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Living in a paradox –

Women's experiences of body and life world after meningioma surgery.

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ABSTRACT

Title. Living in a paradox – Women’s experiences of body and life world after meningioma surgery.

Aims. The aims of the study were to describe how persons who have undergone benign meningioma surgery experience their body and life world, and to illuminate the meaning of the illness, operation and recovery.

Background. Meningioma is the most commonly diagnosed brain tumor and it is for the most part benign. Studies have shown that persons with meningioma tend to be more psychologically affected than persons with other brain tumors. To our knowledge no previous studies have focused on the life world or body experience of these persons.

Method. Narrative interviews with seven women conducted over a 6-month period (2008-2009) were analyzed using a phenomenological hermeneutical method.

Findings. Four themes emerged: *In between double threats: the tumor and operation.* The women seemed to perceive a paradox: the tumor was both benign and threatening, the surgery both curing and risky. *The wound as an open gate,* being visibly healed but perceived as unhealed. *The suffering body overflows life.* The women were prevented from regaining their body, feeling fragile and oversensitive to impressions. *The need to be embraced by attention.* Seriously taken needs facilitated understanding the diagnosis.

Conclusion. The women in the present study described a great amount of emotional distress when recovering from meningioma surgery. It is essential for nurses to be aware of the meanings persons ascribe to events that disrupt their lives as well as to the transition process in connection with meningioma treatment.

Keywords: Meningioma, phenomenological hermeneutical, experience, brain surgery, suffering body, recovery.

What is already known about this topic

- There seems to be an increase in emotional distress following surgery for benign brain tumors and especially persons with meningioma seem to suffer from increased distress both before and after surgery.

What this paper adds

- After meningioma surgery, women may find themselves living in a paradox between a benign tumor that is potentially malignant and extensive surgery as the only treatment; this may affect the body and life world.
- When healthcare personnel are ambiguous in their provision of information and treatment, this may intensify the persons' experienced paradox.

Implications for practice

- It is essential for nurses to be aware of the meanings persons ascribe to events that disrupt their lives as well as their transition process in connection with meningioma surgery.
- There is a need of evidence-based interventions to improve information and support provided for persons recovering from meningioma surgery.

INTRODUCTION

The prospect of undergoing brain surgery – the primary treatment for brain tumors (DeMonte et al., 2001) – often give rise to feelings of a threat against the intellect, if not against life (Jaffe, 1987). Studying the postoperative situation, Thorne et al. (2002) found in their survey at a neurosurgical department in the UK that while the respondents considered the neurosurgical care to be satisfactory, the discharge contact with a specialist nurse and written information were considered important but not sufficiently accessible.

In Sweden, however, surgery is typically followed by inpatient rehabilitation. Neurological rehabilitation improves physical and cognitive functioning, and health related quality of life in brain tumor patients, irrespective of whether the tumor is malignant or benign (Greenberg et al., 2006; Mukand et al., 2003). In contrast to persons with malignant tumors who begin continuous contact with healthcare personnel at an early stage after surgery, persons with benign tumors do not normally receive continuous support after discharge from neurosurgical or rehabilitation clinic, with the exception of X-ray check-ups for tumor relapse. This, despite results showing that persons that have undergone benign brain tumor surgery, tend to have difficulties in their transition back to ordinary life (Arlt et al., 1997; Tufarelli et al., 2007).

BACKGROUND

To our knowledge, no previous studies have used a qualitative approach to investigate the experience of having had a benign brain tumor. However, a quantitative study by Mainio et al. (2006) revealed that persons experience decreased quality of life in connection with decreased functional status after surgery for benign brain tumors. This was found to a lesser degree in persons treated for malignant tumors. Furthermore, this result was particularly evident among women and persistent for a year postoperatively. Studying persons treated for the benign tumor vestibular schwannoma, Kelleher et al. (2002) showed a higher degree of depression among those who underwent open surgery than among those who were treated conservatively.

