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Correspondence between primary and secondary care about patients with cancer: A qualitative mixed-methods analysis

Mariken E. Stegmann¹  | Jiska M. Meijer¹ | Janine Nuver² | Klaas Havenga³ |
Thijo J.N. Hiltermann⁴ | John H. Maduro⁵ | Jan Schuling¹ | Annette J. Berendsen¹

¹University of Groningen, University Medical Center Groningen, Department of General Practice, Groningen, The Netherlands

²University of Groningen, University Medical Center Groningen, Department of Medical Oncology, Groningen, The Netherlands

³University of Groningen, University Medical Center Groningen, Department of Abdominal Surgery, Groningen, The Netherlands

⁴University of Groningen, University Medical Center Groningen, Department of Pulmonary Diseases, Groningen, The Netherlands

⁵University of Groningen, University Medical Center Groningen, Department of Radiation Oncology, Groningen, The Netherlands

Correspondence

Mariken E. Stegmann, University of Groningen, University Medical Center Groningen, Department of General Practice, HPC FA 21, Postbus 30.001, 9700 RB Groningen, The Netherlands.
Email: m.e.stegmann@umcg.nl

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Abstract

Cancer care is complex and involves many different healthcare providers, especially during diagnosis and initial treatment, and it has been reported that both general practitioners and oncology specialists experience difficulties with interdisciplinary communication. The aim of this qualitative study was to explore information sharing between primary and secondary care for patients with lung, breast or colorectal cancer. A qualitative content analysis of 50 medical files (419 documents) was performed, which identified 70 correspondence-related items. Six main topics were identified in most referral letters from primary to secondary care, but it was particularly notable that highly relevant information regarding the past medical history was often mixed with less relevant information. To lesser extents, the same held true for the medication list and presenting history. In the letters from specialists, nine topics were identified in most letters. Although information about actual treatment was always present, only limited detail, if any, was given about the intent of the treatment (curative or palliative) or the treatment alternatives. Interviews with nine healthcare providers confirmed these issues. These findings indicate that neither the initial referral nor the specialist correspondence is tailored to the needs of the recipient.

KEYWORDS

cancer patients, correspondence, primary care–secondary care interface, qualitative design, referral letters, specialist letters

1 | INTRODUCTION

An estimated 14.1 million new cases of cancer were reported worldwide in 2012, and this incidence is increasing, with cancer now being the second leading cause of death worldwide (Jemal et al., 2008; Torre et al., 2015). The three most common types of cancer are lung, breast and colorectal cancer (Torre et al., 2015). Cancer care is complex and involves a range of healthcare providers both inside and outside hospitals (Sussman & Baldwin, 2010), and patients find

it important that these providers exchange relevant information appropriately to ensure smooth continuity of care (Nazareth et al., 2008; Spiegel et al., 2010). In countries where general practitioners (GPs) provide that continuity of care and function as gatekeepers, communication between primary and secondary care is particularly relevant and especially for patients in complex situations such as cancer (Brandenburg et al., 2014; Klabunde et al., 2009; Rubin et al., 2015). In the Netherlands and other countries with a similar system, all patients do have a GP and they often see their GP also during

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specialist treatment, not only for other health problems but also for explanation and for emotional support.

Formal communication between different healthcare providers in these countries is mostly by written correspondence, which is often sent digitally. When a GP refers a patient to a hospital specialist, they must write a "referral letter" that mentions the reason for referral. Then, when the hospital specialist has seen a patient, a "specialist letter" should be returned to the GP detailing the findings, treatment and follow-up plans. Because of the coordinating role of the GP, this letter should be sent within 5 days and sooner if needed to ensure continuity of care (NHG-FMS-kerngroep Revisie HASP 2017).

