

RESEARCH ARTICLE

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Preparing general practitioners to receive cancer patients following treatment in secondary care: a qualitative study

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Abstract

Background: Many patients consider the interface between secondary and primary care difficult, and in particular, the transition of care between these different parts of the healthcare system presents problems. This interface has long been recognized as a critical point for quality of care. The purpose of our study is to formulate solutions to problems identified by cancer patients and healthcare professionals during the transition from hospital back to general practice on completion of primary treatment for cancer.

Methods: A qualitative study based on focus groups at a seminar for professionals in both primary and secondary healthcare. Participants discussed solutions to problems which had previously been identified in patient interviews and in focus groups with general practitioners (GPs), hospital doctors, and nursing staff. The data were analyzed using framework analysis.

Results: Solutions, endorsed by all groups at the seminar to improve transition back to general practice after primary treatment for cancer, were: 1) To add nurses' discharge letters addressing psychosocial matters to medical discharge letters; 2) To send medical discharge letters earlier from some hospital departments to GPs; 3) To provide plans and future affiliations for patients when they leave a department, and 4) To arrange a return visit to general practice dedicated to discussion of the patients' cancer disease and the treatment experience.

Conclusions: The transition of care of cancer patients appears too complex to be coordinated by administrative standards alone. We recommend that healthcare professionals are more engaged and present in the coordination of care across organizational boundaries.

Keywords: Transition of care, Coordination, Continuity of care, Organization and administration, Primary healthcare, General practice, Cancer, Qualitative study

Background

Many cancer patients experience difficulties in the relationship between hospitals and general practice [1, 2], and one in six experiences unmet coordination needs [3]. Patients are vulnerable during and after treatment; they often feel insecure in the transition of their care [4] and wish for better continuity [5]. Patients, and their relatives, find the role of the general practitioner (GP) important and they have expectations of their GP with regard to follow-up care. The European Association for

Quality in General Practice (EQuiP) has pointed to the interface between secondary care and GPs as a critical point for quality of care [6].

In the Danish healthcare system, GPs are expected to continue to care for patients when they are discharged from hospital. While the descriptions of the integrated cancer pathways in Denmark specify the role of the GP in the diagnostic process in detail, this is not the case when it comes to the transition of care from hospital back to primary care following treatment e.g. [7, 8].

GPs often say that they lose contact with their cancer patients during hospital treatment [9–11]. This may accentuate the difficulties GPs face in responding to

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patients' queries and needs, especially when patients have finished their primary treatments.

Objective

The objective of our study was to formulate solutions to problems identified by cancer patients and healthcare professionals during the transition from hospital back to general practice on completion of primary treatment for cancer.

Methods

Our study is based on interprofessional focus groups held at a seminar with healthcare professionals from both primary and secondary care. We prepared for the seminar by interviews with cancer patients and focus groups with healthcare professionals. See Fig. 1.

Twelve cancer patients took part in in-depth interviews during 2007–2008. They had been treated for lung

cancer, colorectal cancer, or prostate cancer. The patients' antineoplastic treatment had either been going on for a while or had recently terminated. The inclusion criterion was that cancer treatment was provided in two or more hospital departments, and the exclusion criterion was terminal disease. We interviewed each patient with regard to the trajectory s/he had experienced. From these trajectories, we extracted examples of problems and used them in an interview guide for six focus groups [12] of healthcare professionals. Patient experiences were presented as a vignette representing common issues reported by the patients. The make up of the focus groups was: two groups of GPs; one group of home care nurses; one group of nurses in outpatient clinics; one group of nurses in wards, and one group of hospital doctors, specializing in the care of patients with the types of cancer included in our study (Fig. 1). All the healthcare professionals worked in the patients' catchment area, either at