The primarily benign meningioma seems to be predominant as a cause of emotional problems and, according to Mohsenipour et al. (2001), to affect life negatively many years after surgery. Mostly affecting women, it is the most common brain tumor (over 33 % of all brain tumors) with a prevalence of 6.03 per 100,000 person-years adjusted for year 2000, US standard population (CBTRUS, 2009). Meningiomas can cause suddenly onset depression and anxiousness (Gupta & Kumar, 2004) as well as increased preoperative anxiety (Pringle et al., 1999). Age seems to be of importance to postoperative outcome in persons who have undergone meningioma surgery such that younger persons (i.e. <55 years) with no or minor complications show less satisfaction with life, longer recovery periods and lower self-esteem compared to those over 55 years. Furthermore, younger persons tend to compare themselves with persons with major neurological problems (Krupp et al., 2009).

Aspects of individuals' perspectives on having had meningioma remains to be studied, for example how they cope with the diagnosis, treatment and returning to ordinary life.

THE STUDY

The aims of the study

The aims of the study were to describe how persons who have undergone benign meningioma surgery experience their body and life world, and to illuminate the meaning of the illness, operation and recovery.

Method

A qualitative descriptive design with a phenomenological hermeneutical approach inspired by Lindseth and Norberg (2004) was used to interpret narrative interviews.

Narratives were used because they are a possible entry way into peoples' experiences (Lindseth & Norberg, 2004), which are essential to understanding illness-as-lived (Toombs, 1993). Furthermore, investigation of the life world broadens our understanding of being

human (Dahlgren et al., 2001). The life world is formed through consciousness perception (Bengtsson, 1998) and understood through background meaning, our shared world, taken for granted (Benner & Wrubel, 1989). Given that the body is “me”, the center of lived meaning (Merleau-Ponty, 1962), it would seem necessary to consider the experience of body in order to understand illness-as-lived after meningioma surgery.

Transforming narratives into text liberates the event from the narrator’s lived situation (Ricoeur, 1976). Following the text’s movement “from what it says, to what it talks about” (p. 146) the meaning becomes visible in front of the text as opposed to a psychological interpretation behind the text (Lindseth & Norberg, 2004).

Participants

A sample of ten persons who had undergone meningioma surgery was asked to participate. Heterogeneity were sought to broaden the substance of the interviews (Maxwell, 2005; Patton, 2002). The inclusion criteria required that participants should be between 18 and 65 years of age, had undergone benign meningioma surgery at a Swedish university hospital, had undergone rehabilitation at a rehabilitation hospital, and were to be able to speak and understand Swedish. The exclusion criteria were cognitive or physical impairments. Individuals were selected who had been discharged from the rehabilitation hospital, after consulting the physicians responsible for their treatment. Shortly after discharge, the first author contacted the individuals by telephone. Oral information was given. If preliminary interest in participation was expressed, the individuals were sent written information about the study together with a consent form.

Data collection

A pilot study performed in spring 2008 verified that Lindseth and Norberg’s (2004) method was appropriate. Material from the two pilot interviews was not included in the present study.

The narrative interviews were performed over a 6-month period (2008-2009) and conducted by the first author. The focus was on participants' experience of having had and been treated for meningioma and they were encouraged to tell their stories freely. The interviewer started by asking: Can you tell me what happened – can you start from the beginning? An interview guide was used loosely as a support for the interviewer; it covered the following areas: meaning of the tumor, experience of the operation, operation wound, embodiment, everyday life, significant others and health care. To avoid misunderstandings caused by different pre-understandings and to stimulate further narrating, the interviewer asked questions like “what do you mean?”; “how did you experience that?”; “what did you feel then?” (Lindseth & Norberg, 2004). The interviews were tape-recorded and transcribed verbatim by the interviewer in close connection with the interview.

Ethical considerations

Approval for the study was obtained from a regional ethics review board. Participants were informed orally and in writing about the aims of the study and what participation required. Before being asked to provide their written consent, participants were informed that participation was confidential, voluntary and that, if they chose to participate, they would be free to withdraw at any time without giving a reason and without any effect on their present or future care. In the transcripts, a pseudonym in the form of a capital letter from A to G was assigned to each participant to ensure confidentiality.

Data analysis

The method of Lindseth and Norberg (2004) was followed. It involves moving between understanding and explanation, the whole and parts, to capture the meaning of the text. The method consists of three phases: naïve understanding of the whole, dividing the text into parts in the structural analysis and, to achieve deeper understanding, formulating comprehensive understanding through final interpretation.