However, primary and secondary care each have their own needs and expectations, which can lead to communication difficulties (Admi et al., 2013; Berendsen et al., 2009; Farquhar et al., 2005; Milliat-Guittard et al., 2006; Westermann, Hull, Bezemer, & Gort, 1990). Moreover, each party typically reports the quality of correspondence as being low from the other party, with disagreement cited about the precise issues (Berendsen et al., 2009; Westermann et al., 1990). Referral letters are often said to lack relevant clinical information or a specific request (Grol, Rooijackers-Lemmers, van Kaathoven, Wollersheim, & Mookink, 2003; Westermann et al., 1990), whereas specialist letters are reported to lack information about what the GP needs to know (McConnell, Butow, & Tattersall, 1999; Tattersall et al., 1995), and can arrive late after a consultation (Farquhar et al., 2005; McConnell et al., 1999). According to both patients and physicians, inadequate communication between healthcare providers can lead to suboptimal quality, poor coordination, discontinuity and suboptimal quality of care (Kamradt et al., 2015; Walsh et al., 2010).

The aim of this qualitative study was to explore the information that is shared in referral letters and specialist letters between primary and secondary care during the process of diagnosis and initial treatment of patients with lung, breast or colorectal cancer.

2 | METHODS

2.1 | Design and setting

In this study, we performed a qualitative analysis of correspondence because of the explanatory nature of the research question. The medical records of patients diagnosed with lung, breast and colorectal cancer in the north of the Netherlands in 2014 or 2015 were assessed. These tumours were chosen because they are the most common types (Torre et al., 2015) and because both oncology specialists and GPs are frequently consulted about them during treatment (Brandenburg et al., 2014; Roorda et al., 2012). To provide a comprehensive overview and confirmation of our findings, we performed data triangulation (i.e., cross verification with other sources) was performed (Kuper, Reeves, & Levinson, 2008) through semi-structured interviews with GPs and oncology healthcare providers. The Institutional Review Board of the University Medical

Centre Groningen reviewed the protocol and informed consent was obtained from all interviewees. We report this research based on the Consolidated Criteria for Reporting Qualitative Research (Tong, Sainsbury, & Craig, 2007).

2.2 | Data collection of medical files

Medical hospital files were selected by purposive sampling. We aimed to include patients of different age, gender and tumour stage who were treated by oncology specialists and GPs of different experience levels, ages and genders.

We extracted all referral letters from medical files, including those sent by mail or fax, and those sent digitally using ZorgDomein (Care Domain) (Bal, Mastboom, Spiers, & Rutten, 2007). The ZorgDomein system provides GPs with a predefined format that automatically imports some key information (e.g. prescriptions or past history) from the GP's file into the referral letter. This system has become widely used in the Netherlands over the last decade. The precise format differs slightly by the reason for referral and by department, as all formats are composed at a regional level by collaboration between specialists and GPs (Bal et al., 2007).

Next, we extracted the specialist letters written from the time of referral to the end of the initial phase of treatment (which was defined as the first three months after diagnosis and the start of any other treatment thereafter, if described in the initial treatment plan). Notes were also extracted regarding outpatient visits, allied health professional (e.g. psychotherapists, social workers and dieticians) visits, telephone calls and multidisciplinary meetings. In the multidisciplinary meetings, all patients diagnosed with a specific type of cancer were discussed by specialists of different relevant departments (e.g. surgeons, medical oncology specialists, radiologists, pathologists, pulmonologists and radiation oncology specialists), but without input from GPs. However, sometimes reports of these meetings were sent to GPs. We excluded documents used to exchange information between in-house healthcare providers.

2.3 | Data collection of interviews

To confirm our data, healthcare providers were recruited for the interviews by purposive sampling. We aimed to include GPs and oncology specialists from different departments, age and gender. Discussed topics were the content and quality of any referral letters, specialist letters, other ways of communication and non-shared information. All interviews were recorded, five were fully transcribed, and for the others, all relevant quotations were written down.

2.4 | Data analysis

Descriptive statistical analyses are given about the number of pages of correspondence and the time interval between consultation and correspondence. To illustrate the findings of the medical files and interviews, quotations (Q) are presented and identified by a department and a document number.

During a pilot study of five files of patients with breast cancer, a preliminary code list was produced, and checked by two other researchers, which was used when analysing the patient files. Relevant text fragments were identified and coded, before the coded text fragments were analysed thematically, all supervised by experienced researchers (Malterud, 1993, 2001; Pope, Van Royen, & Baker, 2002). Codes concerning the same topic were grouped into a theme. For each tumour site (lung, breast or colorectal), a second researcher independently analysed random samples of the documents. Agreement between the researchers was calculated as the percentage of exactly corresponding codes. Any discrepancies were discussed until consensus was reached, and if necessary, the coding list was refined in an iterative process. In the interviews, two researchers independently identified relevant text fragments.

