivers typically provide care to their parents.⁴ Emanuel et al suggest that even for care that requires qualification (eg, nursing), patients generally receive care from family members or friends rather than from paid caregivers.⁷ However, family members often indicate a lack of self-confidence in providing care for their relatives.⁸

The FOPH states in its report on the PC situation in Switzerland that the inclusion of informal caregivers in the provision of care is a central need of PC patients. The report also emphasizes that patients fear that they could be a burden for their family caregivers.⁹ According to a generally accepted definition, a burden is a weight or task—in a physical and psychological sense—that is difficult to

¹ Institute for Biomedical Ethics, University of Basel, Basel, Switzerland
² Division of Clinical Pharmacology and Toxicology, Pain and Palliative Care Consultation, Geneva University Hospitals, Geneva, Switzerland
³ Palliative Care, University Hospital Basel, Basel, Switzerland
⁴ Centre for Palliative Care, University Hospital Bern, Bern, Switzerland

Corresponding Author:
Milenko Rakic, Institute for Biomedical Ethics, University of Basel, Bernoullistrasse 28, Basel 4056, Switzerland.
Email: milenko.rakic@unibas.ch
accept or carry, whereas overburden indicates that this weight or task—in our case caring for PC patients, their families, and friends—cannot be carried anymore.\textsuperscript{10,11}

Compared to younger PC patients, older patients are more frequently isolated (eg, loss of partner) and have a limited informal care network. Family caregivers who provide care for older patients may feel burdened by such a challenging task.\textsuperscript{12} Furthermore, the ethical principle of autonomy, which is highlighted by the FOPH, might be difficult to respect and implement fully because of possible barriers regarding the provision of home care.\textsuperscript{9} For example, patients want to spend their last days at home, but their relatives cannot provide the desired home care as it is too burdensome.\textsuperscript{13} The family’s needs should also be recognized and taken into account, so they can support their loved one. Hence, it is important to address possible hindering factors—such as burden and overburden of patients and their families.

Since the number of patients in need of PC will increase in the future\textsuperscript{1} and caregivers often feel burdened by caring for them,\textsuperscript{14,15} our study focused on the different notions of burden and overburden in a PC context. More precisely, we looked at patients’ notes to determine what is being reported about burden and overburden in the medical records and who seems to be mostly affected according to these notes. To do so, we focused on written notes of the health-care staff working in a PC setting. Using latent content analysis, we analyzed 300 medical records of patients who received PC at 3 Swiss university hospitals.

Methods

Study Design

We employed a qualitative research design since it helps to investigate patients’ attitudes and preferences in more depth than quantitative research.\textsuperscript{14} We used content analysis to analyze the large amounts of textual data (notes or comments in medical records).\textsuperscript{15} Moreover, in order to ensure high quality in reporting qualitative research, we have applied—where possible—the 32-item consolidated criteria for reporting qualitative research (COREQ) checklist.\textsuperscript{16} In total, we examined 300 medical records from 3 university hospitals in Switzerland using a self-developed data extraction sheet.

Data Extraction Sheet

The data extraction sheet focused on patients’ conditions and specifically on their attitudes and preferences regarding PC. The extraction sheet covered the following aspects: (1) demographics, (2) diagnosis, (3) information about advance directives, and (4) all notes written by the medical team about patients’ attitudes and preferences regarding PC. The extraction sheet consisted of items with categorical responses (eg, gender), continuous variables (eg, age), and open-ended items (eg, notes about patient wishes and preferences). Items were developed from the research team’s knowledge in the field (M.R., I.W., and B.S.E.) and based on discussions with collaborating physicians (M.E., S.E., and S.Z.).

Study Population

Inclusion criteria were (1) patients received PC at 1 of the 3 Swiss university hospitals, and (2) patients were older than 18 years of age. The necessary information (lists of patients) was provided by the research partners at the 3 university hospitals (A, B, and C). Exclusion criterion was if a patient’s medical record had already been collected and the same patient appeared again later on in the list because of multiple visits in the hospital during the period of data collection. In such a case, this patient was excluded in order to avoid a duplicate. All information that could lead to an identification of patients was deleted after data collection.