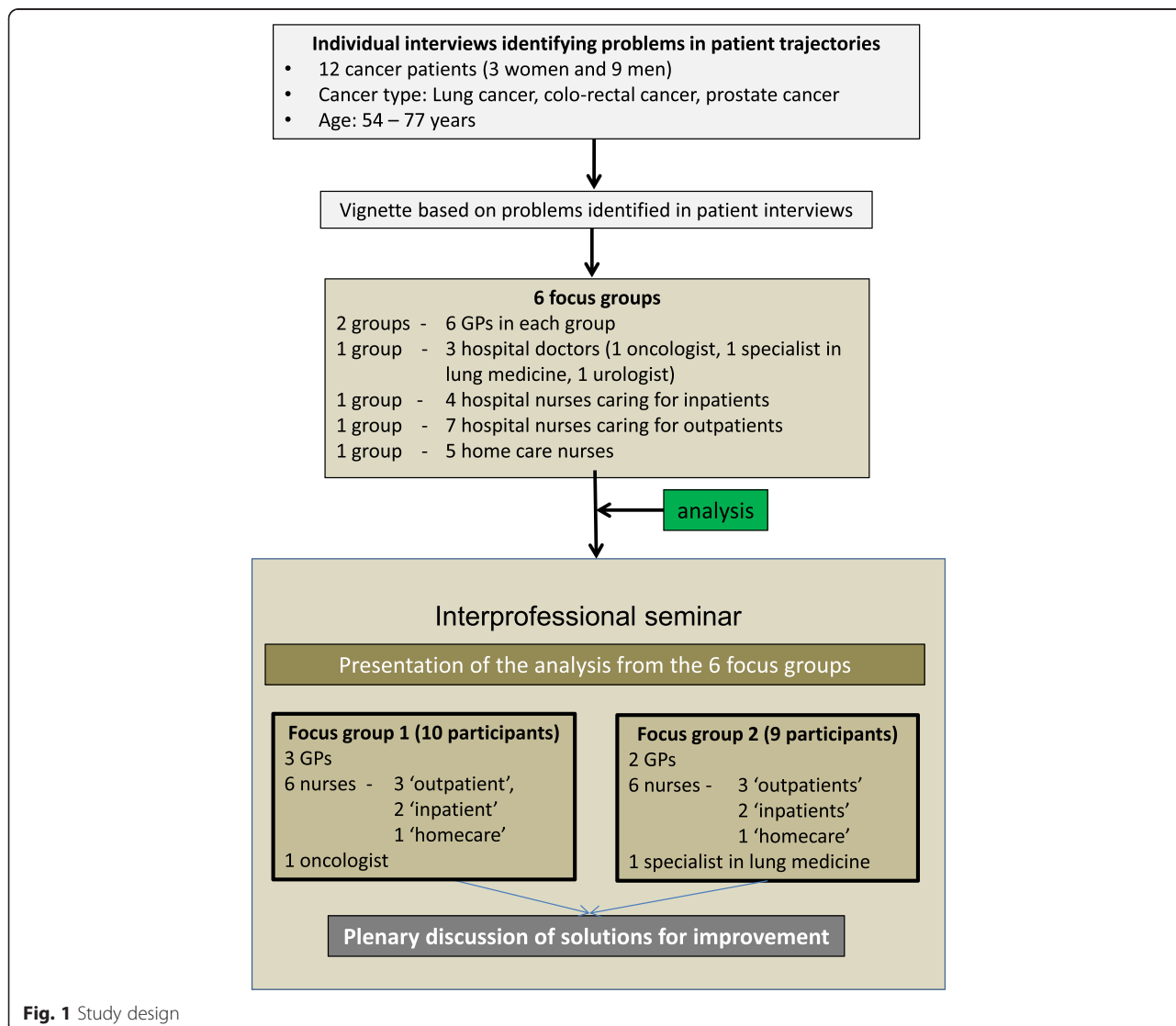


Fig. 1 Study design

the hospitals or in primary care. We asked each group about integration and coordination of care pathways, and how they experienced their own role in the pathways. The groups reflected on the patients' problems, identified further problems themselves, and came up with suggestions for improvements. The main problems identified by patients and professionals were: 1) Information to the GPs was not always timely and adequate; 2) Some patients did not know which part of the healthcare system to attend when in need of help after hospitalization; 3) Patients who had left one hospital department and were waiting for the first visit at the next department did not always know where to attend when a problem occurred while at home, 4) Distrust made it difficult for some patients to return to general practice, and GPs were not prepared to discuss cancer when patients attended for other reasons. Specific aspects of these problems are presented in the results section in the context of the solutions suggested to address them.