Sampling was continued until saturation, which was defined as the moment that no new codes were identified. When saturation was reached for one tumour type in one hospital, we analysed two more medical files to ensure saturation. All documents and notes were anonymously uploaded in Atlas.ti (version 7.15.12).

Any discrepancies were discussed with a third member of the research team until consensus was reached. Finally, the results were discussed in a multidisciplinary meeting with all co-authors.

3 | RESULTS

3.1 | Sample characteristics

All six departments that we approached agreed to collaborate. In total, 50 patient files containing 419 documents were analysed and nine healthcare professionals were interviewed. The purposive sample of interviewees consisted of four GPs, four oncology specialists and one specialist oncology nurse. The characteristics of the included patients and the interviewed healthcare providers are detailed in Table 1.

3.2 | Coding

First, the files of three departments in an academic hospital were analysed, and saturation was reached for lung, breast and colorectal cancer after 19, 15 and 11 files respectively. Thereafter, we analysed the files of two non-academic hospitals until saturation was reached. The final code list contained 70 codes in 13 themes (Supporting Information Table S1). Agreement between the coding researchers was 90% on average. No additional codes were identified from interviewing the healthcare professionals.

| | | |
|-----|------------|--|
| Q1: | 16-07-2010 | Proximal phalanx left 5th digit fracture |
| | 30-11-2009 | Osteoporosis |
| | 02-07-2009 | Diabetes Mellitus type 2 |
| | 02-03-2008 | Rib # right, liver contusion (dd rupture) after fall |

TABLE 1 Sample characteristics

| | Patient files (%) n = 50 | Interviews (%) n = 9 |
|----------------------------------|-----------------------------|-------------------------|
| Patients | | |
| Gender | | |
| Male | 19 (38%) | |
| Female | 31 (62%) | |
| Tumour site | | |
| Lung | 20 (40%) | 4 (44%) |
| Mamma | 16 (32%) | 3 (33%) |
| Colorectal | 14 (28%) | 2 (22%) |
| Age (mean, SD) | 65 (10) | |
| Tumour stage | | |
| Stage I | 9 (18%) | |
| Stage II | 11 (22%) | |
| Stage III | 16 (32%) | |
| Stage IV | 14 (28%) | |
| Oncological healthcare providers | | |
| Gender | | |
| Male | | 3 (60%) |
| Female | | 2 (40%) |
| General practitioners | | |
| Gender | | |
| Male | | 3 (75%) |
| Female | | 1 (25%) |

3.3 | Referral letters from GPs

In total, 50 referral letters were analysed; 96% of these were written using *ZorgDomein*, the others were written without a programme. The referral letters were one to two pages long, although a medication list was sometimes attached on a separate page. Box 1 contains a summary of the information provided in most referral letters.

In general, the referral letters tended to contain relevant information for the oncology healthcare provider mixed with information less relevant for the current problem. This was most notable in the past medical history, where major and minor health problems were often detailed in one list without prioritisation (Q1), and sometimes without a chronological order. To a lesser extent, the same held true for the medication list and history of the presenting complaint. In the latter case, information about different aspects of the patient's history was mixed, often with information about the physical examination. This mixed presentation of data was also mentioned in the interviews. An example of this problem can be seen in Q1.

| | |
|------------|--|
| 01-01-2005 | Polyarthralgia based on arthrosis |
| 01-01-2000 | Morton's neuroma |
| 01-01-1999 | Mamma reduction |
| 01-01-1987 | Rotator cuff syndrome |
| 01-01-1963 | Adenomyosis of gallbladder, because of which cholecystectomy |
| 01-01-1980 | Sterilisation |
| 01-01-1973 | Appendectomy |
| 15-10-2013 | Coughing |

Referral letter – past medical history. (Lung cancer, doc90). This quotation shows a non-chronological order and a mix of information that is (e.g. diabetes mellitus) and is not (e.g. sterilisation) relevant for the current health problem.