Data Collection

Data collection took place between April and September 2016 and was carried out by 4 research team members. Ethical approval was obtained from the local research ethics committee (EKNZ; Nr. EK 2015-197). Because only routine nongenetic data were collected, informed consent from each patient was not needed (providing an opt-out), based on the Swiss federal law of human subject research.\textsuperscript{17} Patients are routinely informed that health-related data may be collected for research purposes during their hospital stay, and those who refuse such data collection must actively request exclusion. Before starting with data collection, the responsible physicians and data managers from each university hospital provided access to patients’ medical records. All medical records were available in digital format. We collected data throughout the patients’ medical records (eg, cover page with mostly demographic information, such as age, sex, and diagnosis), PC reports (special focus on advance care planning, patient’s wishes, and discussions which took place with the patient), and discharge reports (which provided a good summary of the whole hospitalization of a patient). We searched the notes written by all health-care professionals (eg, physicians, nurses, psychologists). We included in the analysis summarized discussions, which took place between patients and health-care professionals (eg, case manager, social worker, physician, nurse) and between physicians and families (and patients). We used the information written between the first PC consultation and the day the patient either left the hospital or died. Each patient received a special code, which ensured anonymity regarding the gathered data. Researchers who extracted the data discussed the first 5 extractions to achieve standardization of extraction and continuously discussed their extractions when needed. Patients were included sequentially. More specifically, we started with the patient who received PC on January 1, 2016, and continuously went back until the year 2015, thereby extracting 100 medical records per hospital. The same procedure was followed in all 3 university hospitals resulting in a final number of 300 extractions. Patients’ demographics and characteristics are presented in Table 1.

Data Analysis

Data were analyzed using software for qualitative research (MAXQDA 12). Content analysis was chosen as it helps
develop categories and analyze large amounts of textual data qualitatively. We were particularly interested in the underlying concepts of what was written. This approach is known as latent content analysis. The analysis process started with several readings of all extracted data by 1 researcher (M.R.), aiming for an overview of the data. In the next step, 2 members of the research team (M.R. and I.W.) agreed on the main themes that emerged from the data. In this article, we report on one of them: health-care staff’s perception of burden and overburden. This topic was considered important as it was found recurrently across the medical records. M.R. started with an initial open coding and then organized the codes into main categories as well as subcategories. I.W. crosschecked the coded passages. Then, based upon the text material, they made a distinction between “burden” and “overburden.” We used the generally accepted definition of burden and overburden, that is, a burden is a weight or task—in a physical and psychological sense—that is difficult to accept or carry. Overburden indicates that the weight or task—in our case caring for PC patients, their families, and friends—cannot be carried anymore. As found in the literature, the term “family” was understood in a broader way, and we therefore also included the category “friends” in our analysis. The research team defined “burden” and “overburden” as the 2 main categories, after checking that both terms were used in the research literature. M.R. started with the coding regarding “burden” and “overburden.” To guarantee accuracy and consistency of the coded segments, I.W. reread all the previously coded text passages and crosschecked them. All transcripts were analyzed in the original languages (French, German). Quotes were translated into English, and this translation was edited by a native English-speaking researcher. All authors agreed on the conceptual map of main categories and subcategories presented in the Results section (see Table 2).

**Table 1. Demographics of Palliative Care Patients for Each Hospital.**

<table>
<thead>
<tr>
<th>University Hospital</th>
<th>A</th>
<th>B</th>
<th>C</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, M (SD)</td>
<td>70.55 (14.77)</td>
<td>63.02 (14.87)</td>
<td>69.11 (14.5)</td>
</tr>
<tr>
<td>Age, min-max</td>
<td>23-98</td>
<td>22-91</td>
<td>27-94</td>
</tr>
<tr>
<td>Gender (female)</td>
<td>51%</td>
<td>39%</td>
<td>53%</td>
</tr>
<tr>
<td>Diagnosis (cancer)</td>
<td>73%</td>
<td>78%</td>
<td>70%</td>
</tr>
</tbody>
</table>

Abbreviations: M, mean; SD, standard deviation.

“N = 300.

**Results**

Our analysis identified burden and overburden as main categories, which were further divided into 2 subcategories: patients and families (see Table 2).

**Study Sample**

Forty-seven percent (143/299) of the patients were female. Mean age was 67.6 years, ranging from 22 to 98 years. Cancer was diagnosed in 73% (211/287) of the patients (see Table 1).

