

**The impact of the environment on experiences of hospital admissions from the perspectives of patients with palliative care needs**

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Word count: 3,580

## **Abstract**

**Objective:** To explore the impact of the environment on experiences of hospitalization from the perspective of patient's with palliative care needs.

**Methods:** A qualitative study design using longitudinal semi structured, face-to-face interviews were used to elicit the views of patients with palliative care needs admitted to hospital in one large urban acute hospital in New Zealand. The sample comprised of 14 patients admitted to between July 2013 and March 2014 who met one of the Gold Standard Framework Prognostic Indicators for palliative care need.

**Results:** Almost all participants described a range of factors associated with the environment which impacted negatively on their experiences of hospitalization. This included challenges with the physical surroundings, the impact on social relationships with other patients, families and health professionals and the influence of the cultural milieu of the hospital setting.

**Conclusions:** Emulating the 'ideal' environment for palliative care such as that provided in a hospice setting is an unrealistic goal for acute hospitals. Paying attention to the things that can be changed, such as enabling family to stay and improving the flexibility of the physical environment whilst improving the social interplay between patients and health professionals, may be a more realistic approach than replicating the hospice environment in order to reduce the burden of hospitalizations for patients with palliative care needs.

## Background

The environment of a care setting is known to impact on a patient's recovery from illness, as well as their overall well-being. For example, studies have shown that certain aspects of the physical environment can impact positively on patients' experiences of care and their quality of life.<sup>1,2</sup> For those at the end of life, a sense of 'homeliness' and an environment that provides opportunities for social interaction and privacy, are considered important elements of an inpatient setting.<sup>3</sup>

In developed countries, most people with a life-limiting illness will spend some time in hospital during the last year of their life.<sup>4</sup> However, the hospital environment is reported to be a consistent source of dissatisfaction for patients with palliative care needs.<sup>5</sup> An integrative literature review by Brereton et al<sup>6</sup> identifying key elements of the physical hospital environment for end of life care of older adults and their families found that more than any other aspect of care, deficiencies in the physical environment was a source of significant dissatisfaction for patients, families and staff.<sup>6</sup>

In response to the recognition of the inadequacies of the hospital setting, hospices have worked towards developing an environment that better meet the needs of patients and their families. The hospice environment is often described as quiet and homely and the ratio of staff to patients is favourable compared to that of the acute hospital.<sup>7</sup> Bereaved families report a high level of satisfaction with hospice inpatient care in terms of their relationship with care providers and with aspects of the physical environment such as cleanliness of the facility, a home-like feeling and proximity to nature.<sup>8</sup> It is unsurprising, therefore, that the hospice continues to be overwhelmingly preferred to hospital as a place of care and death<sup>9</sup>. However,

the reality is that most people in developed countries will be cared for and die in other care settings, notably hospital.<sup>10</sup> Given that patients with palliative care needs comprise one quarter to one third of the total inpatient population,<sup>11, 12</sup> identifying how the hospital environment can be modified to better meet their needs must be a priority.

While the environment has been shown to be a key factor influencing patients' experience and satisfaction with hospital care<sup>6</sup> evidence is limited by a lack of definition or conceptualisation of what is meant by "environment" and few studies have collected data prospectively from patients themselves<sup>6</sup> Understanding the difficulties patients experience in relation to the hospital environment is essential if we are to identify strategies that will improve the provision of palliative care in this setting. This paper will address this gap in knowledge by exploring the impact of the environment on experiences of hospitalizations from the patients' perspective.

## **Design**

Given the exploratory nature of the study, a qualitative approach was adopted. Critical realism was used to inform the study design.<sup>13</sup> Critical realism acknowledges "the empirical (that which is experienced and perceived), the actual events that occur (whether perceived or not) and the real underlying structures that can cause changes in those events".<sup>14</sup>

The experiences of patients with palliative care needs admitted to a large urban hospital in New Zealand were elicited using face-to-face semi-structured interviews. Participants were interviewed on two occasions. Serial interviewing provides opportunities for the researcher-participant relationship to develop in a way that creates a trusting relationship enabling the participant to share personal accounts of their experience over time.<sup>15</sup>