Box 1 Common topics in referral letters

The following information was given in most referral letters

- Reason of referral/specific request
- Past medical history and current use of medication
- History, family history and intoxications
- Physical examination
- Additional diagnostic information
- Policy (policy by the GP awaiting referral, sort of referral and expectations)

Box 2 Common topics in specialists' letters

The following information was given in most specialist letters

- Date of consultation or hospitalisation
- Relevant past medical history, including, if applicable, current diagnosis and recent treatment
- History paragraph (e.g. which symptoms does the patient have)
- Physical examination, often restricted to abnormal findings
- Results from additional diagnostic tests (e.g. blood results)
- (Preliminary) diagnosis
- Policy (e.g. additional diagnostic test, new treatment, next visit)
- Meta-communication (what does the patient know)
- Summary

3.4 | Specialist letters

In total, 369 specialist letters were analysed. A structured format was used in all letters, but these formats differed between departments and hospitals. The lengths of the letters ranged from 1 to 4 pages, and the interval between date of consultation and date of sending the letter ranged from 0 to 40 days (median 3 days, interquartile range 1–9 days). In a few cases, treatment was started before the GP had received written information about diagnosis and treatment. The information provided in most specialist letters is summarised in Box 2.

All these letters contained information about actual treatment. Often this information was comprehensive and provided details about the exact type of surgery, chemotherapy or radiotherapy, together with the dose, frequency and period of treatment. However, an explicit statement about whether the treatment was given with curative or palliative intent was rare. Treatment alternatives and patient preferences were also seldom written down. If they were mentioned, it was mostly because an alternative had been chosen for medical reasons, such as for severe comorbidity or certain tumour characteristics (e.g. a specific mutation; see Q2). In the interviews, GPs also mentioned a lack of specific information about the curative or palliative intent of a treatment.

Q2: Wait for mutation analysis. To choose either a TKI-inhibitor or chemotherapy with cisplatin-pemetrexed.

Specialist letter – policy

(Large non-academic hospital, lung cancer, Doc19)

Plain language: Wait for a specific genetic test, based on which we will choose for either immunotherapy or chemotherapy.

All specialist letters contained details of the patient's history, but often provided other information too; in some cases, no history was provided at all. A typical example (e.g. Q3) included information about what was discussed with the patient during the consultation.

Q3: History: Patient visited our outpatient clinic together with four children. Results discussed.

Specialist letter – history.

(Academic hospital, lung cancer, Doc49)

Additional diagnostic tests were reported in detail. In most cases, the report of the radiologist or pathologist was given without description of their implications for diagnosis or treatment. Many

letters also mentioned the potential side effects of proposed or given treatment. In some letters, specific recommendations were given to the GP about how to handle side effects, but in others, either a simple reference to a protocol or guideline was provided, or no recommendations were mentioned (e.g. Q4). Late effects were almost never mentioned.

Q4: The surgical operation, the expected course, but also the complications related to the treatment, were discussed with her.

Specialist letter – policy.
(Small non-academic hospital, colorectal cancer, Doc6)

Although many letters reported that information was shared with the patient, this was not very specific in most cases. The emotional reaction of the patient to receiving specific information was seldom reported (e.g. Q5). In the interviews, GPs mentioned that they would like to receive information about what was discussed with the patient regarding treatment and prognosis.

Q5: Patient and daughter are very relieved that we did not opt for chemotherapy; they agree with the therapy proposed.

Specialist letter – policy.
(Academic hospital, breast cancer, Doc50)

3.5 | Both referral and specialists' letters

Abbreviations were used in all letters. Most were common medical abbreviations (e.g. Q6), but some were department-specific (e.g. Q7). In the interviews, GPs mentioned that they did not understand all abbreviations that were used, and some medical specialists stated that they tried to avoid abbreviations and department-specific terms whenever possible (e.g. Q8).