**Table 2. Main Categories and Subcategories From Content Analysis.**

<table>
<thead>
<tr>
<th>Main Categories</th>
<th>Subcategories</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1) Burden</td>
<td>(a) For patients</td>
</tr>
<tr>
<td></td>
<td>(b) For families</td>
</tr>
<tr>
<td>(2) Overburden</td>
<td>(a) For patients</td>
</tr>
<tr>
<td></td>
<td>(b) For families</td>
</tr>
</tbody>
</table>

**Table 3. Family.**

“He also means that he is glad that his family is not always with him, as he also needs time for himself.” [Patient record (PatRec) 1]

“(…) [Patient] reports difficulties in informing her family about the disease and its progression. She [patient] fears that everyone will cry, actually she wishes for strong people.” [PatRec 2]

“She [patient] said that she was ashamed to cry and she didn’t do it in order not to worry her close family and friends.” [PatRec 3]

“The patient was very sad and scared, he wanted to meet the whole family in the presence of the psychologist in order to discuss about his father role. He had had his first son with his ex/first wife and he was feeling guilty toward this first son.” [PatRec 4]

**Cause of Burden for Patients**

Patients’ perceived burden was mostly related to obligations they felt toward their own family. Diseases were also often mentioned as a cause of burden for patients. Other less mentioned burdens were related to financial problems or to current domestic situation.

**Family.** Examining possible causes for why patients felt burdened, we found that patients experienced a feeling of burden as they had insufficient time and space to be alone without family being constantly around them. Moreover, patients were said to have problems talking about diagnosis with the family, because they were worried about the family’s reaction. Other patients were described as being afraid to express their emotions because they were embarrassed and because they wanted to protect their family and friends. Sometimes, patients were reported to be more worried about other family members than themselves. At times, the health-care staff noted that this could cause burden for the patients. In these difficult moments, the notes indicated that patients felt the need to clarify their relationship with their children (see Table 3).

**Disease.** The notes indicated that patients seemed aware that their disease was continuous and life-prolonging measures were counterproductive and, as such, felt burdened by the illness. We found that patients were described as feeling helpless regarding their own illness. Moreover, pain and lack of physical autonomy were sometimes noted as burdensome (see Table 4).

**Financial problems.** According to the notes of health-care personnel, an additional reason that patients felt burdened was monetary concerns. It was also evident that worrying about money issues sometimes caused additional anger for patients (see Table 5).
Cause of Burden for Families

Issues related to patients’ medical condition. The notes in the medical records mentioned patients’ condition and issues related to it (eg, being in the final stage of the illness) as the most frequent reason why partners felt burdened. Family members mentioned that they needed some space for themselves. Sometimes, they seemed to feel burdened because of the patients’ imminent transfer to a hospice. Moreover, relatives were described as having expressed the difficulty of accepting the patient’s current medical condition and treatment. Nevertheless, it must be underlined that an initial burden could turn into relief for the family (see Table 8).

Fear of putting too much burden on the partner. Some patients were reported as scared of asking too much from their partners. Patients seemed to realize that their partners also needed some help at home and consequently wished for supervision at home. Sometimes, patients did not want their care to be continued at home because they knew that their partner could not provide the needed support for them (see Table 6).

Situation at home. An important finding was that the current household situation could lead to further burden not only for partners but also for patients. For instance, the illness of their partner was noted to create an additional burden for the patient (see Table 11).

Overburdening was most often caused by patients’ disease. Disease aggravation could also lead to the inability to cope with the disease. Moreover, a poor symptom management could represent a source of overburden (see Table 12).

Issues related to patients’ medical condition.

<table>
<thead>
<tr>
<th>Table 4. Disease.</th>
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<tbody>
<tr>
<td>“Patient loves her family, but she knows that the disease has progressed and that life-prolonging measures are just a prolongation of suffering.” [PatRec 5]</td>
</tr>
<tr>
<td>“Psychologist noticed that this anger was related to a feeling of helplessness regarding his disease.” [PatRec 6]</td>
</tr>
<tr>
<td>“Patient feels burdened by pain and the associated immobility.” [PatRec 7]</td>
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</tbody>
</table>

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<thead>
<tr>
<th>Table 5. Financial Problems.</th>
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<tr>
<td>“The patient was worried about financial problems.” [PatRec 8]</td>
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<tr>
<td>“[…] this anger was related to a feeling of helplessness regarding his disease, his financial and family situation.” [PatRec 9]</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Table 6. Fear of Putting Too Much Burden on the Partner.</th>
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<tbody>
<tr>
<td>“Patient wishes for support at home, also to relieve his wife.” [PatRec 16]</td>
</tr>
<tr>
<td>“Patient knows that she cannot go home, because her partner relies on her “guidance.” Partner cannot take care of her.” [PatRec 17]</td>
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<tr>
<th>Table 7. Situation at Home.</th>
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<tbody>
<tr>
<td>“Patient reports about difficult domestic situation, because his partner is suffering from Parkinson’s disease.” [PatRec 10]</td>
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</table>