The focus group discussions were further analyzed for requests to other professional groups that could improve interprofessional collaboration, and for suggestions of possible contributions to such collaboration by the professionals themselves. The results of this analysis were discussed at an interprofessional seminar in 2009. The analysis in this paper is based on data from that seminar, at which 19 healthcare professionals participated. Sixteen of them had participated in the focus groups preparing for the seminar (2 GPs, 2 home-care nurses, 4 hospital ward nurses, 6 ambulatory nurses, and 2 hospital doctors). Three GPs who had not participated in the previous focus groups attended the seminar, and one of these GPs was a municipal practice consultant.

At the seminar, the relevance and importance of the summarized suggestions were discussed in two interprofessional focus groups, followed by a plenary discussion addressing the outcomes of each group. The discussions resulted in the selection of suggested improvements that could be endorsed by all groups. In the analysis of the focus groups and in the plenary discussion at the seminar, we focused our attention on solutions that would assist patient transition from secondary care to primary care following primary cancer treatment. This was identified by patients as a difficult time in terms of affiliation and transition of care. The majority of patients in our study did not feel any need for their GP while hospital treatment was ongoing [13].

The data were analyzed using framework analysis [14, 15]. ADG read the transcripts of the recordings of focus groups at the seminar and the plenary discussion repeatedly to identify emerging themes and to develop a thematic framework. The framework was discussed with

and validated by TT who participated as an observer and a facilitator at the seminar. Data were organized in accordance with the resulting framework. Further analysis of each theme to cover the range and association of issues was carried out by ADG and TT in collaboration. Framework analysis is a pragmatic approach for applied policy research appraising what exists and identifying new policies and actions [14]. It is useful when the objectives of the investigation are set in advance and shaped by specific information needs as in our study [15].

This study is part of a larger qualitative study identifying problems in the trajectories of cancer patients, and analyzing the role of the GP in coordination, the results of which have been reported elsewhere [13].

According to the principles of national ethics committees, qualitative studies are not evaluated. Written informed consent was obtained from patients participating in the study.

Results and discussion

Results

The following suggestions for improvements in the transition of cancer patients from secondary to primary care were considered relevant and feasible by all the healthcare professionals who participated in our study:

1. Nurses' discharge letters should be communicated to GPs
2. GPs need to receive medical discharge letters from more hospital departments earlier than is currently the case
3. Plans and future affiliations should be described when patients are discharged from a hospital department
4. Return visits to general practice should be established after primary treatment for cancer

Nurses' discharge letters should be communicated to GPs

Information about patients' well-being and their social situation are included in nurses' discharge letters to home care nurses. The letters provide information on the patients' need for care and instructions on how to handle specific problems such as pain, nausea, or other frequent problems. The GPs are interested in this information; therefore access to nurses' discharge letters would be appreciated by them.

GP 3, group 1: *It actually appealed to me, the idea that you could get a copy of the nursing plan that was provided for the home care nurses, and it could then be supplemented with a quick discharge letter by the doctor discharging the patient with the diagnosis and the plan, it would really be quite ideal.*

According to the GPs, the medical discharge letters only provide information on technical aspects of the treatment and do not consider the patients' overall situation. Information concerning patients' well-being and their social situation is rarely seen in medical discharge letters. Furthermore, discharge letters and other copies of patient records are very brief.

GP 1, group 1: *They are extremely technical and not really focusing on information to the GP. It is usually a brief extract.*

It was unclear, however, how nurses' discharge letters could be communicated to GPs. No systems supported such communication. Faxing individual discharge letters or asking patients to hand them over were mentioned as the existing possibilities. The professionals were not aware of how, or by whom, an agreement to communicate nurses' discharge letters systematically could be decided.

In addition to discharge letters, nurses offered to call GPs when a patient might need help soon after leaving hospital. This would generally be appreciated by GPs, although some GPs said they would prefer hospital nurses to call practice nurses, and not the GP him/herself.