Q6: Cor ne, pulm vbs, abd nca, shoulder limited mobility. *Full version: Cor normal examination, pulmones vesicular breathing sounds, abdomen no clear abnormalities, shoulder limited mobility.*

Referral letter – physical examination.
(Lung cancer, Doc17)

Q7: During positioning of PCEA, patient developed AF, for possible post-surgical anticoagulation PCEA abandoned. After resection ICG-clearance 8%. *Full version: During positioning of patient-controlled epidural analgesia, the patient developed atrial fibrillation. For possible post-surgical anticoagulation, patient-controlled epidural analgesia was abandoned. After resection, the indocyanine-green clearance was 8%.*

Specialist letter – surgery report.
(Academic hospital, colorectal cancer, Doc6)

Q8: I really try to avoid using abbreviations, since knowing all different abbreviations by all different specialisations is not doable for a general practitioner.

Interview of specialist nurse.
(Academic hospital, breast cancer, I3)

3.5.1 | Rarely used codes

Almost no remarks were found about advance directives (e.g. do not resuscitate) in either referral letters or specialist letters. In some letters, a special heading regarding this subject was available, but was often not completed. In addition, psychosocial information was only very rarely found in either referral or specialist letters. One GP mentioned that psychosocial information was almost never provided in letters, but that it was often shared during telephone contact (e.g. Q9). Some specialist letters presented a summary of complaints in organ systems other than the one of primary interest, but this was rare. Equally, it was rare to receive a differential diagnosis of the other possible explanations for the complaints.

Q9: In case of malignancies, I always have contact by telephone with the treating specialist in between his consultations. This provides me with relevant information on how a patient is coping.

Interview with GP1.
(Rural general practice, I1)

3.5.2 | Reports

All patients were discussed at least once in a multidisciplinary meeting/setting. In some departments, the comprehensive reports of these meetings were sent to the GP. In other departments, the report was available in the hospital file, but was not shared with the GP. In those cases, the conclusions of the multidisciplinary meetings were often summarised in the specialist letters. Some of these reports contained more information about alternative treatment options and the choices made compared with the specialist letters (see Q10 and Q11 for examples). Some GPs mentioned they would prefer to receive these reports, since they often provide a summary of diagnoses and planned treatment. Other GPs thought these reports did not add any value to the specialist letters.

Q10: Treatment plan: in case the patient prefers a breast saving treatment, there is an indication for neo-adjuvant chemotherapy. Otherwise mamma ablation and axillary lymph node dissection.

Multidisciplinary meeting report.
(Academic hospital, breast cancer, Doc101)

Q11: Treatment plan: modified radical mastectomy

Specialist letter. (Academic hospital, breast cancer, Doc12)

Q10 and Q11 are about the same patient at the same moment.

Reports of invasive diagnostic procedures (e.g. colonoscopy or bronchoscopy) were almost always sent to the GP, either separately or integrated in a specialist letter. The same held true for surgery reports. Reports from consultations with allied health professionals and medical consultants were available in the patient's file, but were not usually detailed in the letter sent to the GP.

3.5.3 | Telephone calls

Both GPs and oncology specialists mentioned that they preferred telephone contact when dealing with oncological diagnoses. However, telephone calls to other healthcare providers were rarely mentioned in either referral or specialist letters or somewhere else in the patient file. In addition, both groups of healthcare providers mentioned that it was often difficult to contact each other by telephone because of limited availability. Some GPs preferred regional hospitals because, compared to university hospitals, it was considered easier to contact specialists (Q12).

Q12: But, talking about [the university hospital]; yes, I prefer not to work with them [...] yes, I often find it difficult to contact them.

*Interview with GP1.
(Rural general practice, I1)*

4 | DISCUSSION

4.1 | Key findings

We identified 70 items of correspondence between primary and secondary care. Six topics were identified in almost all referral letters (Box 1), but it was most notable that highly relevant information was often mixed with less relevant information in the past medical history, medication list and history of the presenting complaint. By contrast, specialist letters included nine common topics (Box 2), and although information about actual treatment was always presented, it was rare for the letters to include information about the intent of the treatment (curative or palliative), whether there had been any discussion about treatment alternatives or about how the patient had reacted to the information received.