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<thead>
<tr>
<th>Table 8. Issues Related to Patients’ Medical Condition.</th>
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<tbody>
<tr>
<td>“Discussion with spouse and daughter of patient; they are told why patient is in a terminal stage. Spouse finds difficult to accept the situation (…).” [PatRec 11]</td>
</tr>
<tr>
<td>“Wife expresses the wish to sleep in a separate room from her husband in order to have some space for herself.” [PatRec 12]</td>
</tr>
<tr>
<td>“Wife reports about difficult past weeks. In the beginning, she had difficulties with the transfer to the hospice, because of the fear of an “end station.” “However she does not feel that way anymore and is looking forward to the transfer.” [PatRec 13]</td>
</tr>
<tr>
<td>“Husband sees situation critically: He has big hope that patient will stabilize, to be mobile. On the other hand, it was always clear for the patient: “Not at all cost.” [PatRec 14]</td>
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<thead>
<tr>
<th>Table 9. Home Care.</th>
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<tr>
<td>“Patient and wife are discussing the transfer to the hospital [name of hospital]. Wife seems to be relieved not to have to take patient home in this condition.” [PatRec 1]</td>
</tr>
<tr>
<td>“Conversation with wife, physicians, and patient: Wife cannot presently imagine a return home, because patient is too much in need of care.” [PatRec 15]</td>
</tr>
<tr>
<td>“Conversation with long-standing friend of patient: patient has always been stubborn; she lives in a shabby flat, if the patient returns home, her friend will hand over her keys, she only sees the patient in a hospital, etc.” [PatRec 20]</td>
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<tr>
<th>Table 10. Patients’ Wishes to Die.</th>
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<tr>
<td>“Partner wants to help her satisfy this wish but seems to struggle with this.” [PatRec 18]</td>
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</table>

| Home care. Another recurring aspect was the burden related to caring for patients at home. More specifically, the most frequent feeling of burden was the inability to take care of the patient at home because the patient was too disabled (see Table 9). |

Patients’ wishes to die. Additional reasons for a partner’s feeling of burden were when the patient wished to die with an organization that supports assisted suicide (eg, EXIT) and the difficulty to accept or deal with this wish (see Table 10).

Financial and social aspects. Another aspect of burden of care was the burden that partners felt when they had to make nonmedical decisions on behalf of the patient, such as bureaucratic or monetary questions. The wife of one patient was worried that she and her son would be left alone after her husband’s death (see Table 11).

Cause of Overburden for Patients

Disease. Overburdening was most often caused by patients’ disease. Often, the fast disease progression made them feel overburdened. Disease aggravation could also lead to the inability to cope with the disease. Moreover, a poor symptom management could represent a source of overburden (see Table 12).
Our objective was to highlight documented information about burden and overburden in the medical records of PC patients. The most frequent cause for feeling overburdened was patients’ medical condition. Moreover, relatives had great difficulties dealing with patients’ present circumstances and their constantly deteriorating health status. Partners sometimes mentioned that patients did not receive extensive medical treatment (see Table 13).

**Table 11. Financial and Social Aspects.**

| “She was also dealing with many administrative and financial issues related to the patient’s inheritance.” [PatRec 19] |
| “She was aware of the severity of the situation and very affected by the speed of the disease and that she was going to be alone with her son in [name of the city], knowing that her social network was little developed in [name of the city].” [PatRec 19] |

**Table 12. Disease.**

| “Patient is heavily burdened by the course of the disease (neurological deterioration).” [PatRec 21] |
| “Because patient cannot continue to live like this, he was in contact with EXIT, he wants to go this way.” [PatRec 18] |
| “Discussion with patient and nursing assistants from institution: Patient’s symptoms are not well-managed, [patient] cries a lot: “I cannot anymore; I cannot stand it any longer.” [PatRec 22] |

**Table 13. Issues Related to Patients’ Medical Condition.**

| “Discussion with wife, cousin and cousins’ husband at patient’s bedside: Wife reports that she is overburdened with the current situation.” [PatRec 23] |
| “Discussion with husband without patient: [husband] reports about overstrain; the constant aggravation of the patient’s situation was a shock for him.” [PatRec 24] |
| “Discussion with wife (alone): she is heavily burdened, she has the impression that patient is not receiving comprehensive care and that he is now ‘abandoned.’” [PatRec 25] |

**Cause of Overburden for Families**

**Issues related to patients’ medical condition.** The most frequent cause for feeling overburdened was patients’ medical condition. Moreover, relatives had great difficulties dealing with patients’ present circumstances and their constantly deteriorating health status. Partners sometimes mentioned that patients did not receive extensive medical treatment (see Table 13).