GPs need to receive the medical discharge letters from some hospital departments earlier than is currently the case

The time interval between a patient's discharge from hospital and the GP receiving the discharge letter showed considerable variation between hospital departments. Some departments provided both discharge letters and copies of records from each outpatient visit on time. Other departments delivered their discharge letters late, and did not provide any information from outpatient visits.

GP 2, group 2: *But in particular in cases where we are taking over, it is important that we know about it the day after or after two days. Then we should have those papers or at least have a report by phone. In cases where we are not expected to step in, in a few days, in this ongoing trajectory, it doesn't matter much.*

Without the information in medical discharge letters, GPs do not know the patients' prognoses and plans for further treatment or control. This impairs the GPs' ability to provide relevant help and advice to patients. It also leaves the GPs with no way of providing information to patients who want to know what really happened at the hospital. Medical discharge letters should be sent contemporaneously in cases where it is known that patients who are being discharged need to see their GP within a short timeframe.

A shared information system would be of great help to GPs in caring for their cancer patients, as it would enable them to search for the required information themselves. This would imply easy access to hospitals' patient records and test results.

Plans and future affiliations should be described when patients are discharged from a hospital department

In order to take good care of patients discharged from hospital, the GP also needs to know the relevant department's future plans and the responsibilities agreed with patients.

GP 1, group 1: *Well, that is really fundamental to it all. A discharge letter that kind of picture what the patient knows, and what has been said, and what is going to happen, and who takes care of it. Well, that is sort of elementary.*

This knowledge is important for the GP if unforeseen problems occur and the patient needs medical help having left hospital, or if the patient needs to be readmitted. In some cases, patients have open access to more than one department where they have previously been treated; in other cases the GP has to make a new referral. The professionals reported that this lack of clarity made patients feel insecure.

Nurse 1, group 2: *One morning a patient calls and says "I was treated half a year ago and I was all done with it, but now I have this and that symptom and I have been talking to the doctor on call at the medical department who put me on antibiotic treatment". I don't even know what department he had contacted but in some way he had made his way into the system, and "Now I have taken these pills for five days and they don't help at all. I get worse and worse. Where should I go now?"*

Even a thorough attempt from the professionals to identify a current affiliation for the patient does not always succeed. Everybody at the seminar agreed that the responsibility for planning and advising the patient about future hospital contacts, if needed, lies with the doctor who discharged the patient. This information should be stated both in the medical record and in the discharge letters, even when no future visits are planned. Patient affiliations were, however, sometimes a matter of dispute between departments.

Return visits to general practice should be established after primary treatment for cancer

When the primary treatment has finished and the patient is no longer attending a hospital department, or is

followed up at lengthy intervals, the patient should be invited to a return visit with their GP.

GP 1, group 2: *Well, I think you should endeavor to have an encounter at the GP surgery when the treatment process is over and if the patient also is in need of home care I think it would be ideal to do it in the home of the patient, so I think they are two really good proposals for solutions we have here.*

Planned return visits dedicated to discussing the patients' cancer disease and treatment experience could prevent patients from experiencing a perceived lack of interest by the GP. Some patients who visit their GP for reasons other than their cancer were not invited to discuss their cancer treatment and how they felt, and they were disappointed that the GP did not ask. When a cancer patient attends the GP's surgery, the GP is usually aware of the cancer diagnosis, but may not have the time to discuss it if the appointment is about something else.

Return visits could also provide an opportunity for the patient and/or the GP to discuss the process that led to the cancer diagnosis. The GPs and nurses who took part in our study knew of patients who felt that their GP had let them down, either by referring them too late for diagnostic procedures, or from lack of awareness. Patients who felt they had been let down by their GP often had difficulty trusting in the care provided in general practice and some of them preferred to visit their GP as little as possible.

Nurse 1, group 2: *I think of the many patients we have here who often have felt misunderstood or sent around the system. Who haven't felt heard enough or felt they have been knocking the GP's door down and nothing happened and then finally they get a diagnosis and feel bitter and overlooked etc etc. They will...the moment they are offered a return visit it (distrust) will be handled early.*

Return visits could help to acknowledge such problems and to discuss possible faults or mistakes made by the GP and what each party had expected from the diagnostic process. In some cases, patients change their GP if they feel that their diagnosis was not properly handled. In these cases, a structured return visit could provide an opportunity for both the GP and the patient to get acquainted with each other.