4.2 | Comparison with the literature

This study adds to the small body of evidence about written communication between healthcare providers, especially that concerning

patients with cancer. We note two features that we believe reflect use of the *ZorgDomein* system. Firstly, in contrast to existing results in the literature (Grol et al., 2003; Westermann et al., 1990), referral letters in our sample typically mentioned the reason for referral. This could be explained by the fact that most GPs in the Netherlands refer patients using *ZorgDomein*, which pre-specifies the information required (Bal et al., 2007). Secondly, the lack of discrimination between relevant and less relevant information has not been mentioned in the literature before. This finding can also be explained using the *ZorgDomein* system that automatically exports information from the electronic patient file into the referral letter. Apparently, GPs fail to adjust the exported information.

Concerning specialist letters, and consistent with the existing literature, we found that the treatment goal and prognosis were seldom mentioned (Graham & Wilson, 1998; McConnell et al., 1999). By contrast, current medication details were almost always mentioned, despite this not being the case in previous research (Tattersall et al., 1995). Also consistent with previous research, technical information about radiation therapy was included in all letters, even though only a minority of the GPs wanted the information (Barnes, Hanson, Neumann, Nikolaichuk, & Bruera, 2000). These findings suggest that letters are sometimes meant to provide a means of storing rather than exchanging information, which may explain why they are poorly tailored to the needs of the recipient (McConnell et al., 1999; Tattersall et al., 1995).

Overall, the findings of our study indicate that both referral and specialist letters were not always written with the primary aim of mutual communication. This aim could be defined as providing the information needed to ensure continuity of care, between hospital and primary care, without giving redundant information (Youngwerth & Twaddle, 2011). To improve communication, it would be interesting to explore the information different healthcare providers find essential or desirable in communication.

4.3 | Strengths and limitations

To the best of our knowledge, this is the first study not to use pre-specified quality criteria when analysing the content of letters concerning patients with cancer. We gathered information in a very open and explorative way, as is needed in qualitative research (Malterud, 2001), and much attention was paid to the sample composition. Indeed, we generated a purposive sample of patients by different hospital types, different cancer types and different tumour stages, and we included both GPs and oncology specialists of different ages and genders. Interviews were also included to ensure data triangulation. Despite the fact that our research was aimed at correspondence about patients with cancer, the findings seem to be not very disease specific and may be generalisable to other diseases.

However, several limitations do exist.

First, all researchers who analysed the data for coding were associated with our Department of General Practice, and this might hamper objectivity. To combat this, however, a value-free code list was used and all results were discussed extensively with co-authors working in different hospital departments.

Second, only written information was used because of the nature of the content analysis. Non-recorded phone calls between healthcare providers were, therefore, not included. Although this does not mean that none occurred, we assume that transparency and continuity of care, as well as medico legal considerations, would mean that notes would have been made of these contacts. Related to this point, our sample only contained letters from the initial treatment period. This may be relevant to items such as late side effects, which often were not mentioned in the present sample, but which might have been mentioned in specialist letters at the end of treatment.

4.4 | Considerations

In the Netherlands, as in other countries, hospitals are now developing a patient record file that cannot only be used by specialists but also by other healthcare providers, such as GPs, and by patients. Consequently, it can be expected that such files will comprise a lot of information, of varying relevance, and that will contain notes from different healthcare providers. This growth in information may make it increasingly difficult to identify the most relevant data; therefore, exchanging summaries of relevant information would appear to be of critical importance.

5 | CONCLUSION

General practitioners and oncology specialists exchange a lot of information in correspondence. In this study, we identified certain problems that were specific to referral letters and others that were specific to specialist letters. Notably, referral letters suffered from a lack of focus, which probably reflected a failure to use referral templates correctly. By contrast, although specialist letters included information about actual treatment, other information relevant to primary care was often missing; this included the intent of the treatment (curative or palliative), the alternative treatment options and the details of any discussion with patients. Our findings indicate that neither referral nor specialist letters are tailored to the needs of the recipient. Further research should focus on the information different healthcare providers would like to receive. In the meantime, however, it seems prudent to recommend that all correspondence should be written with the receiver in mind and that summaries of relevant information be included in a prominent position in all correspondence.

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DISCLOSURE

There are no conflicts to disclose.

ORCID

Mariken E. Stegmann  <http://orcid.org/0000-0001-8491-1407>

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.

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