**Home care.** Partners often mentioned that they could not take care of patients anymore because they needed continual support. Some patients realized that their partners could not take care of them because of the amount of care they needed. Sometimes partners who were already taking care of children felt overloaded by additionally taking care of patient (see Table 14).

**Decision-making.** Partners who needed to make a decision regarding the patient’s medical treatment sometimes felt overburdened by this role. Another report shows that not only medical decisions but all kinds of decisions were overburdening for the patient’s partner (see Table 15).

**Discussion**

Our objective was to highlight documented information about burden and overburden in the medical records of PC patients. More precisely, we wanted to analyze the possible challenges faced by patients and informal caregivers as documented by health-care staff. Furthermore, we aimed to understand the possible underlying reasons which made these stakeholders feel burdened and sometimes even overburdened. So, we analyzed how burden and overburden of patients and their families were documented in the patients’ medical records. The distinction between burden and overburden was evaluated to analyze when burden becomes overburden. Burden can be further divided and refined into caregiver burden (CB; eg, burden which arises of taking care of patients) and self-perceived burden (SPB; eg, patient’s perception of being a burden to their family members). Moreover, Lee et al showed a connection between both kinds of burdens and PC treatment. They conclude that patients could choose certain treatments to avoid putting burden on their informal caregivers or if they have the feeling to be a burden (SPB) to their family members. On the other hand, burdened informal caregivers could influence patients’ decision regarding certain treatments. Finally, the authors demonstrate that higher CB or SPB could lead to a deprivation of patient autonomy. These findings align with our results. Our analysis showed that it was recurrently written in the medical records that patients expressed the fear of putting too much burden on the partner. A study suggest that CB and SPB can be decreased through several interventions, such as support programs for informal caregivers, advance care planning for patients, promotion of communication, and the organization of “family conferences” to discuss matters important to patients and their relatives. Our results also suggest that particular attention should be given to families because of their role as informal caregivers. More specifically, we found that home care was often mentioned as being a cause of burden and overburden for patients’ families. Our findings agree with the current literature. Interview studies with informal caregivers pointed out that they faced a high risk of being burdened as a
consequence of caring for their loved one.\textsuperscript{24,25} Proot et al concluded that caring for a patient at home could be both a mental and physical burden.\textsuperscript{24} Given et al summarized that the burden on informal caregivers was different from anxiety or depression. As a possible reason for this burden, the authors listed disease progression and the subsequent greater need of care.\textsuperscript{26} This topic was also found in the medical records, as it was noted that issues related to patients’ medical condition (e.g., disease progression) act as a possible factor for patients’ families to feel burdened and overburdened.

Our results show that disease, home care, patients’ wishes, financial concerns, and social issues were objective things that patients and families had to deal with and which might let them to feel burdened and even overburdened. Findings regarding what was documented in the medical records are inasmuch important, as they point at the health-care staff’s awareness of possible weights and tasks that might be burdensome for PC patients and their families. Moreover, these issues documented by health-care staff appeared to confirm findings from other empirical studies regarding causes of burden and overburden in PC.\textsuperscript{22,24-26}

**Limitations**

Medical notes were written by health-care professionals, but these notes might not be exhaustive. What is more, if health-care staff are not sensitive enough to the burden issue, their feelings expressed by patients and their families and friends might not be fully recorded in the notes. Furthermore, the medical team might superficially misinterpret signs of burden (e.g., tiredness or physical exhaustion). Finally, these notes might not always give the details or verbatim wording of the dialogue. Sometimes, documentation in medical records of communication leaves out important verbal and nonverbal information.

**Conclusion**

Our results indicate that, according to the written notes, patients felt burdened or overburdened because of their own disease, the situation at home, or their own family. Moreover, the analysis of medical records suggests that families often seemed to mention issues related to the patient’s medical condition, the decision-making process, and social and financial issues as being burdensome. To conclude, our analysis showed that—according to the FOPH\textsuperscript{9}—the central aim of including informal caregivers in the provision of care for PC patients might be difficult to implement. Attention should be drawn to the documentation of medical records in order to identify recurrent difficulties—such as feelings of burden and overburden documented in the medical records—and to help discuss these difficulties (e.g., “family conferences”).\textsuperscript{23}

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