The healthcare professionals in our study considered it feasible to recommend return visits to all patients. However, they recognized that not all patients needed such visits; therefore the responsibility for making an appointment with the GPs should be left with the patient, or delegated by the patient to the relevant hospital department.

Other possibilities for handover procedures were discussed. Discharge conferences, which some participants knew from earlier experiments, were deemed unrealistic due to logistics and shortage of time. Inviting home care nurses to participate in return visits at the GP's clinic or in the patient's home could, however, be relevant in many cases. Some participants suggested that better communication between home care nurses and GPs might alleviate the challenges of the GP in other respects as well, but the lack of available channels for this type of communication were perceived as a barrier.

Discussion

Analyses of the focus groups from the seminar, that was both interdisciplinary and intersectoral, resulted in the selection of solutions to problems in the transition of patients back to primary care following primary treatment for cancer that could be endorsed by all groups. The solutions aimed to prepare GPs to receive individual cancer patients with better responsiveness, and to avoid the problems identified by both patients and healthcare professionals. The suggestions covered GPs' access to hospital nurses' discharge letters, earlier receipt of medical discharge letters containing more thorough information, better descriptions of plans and affiliations, and the possibility of offering patients a return visit to primary care dedicated to discussion of their cancer disease and their treatment experience.

Our study suggests that the addition of nurses' discharge letters to medical discharge letters would ease the transition of care to general practice after primary treatment for cancer. There was general agreement between the healthcare professionals who took part in this study that medical discharge letters did not provide a sufficiently broad background for the transition of care to general practice. Previous research has demonstrated that GPs think information about psychosocial aspects of the patient's situation is missing from medical discharge letters [16, 17]. Attempts to improve discharge letters for the benefit of GPs have focused on factors such as plans concerning psychological and social problems [18]. However, discharge letters are not solely for GP use and they also deliver information to physicians from other specialties who may need more technical information, such as details of surgery, diagnostic procedures, and treatments. The different needs for information from discharge letters may compete with each other. The solution could be to make nurses' discharge letters available to GPs as a supplement to medical discharge letters. Traditionally, it is physicians who provide treatment and nurses who provide care in a hospital setting. This is not the case in general practice where GPs aim to represent both the biomedical and the care perspectives [19]. However, as a consequence of the way care is delivered in secondary

care, the information provided by hospital nurses is communicated to home care nurses and not to general practice.

One of the possible improvements to the transition of care to general practice identified in this study was to invite patients to a return visit to general practice. This suggestion appears to coincide with a similar interest among patients [5, 20, 21]. Return visits could demonstrate the GP's interest in the patient's treatment experience and also a willingness to discuss the GP's role in the diagnostic process. A return visit of this type could improve the patient's opportunities to receive the help s/he may need from general practice when treatment at hospital is finished or is becoming less intensive. Interviews with cancer patients support the view that the most useful time for a review with their GP would be at the completion of initial cancer treatment [21].

Research shows that cancer patients visit their GP more frequently than other patients, therefore GPs would appear to have many opportunities to take on follow-up activities for this group of patients. A UK study reported that one third of cancer patients had seen their GP within the last two weeks; while patients with other diseases did not see their GP so often [22]. In Denmark, patients with cancer diagnoses visit their GP more frequently than the background population [23]. This increase in contacts continues at least for the first year after diagnosis. Therefore, it is intriguing that some research studies show that GPs lose contact with their cancer patients during treatment [10, 17, 24]. Our finding, that GPs do not necessarily discuss the cancer disease or treatment with patients when they visit for other reasons, might go some way to explaining this. GPs' often say that there is no time to discuss the cancer experience if patients visit for other reasons. However, GPs' uncertainty about their own role might add to this perceived distance. While the role of the GP in palliative care is thoroughly described e.g. [25–28], the same does not appear to be the case for the GPs' role in the follow-up of cancer patients in general. This is despite the fact that GPs are expected to play a role for cancer patients after primary treatment has finished eg. [7, 8]. Return visits may alleviate this uncertainty and help avoid cases where patients' cancer treatment is not discussed.