Rigor

To assure validity Lindseth and Norberg's (2004) method was followed as close as possible. The structural analysis was conducted carefully as it is the validating, explanatory part (Ricoeur, 1976). Furthermore, a pilot study was performed to assure congruence between the research questions and method. In accordance to Patton (2002), we interviewed a criterion sample of participants, meaning that they all had one experience in common. While the first author performed the main part of the analysis, the whole research group read selected interviews, discussed every step of the analysis and the trustworthiness of the findings, until consensus was reached.

In the results section, quotes to illustrate the participants' experiences were used to validate the research findings (Sandelowski, 1994). The first author translated the quotes, staying as close to the original spoken language as possible. A double slash in the quotes indicates missing words or sentences. Three dots mean the interviewee took a pause while narrating.

FINDINGS

Participants

Seven women, 37 to 60 years of age, agreed to participate. Three more persons, one man and two women, were informed about the study, but chose not to participate. The participants differed with regard to socio-economic and family status; five were of Swedish and two of non-European origin. The interviews lasted between 75 minutes and two and a half hours, and were conducted in the participants' homes, between 35 and 114 days after surgery.

Naïve understanding

The naïve reading showed that the participants' had experienced the diagnosis as a deadly risk, a barrier in life but also a non-threatening tumor that explained physical and

psychological problems. The participants considered the operation both threatening and trivial. After surgery, the participants were happy to be alive and intact, although they were troubled by sequelae such as memory problems. Suffering from headaches, sleep problems, fatigue and oversensitivity to impressions, they accepted their fragile body's need for care and training. To deal with the implications of the large size of the scar, they needed to understand how the surgery was done and how the wound was sealed. The women avoided touching their scar, afraid of disturbing the healing process. They were in constant fear that the operation would burst, partly owing to the feeling of pressure and sounds inside the head.

Attention and information from the healthcare personnel facilitated coping. On the other hand, when needs were not met, the participants felt abandoned and left with their thoughts about the risk of tumor and about their own mortality. Home again, limited by fatigue and sensitivity to impressions, they tried to reestablish normality while reflecting on their changed personality and life. A struggle began to find a balance between their own strength and expectations and determining how to avoid things that counteracted the healing process. The women felt strange and weak when surrounded by too many people. Their scar and bruises caused suspicion among people around them and thus were hidden – or borne without shame.

Structural analysis

The wholeness of the text was condensed into four main themes abstracted from twelve subthemes, as shown in Table 1. The main themes were: *In between double threats: the tumor and operation*, which meant that the tumor was benign but threatening given where it was growing; surgery was necessary for survival but it was also dangerous. *The wound as an open gate* implied that the wound was experienced as unhealed, threatening to burst despite the healed scar. *The suffering body overflows life* meant that the body was fragile and the mind oversensitive to impressions, preventing the women from regaining their bodies. *The need to*

be embraced by attention implied that seriously taken needs facilitated understanding the diagnosis.

Table 1. Overview of themes based on the analysis of narratives from persons who have undergone benign meningioma surgery (n=7).

Themes	Subthemes
In between double threats: the tumor and operation	The threatening benign tumor
	The operation as threat and possibility
	Understanding the operation promotes acceptance
The wound as an open gate	The scar as testimony
	The unhealed inner wound
	Mirrored in others' eyes
The suffering body overflows life	When illness overflows life
	Fragility is mortality
	Coming home means balancing the weakness
	Me, a stranger
The need to be embraced by attention	Good healthcare is attentive
	Poor healthcare is excluding

In-between double threats: the tumor and operation

The diagnosis meningioma came as a shock even when the participants had suspected something was wrong. They did not know whether they should be relieved because the tumor was benign or frightened because it could become malignant or relapse. The women apprehended the scope of the approaching surgery in an ambiguous way; both as trivial and a threat. They considered the risk of cognitive impairment, of waking up unable to recognize themselves. Participant (G) narrated that despite good support from healthcare personnel she considered the operation equivalent to death. She had written her last will and testament and arranged her own grave prior to surgery.

The women expressed that waking up from the operation was a relief. Some of them felt better than they had for a long time. Others could not free themselves from the feeling of being under a deadly threat or were worried because of initial memory loss. Participant (D) explained that she often regretted the operation; she did not recognize her own person and had an unpleasant feeling that her head was empty. Other women felt insecure and emotionally affected because they did not know how the operation had been carried out.