## **Study setting**

Auckland City Hospital, New Zealand, (ACH) is the largest public hospital in New Zealand. A recent census of admissions found that one fifth of adult inpatients at ACH met criteria for palliative care needs, the majority of whom were aged over 70 years.<sup>12</sup>

## **Study population**

The study sample comprised of patients admitted to ACH between July 2013 and March 2014 who met one of the Gold Standard Framework Prognostic Indicators (GSF-PIG) for palliative care need. The GSF-PIG consists of clinical indicators associated with a range of life limiting illnesses that indicate palliative care need. Whilst primarily developed for the primary health setting, the GSF-PIG has been successfully used in research settings to identify hospital inpatients with palliative care needs.<sup>12,17</sup>

## **Sampling**

According to hospital admission data (unpublished data, December 2012) general medicine, oncology (medical and radiation), urology and general surgery account for nearly 31% of admissions for patients with a GSF diagnosis. For this reason, recruitment of participants was confined to these four services. Admissions to these services were reviewed along with past and current clinical notes to assess for eligibility (see table 1). As the researcher (JR) was also employed in the hospital palliative care team, any patients that had been referred to the service at the time of screening were excluded. No participants recruited to the study were referred to the service.

<b>Inclusion criteria</b>
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Admitted less > 48 hours ago
Speaks English
Not referred to hospital palliative care team
Meets one or more of the GSF PI's
Aged >18 years old

Table 1: inclusion criteria

A ward nurse approached eligible patients to determine whether they wished to take part in the study. The researcher was contacted directly by the nurse if the patient agreed to take part. Written information regarding the study was provided to all participants. Written consent was obtained from all participants and any family who the participant requested to be present.

A purposive approach to sampling as described in Coyne<sup>18</sup> was used. Sample characteristics were not pre-determined, however factors identified from the literature known to influence experiences of hospital admissions such as age, diagnosis and ethnicity<sup>19-21</sup> were taken into account during the initial sampling process. As the study progressed and data were analysed, other characteristics were identified and used to guide subsequent participant selection.

Recruitment continued until no new themes were emerging from the data.

### **Data collection**

Participants were interviewed on two occasions. The first interview occurred within 48 hours of admission, was conducted on the ward by JR, and lasted 20-30 minutes. The purpose of this interview was to understand participants' expectations of the hospital admission. It was also an opportunity to for the researcher to establish a relationship with the participant in preparation for the second interview.

Within one week of discharge from hospital participants were interviewed again. The purpose of the second interview was to explore fully participants’ experiences of having been in hospital. Participants were given a choice of where this interview took place. Eleven participants chose their place of residence to be interviewed, two were interviewed at the hospital after attending an outpatient clinic appointment and one was interviewed at a friend’s house. The second interview took between 45-90 minutes.

Separate interview guides were developed for the first and second interviews based on a review of the literature related to patient’s experiences of hospital admissions within a palliative care context.<sup>5</sup> Participants were asked about their perceptions of the expected and actual benefits and burdens associated with being in hospital (see table 3). The interviewer used a relatively unstructured approach to interviewing which allowed for the emergence of new themes that were relevant to the overall study aim.<sup>22</sup>

Interview 1	Interview 2
What were the circumstances that caused you to end up in hospital?	Tell me about your experience of having recently been in hospital
How do you think being in hospital will help you with your illness?	Thinking about what happened during your stay in hospital, was there anything you found particularly difficult or distressing?
What do you think the difficulties will be for you while you are in hospital?	On reflection, was there anything/useful about having that time in hospital? How was it helpful/useful?
How do you feel about being in hospital?	Is there any reason you think might have to go back to hospital again?
If you could have got the help you needed would you have preferred to have stayed at home/residential care facility/hospice?	How would you feel about having to go back to hospital again?

Table 3: examples of interview questions

## Data Analysis

All interviews were audio recorded and transcribed verbatim by JR. The software programme *N-Vivo* was used to aid categorisation of the data. JR conducted and transcribed all interviews. CG and JR reviewed two transcripts independently to ensure consistency in coding and to clarify coding decisions. Regular meetings were held with MG, CG and JR to review coding decisions and the development of themes.