Danish cancer pathways do not incorporate follow-up in general practice or specify tasks such as return visits after treatment eg. [7, 8]. Even if such descriptions were included, it would probably not solve the problems for patients returning to general practice, because good transition of care needs to be adapted to individual patients and situations. For example, the return visits suggested in this study might not be relevant to all patients, which is supported by a study investigating the effect of such visits [29]. Furthermore, some patients in need of a

return visit would prefer to contact their GP themselves, while others would need the help of a hospital nurse to arrange for follow-up. Likewise, for those patients who need the help of their GP immediately after discharge, a phone call from the hospital nurse to the GP could be relevant. Complex trajectories like those identified in this study are too unpredictable to fit into an administrative coordination effort like cancer pathways. This level of administrative coordination requires that all tasks can be identified in advance ([30], p.92–93), and this does not seem to be possible in transition of care. More individualized coordination arranged by healthcare professionals might help to adjust to individual needs in the follow-up of these patients. This could reduce the number of cases where problems in transition of care to general practice remain unnoticed. Such a dynamic involvement of healthcare professionals in coordination tasks happens to a larger extent in Swedish healthcare [31]. A hospital doctor or nurse should discuss a return visit with the patient at the time initial treatment ends.

Efforts to improve the transition of care for cancer patients, by including those healthcare professionals involved in the patients' trajectory, are limited by a lack of proper channels of communication. One such channel, currently missing, is for communication between hospital nurses and GPs. Our study indicates that making hospital nurses' discharge letters available to GPs would enable more complete transition of care from hospital back into general practice.

Validity and transferability

No patients participated in the interprofessional concluding seminar in our study, where solutions to problems in transition of care were discussed. We do not know if patients would support the proposed solutions, however they seem to compare well with the solutions reported by a patient panel on trajectories for illnesses other than cancer [32]. The GPs who took part in our study may have an above average interest in care for cancer patients than the majority of GPs, so the proposal about return visits to general practice may not apply to all GPs. However, we would still recommend return visits as a solution.

The triangulation of the perspectives of GPs, physicians working in specialized hospital care, nurses in outpatient clinics and wards, as well as nurses in home care, supports the validity of our findings.

Our study was carried out in Denmark and local aspects of healthcare might limit the transferability of the findings to other healthcare contexts. However, similar problems in transition of care to general practice after primary treatment for cancer have also been described in studies from other countries [4, 5, 17, 24]. In our

view, the solutions suggested in this study could prove instructive to other healthcare systems.

The patterns of problems and proposed solutions were consistent for patients included in this study, despite the fact that they had different cancer types and treatment schedules. We believe that our findings could be relevant to cancer patients in general.

The time lapse between data collection and the present analysis could have made the findings of this study less relevant. However, the results of more recent studies indicate that the problems we identified are still current [2, 3]. The interprofessional concluding seminar we report took place in 2009, and the organization of Danish cancer care has not changed substantially since then.

Conclusions

GPs experience insufficient support from secondary care when cancer patients have completed their initial cancer treatment and return to primary care, where the responsibility for continuous care is placed. Suggestions to ease the transition of care between the two sectors include: provision of hospital nurses' discharge letters to GPs; improvements in more hospital departments to provide earlier medical discharge letters; more precise descriptions of future plans for the patient's treatment, affiliations, and follow-up; and planned return visits to general practice after primary cancer treatment. Return visits could provide opportunities to discuss patient experiences, make time for a medical status, and align expectations between the patient and the GP for future contacts. These measures could result in relevant improvements in the transition of care for cancer patients.

Abbreviation

GP: General practitioner.

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

ADG revised the study protocol, conducted patient interviews, prepared and moderated focus groups, lead the analysis, and drafted the manuscript. LJ revised the study protocol, introduced the research group and the project to the hospital, participated in the selection of cancer patients to be interviewed, and critically revised the manuscript. TT conceived of the study, moderated focus groups, contributed to analysis, and helped draft the manuscript. All authors read and approved the final manuscript.

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