I would very much like to know exactly what they have done! // where they sawed, where they cut, where, how they sewed, did they drill small holes in the skull // the more I know the easier I accept // it would be easier for me to leave it behind. (A)

The women brood on how the tumor negatively affected private and working relationships, how anxiety or memory loss made them behave strangely and how the body had stopped working properly. They thought they would live with the memory of the tumor and surgery, always aware that the tumor could relapse.

The wound as an open gate

The size of the scar was frightening as it was much bigger than the participants had expected – evidence of the fact that the head had been opened. The participants avoided touching the scar, afraid that it would disturb the healing, and some women found the scar difficult to look at. Participant (F) saw the scar as a beautiful handicraft, but stated firmly that it was a “professional business”. While the wound was healing the women were troubled by scabs not falling off, a persistent bruise, pain or changed sensation of touch. They were not sure that the wound was healing, afraid that it would suddenly burst – a fear connected with strange sounds inside their heads: “Yes, it sort of rumbled // And I thought that everything was cracking up... and falling apart” (E).

After the surgery most of the participants preferred a restricted number of adult significant others as visitors, knowing that their children and friends would be frightened by their scar, bruises and contorted swollen face. Woman (F) decided to proudly carry her scar as a sign of experience and to avoid dramatization. But people stared at the scar: “some perhaps think, yes; think that you are strange in some way. Because you don’t see so many with scars on their heads” (D).

The suffering body overflows life

The participants’ bodies reacted when the process of postoperative healing encountered everyday life: The body was weak and fragile and the mind needed shelter from impressions. The women narrated that food had no taste – eating served only to nourish the body. They had sleeping problems, either without evident reason or because of steroid treatment, headaches or worrying thoughts. At the same time, they were tired in a strange way. Different feeling of being a stranger to oneself were expressed, as by woman (A) when describing the days after returning home:

I don’t dare to do things I want to do! // once when I got one of those huge bouquets here (A gesticulates around in the room). And then I got, then sort of

like this “klu” (makes a sound). I started to feel it in my head, so I had to go and lie down and take it easy. // then I get scared, I get scared all the time! // And that is probably what it is that makes one not dare, I really don't dare to take my body back.

Participant (D) had a strong sense of recognizing only half of her body: “the left side is me and the right side is not me”. Some women described feeling effects on their personality: being emotional by unexpectedly starting to cry, or having problems with memory and concentration. They tried to understand what this feeling of being fragile meant and implied. The women did not know how long they should be afraid, having discovered that they were mortal. They felt insecure about the body's signals and capacity, afraid of having a stroke or a hemorrhage if they exerted themselves. The sensitivity to being surrounded by many people made the women weak and nervous, as woman (E) narrated about being in shops: “my brain has gone into another dimension in some way // then I get difficulties with my balance // I stop only to let them pass me so I know how I can walk”.

Even if significant others and friends were important and encouraging, they could not share the women's situation and need to rest in their illness. The way the healing process was looked upon could create a cleavage between the women and visitors, the visitors being all at once worried and cheerful. “And everyone that said things like: yes, but now you are going to be so fine // oh, you look so alert and fresh. Yes, maybe I do, but not on the inside” (D). Returning back home, the participants' concentration was occupied with taking care of daily tasks. Being efficient made them worse; efficiency worked “against the healing process” (F).

The need to be embraced by attention

The women needed to be treated as individuals, to be acknowledged and to feel marked attention from healthcare personnel. Woman (F) described:

meet another doctor, and sit in a conversation where I get the question:”can you tell us about your pain?” // in some way feel, here is attention, here are people who understand. // it was good for me, very, to get that treatment and to get so much attention!

According to the participants, attention from staff meant increased ability to manage the diagnosis and surgery, as well as the postoperative period. Being treated seriously as a patient with meningioma seemed important. When the women did not experience this attention, they felt they were in an exposed position in their interaction with the healthcare system and healthcare personnel. Being on the waiting list meant they were under stress, unable to plan their lives. Care not given in time or considered inconsistent caused the women to experience suffering. When needs were not taken seriously such as the need for information or for silence in a noisy hospital environment – the result was distrust in the healthcare personnel, including the surgeons.

Comprehensive understanding

For the women in the present study, the benign meningioma diagnosis and surgery seemed to imply living in a paradox, in between the tumor being benign, but also potentially threatening. The wound was visibly healed but was perceived as unhealed under the scar, threatening to burst. The women’s suffering was intensified when healthcare personnel provided ambiguous information and treatment. They seemed stuck in a paradox: They looked healthy but suffered from feeling fragile and insecure about the body’s capacity. The scar was like evidence of the paradox. As long as the paradox existed, the scar was like an open gate into the head, the body and mind needing care and shelter. Finally, the paradox implied that the women’s suffering was not fully respected when they struggled to regain health in the midst of their life world duties.

DISCUSSION

Methodological considerations

When analyzing rich narratives, the utility of Lindseth and Norberg's (2004) method became evident. The final interpretation may be debatable, as trustworthiness depends on how well the meaning of the phenomena in question – the essence of understanding a person's experience of having had meningioma – is disclosed in the naïve understanding and the structural analysis (Lindseth & Norberg, 2004). Trustworthiness also depends on how well the researcher can argue for the interpretation (Ricoeur, 1976). The interpretation of the meaning of the structural analysis results were discussed until coherence was reached. The results represent our understanding of the women's experiences of recovering from the illness.

Transferability was limited as only women were included, even if heterogeneity was sought. Considering the predominance of women among persons with meningioma, the sample mirrors the majority of affected persons. We do not know, however, whether the results would have been different had men been included. Furthermore, we also do not know if the life world would have shown other manifestations if the time interval between surgery and interview had been different.

Reflections on the findings

In the present study, four themes emerged mirroring what could be interpreted as paradoxes. The women seemed to be stuck in paradoxes of double messages coming from the head and body, healthcare personnel, friends and significant others, and in the interaction between all these factors. Consequently, this led to uncertainty, which was described by Penrod (2006) as a perception of lost control and confidence. While persons with malignant tumors usually *know* the severity of their disease, participants in the present study *did not* know. Knowing entails concrete expressions of fighting and mourning, as described by Adelbratt and Strang (2000), and of coping by creating “protection and hope”, building “an illusion which palliates the strain” (Salander et al., 1996, p. 993). Not knowing meant having a range of possible

interpretations. The women under study here did not know whether to mourn or to fight, and instead of creating protective illusions, they had to go home and continue living. In their transition back to ordinary life, not knowing enough about what had happened to them, what was happening to them now and would happen in the future, prolonged the suffering from uncertainty.

Uncertainty about what the surgeon had actually done inside their head caused the women to feel dubious of the invisible threat that may lie under the scar. What posed the greatest threat – the tumor or the surgery – was not evident. Perhaps the tumor was perceived to be more concrete and therefore understandable – threatening or not – while the surgery was perceived to be more diffuse. These perceptions were based on the fact that the women understood neither the meaning of what had been done practically nor the consequences of the surgery. Surgery in other vital areas, such as the heart, can give rise to feelings of being petrified – or the opposite: feelings of being familiar with it owing to exposure in media (Lindsay et al., 2000). Yet, in the study above, suffering from uncertainty was caused by not knowing how heart surgery could improve one's chances of survival. According to Cassell (1999), suffering is not caused by the physical state, but when a person perceives his or her integrity to be "threatened or disrupted" (p. 531). In the present study, suffering from uncertainty implied a threat that enveloped the women's entire being following the intrusion of a tumor and a surgery in the center of 'I' – as mirrored in the subtheme "me, a stranger".

According to the theme "the wound as an open gate" the scar was a testimony and the women were determined to protect it. They worried about scabs not falling off, a piece of a suture coming out of the wound, or that the hairdresser might disturb the scar. What, then, is a scar: a sign of uncertainty; evidence that I am material, mortal? The size of the scar astonished the participants. A similar reaction was expressed by brain tumor surgery patients in a study by Lepola et al. (2001); these patients did not recognize themselves in the mirror

postoperatively. According to Brown et al. (2008), many persons with scars somewhere on the body, felt stigmatized, abnormal, and constantly reminded of the associated trauma. This reaction depended more on subjective perception of the scar and its visibility than on objective severity (Brown et al., 2009). In the present study, the women definitely associated the ‘trauma’ with the scar and feelings of stigmatization lingered. More apparent, though, was how they imagined the scar would burst. The participants related to their wounds as unhealed even though many weeks had passed since the operation. The women expressed how better information would have helped them to heal and to leave the illness behind – in accordance with the subtheme “understanding the operation promotes acceptance”.

The body can become alienated in persons struck by disease (Toombs, 1993), but participants in the present study seemed instead to have made their body and mind the objects of nursing. According to Merleau-Ponty (1962) the sensations in one part of the body affect the whole body, not as a gradual process but instantly. As we are our body this could partly explain why the women seemed to extend the unhealed wound to the whole body. Because they were oversensitive to various external stimuli, they were confined in the body’s impaired ability to handle sensations and afraid of taking back their bodies – thereby maintaining their perception of being unhealed. Because they were not finished with their interpretation of “the bodily disruption” (Toombs, 1993, p. 35), they constantly suffered from awareness of, and their limited control over, the mind and body. This feeling of uncertainty was similar to the experience of women after a myocardial infarction who felt that every episode of chest pain meant a new infarction, according to Johansson et al. (2003). These women talked about their heart and body as something to take care of, something that could fail them at any moment. Like the women in the present study, their transitional process to health and reconciliation was not smooth, particularly when sensitive and individual support and information from healthcare personnel were lacking.

The importance of information to regaining life and to maintaining dignity was also stressed by the patients recovering from head injury, in a study by Slettebø et al. (2009). They described how lack of information from healthcare personnel to significant others about the patient's invisible disease caused communication problems. In the present study, the women mentioned how they, themselves, were unable to communicate their invisible wound and sensitivity to friends, significant others and healthcare professionals. The people around them acted in relation to what was visible: a person who was reasonably mentally and physically well. This caused what Arman et al. (2002) called doubled suffering, implying that the women felt their problems were being denied. Apart from sheltering their sensitiveness by avoiding too many people, the women seemed existentially alone, as if no one could share their suffering. This may have contributed to what could be interpreted as their 'self-nursing'; their need to protect themselves and their right to feel ill.

As revealed in the theme "the need to be embraced by attentiveness", the women used the word attentiveness as a marker of being seen and listened to as an individual, of being acknowledged as ill and fragile. Arman et al. (2002) found that suffering is alleviated when it is shared with someone. The women in the present study did not talk about sharing their suffering; they expressed their appreciation for the attention they received from significant others or healthcare personnel. Significant others often find it difficult to participate in an ailing person's struggles (Lindholm et al., 2002). This left the women in the present study to rely to a certain extent on healthcare personnel, who, according to Toombs (1993), can help in the healing process by understanding the patient's perspective. By being professional and knowledgeable and by not giving ambiguous or inconsistent messages, healthcare personnel can probably help to minimize the experience of paradox among persons who have undergone benign meningioma surgery.

CONCLUSION

There seems to be a connection between surgery and emotional distress in persons who have undergone surgery for benign brain tumors. It is impossible to generalize a reason for this based on the present findings. But it is possible to suggest the need for more studies about how persons with benign brain tumors experience the process surrounding surgical treatment, and how better nursing care, including psychological support and information, could be developed.

NURSING IMPLICATIONS

The findings of the present study reveals a need to find a balance between what is considered frightening as opposed to supportive information for persons going through and recovering from meningioma surgery. To support the transition back to ordinary life, involving significant others would probably be advantageous. Furthermore, our findings support the suggestions made by Miao et al. (2010) that persons who have undergone meningioma surgery might benefit from psychological support.

It is essential for nurses to be aware of the meanings persons ascribe to events that disrupt their lives as well as to the transition process in connection with meningioma treatment. Because nursing entails support in transitioning through life-changing episodes and in an illness-health cycle – including the social, biological, physiological and psychological approaches of the individual in her environment (Meleis, 2007) – it would seem appropriate to involving nurses in designing and carrying out the necessary support.

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CONFLICT OF INTEREST

The authors have declared no conflict of interest.

AUTHORS CONTRIBUTIONS

IW, LEE and BE all contributed to conception and design of the study. Data collection was performed by IW while IW, LEE and BE all participated in the data analysis. IW drafted the manuscript assisted by LEE and BE. All authors have read and approved the final manuscript.

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