A process of thematic analysis as described by Braun and Clark<sup>23</sup> was used to analyse the interview data. An integrative approach using both inductive and deductive methods of data analysis was used<sup>24</sup>. No predetermined coding frame was used, instead this was developed as the data were coded and was subsequently applied to all transcripts. Although participants were not asked specifically about the hospital environment, the impact of the environment on participant's experiences emerged as an important theme. An inductive approach to the development of themes was applied. Themes identified from the interview data were organised according to the dimensions of Barnett and Casper's outline of social environment which is defined as "...the immediate physical surroundings, social relationships, and cultural milieus within which a defined group of people function and interact" p465<sup>25</sup>.

## **Findings**

A total of 14 participants were recruited to the study. Twelve participants completed both interviews; two participants died prior to the second interview. Family were allowed to be present during the interviews if requested by participants. Participation by family during the interviews varied. One participant specifically requested that family be present during both interviews and they actively participated in the discussion. Three participants had their spouses present at the first interview however their contribution during the interview was



minimal. Participants were at varying stages of their illness (see table 2). Thirteen participants described a range of factors associated with the environment that impacted on their experiences of being in hospital.

<b>Characteristics</b>	<b>n=14</b>
<b>Mean Age</b>	69.8 years
<b>Gender</b>	
Male	7 (50%)
Female	7 (50%)
<b>Ethnicity</b>	
NZ European	6 (42.9%)
Maori	3 (21.5%)
Pacific	2 (14.3%)
Indian	1 (7.1%)
Chinese	1 (7.1%)
Other	1 (7.1%)
<b>Diagnosis</b>	
Cancer	9 (64.3%)
Non cancer	5 (35.7%)
<b>Age</b>	
18 – 39 years	0 (0%)
40 – 49 years	2 (14.3%)
50– 59 years	1 (7.1%)
60 – 69 years	3 (21.5%)
70 – 79 years	4 (28.6%)
80 – 89 years	4 (28.6%)
>90 years	0 (0%)
<b>Admitting Service</b>	
General Medicine	5 (35.7%)
Oncology	8 (57.1%)
Urology	1 (7.1%)
General Surgery	0 (0%)
<b>Known to hospice</b>	
Yes	8 (57.1%)
No	6 (42.9%)
<b>Survival after interview</b>	
< 6 months	5 (35.7%)
6 - 12 months	4 (28.6%)
> 12 months	5 (35.7%)

Table 2: participant characteristics (n=14)

Aspects of the physical environment were particularly challenging for participants who reported difficulties not having access to personal space including a lack of privacy when

sharing bathroom facilities. This was particularly difficult for those whose illness meant they had to access the toilet frequently.

*“I got the problem with the bladder. I have got to go to the toilet very often for pee and if you got four people in the room, usually it is four people in the room. One is crying and one is snoring. The toilet is 90% occupied and you can’t rest” (60 year old man with cancer)*

As a result of being in multi-bedded rooms some participants reported being near sick and dying people as causing distress. Finding a space that removed them from this environment was often impossible.

*“I hate being with a whole lot of people. I can’t stand a whole lot of squealing people especially when they are sick. Being around other sick people doesn’t help me. It makes me worse and I just want to get away and be in a private room” (57 year old woman with cancer)*

The impact of sharing rooms with very sick people some of whom were thought to be infectious was distressing for some participants. One participant reported how staff did not seem to appreciate the significance of this in terms of the required environment to keep patients free from infection.

*“I was in a crowded room where there was a lot of noise and where a woman had the super bug and the nursing care was very poor. They didn’t isolate us. They didn’t give us our own toilet and shower. I had to go and ask for them and the nurses just seemed*

*to not know about it so I had to ask for a private shower” (57 year old woman with cancer)*

Another participant reported feeling vulnerable due to being with other sicker patients who might cause him to become more unwell.

*“I was in ward XX and there was a guy in there who had a bug of his own. I was terrified that I would catch this and combined with what I had...” (77 year old man with cardiac disease)*

The distress associated with a lack of natural light and being in a multi-bedded room with curtains pulled around bed spaces constantly throughout the admission was reported by one participant.

*“What I found really hard this time was that I had a space around the corner as you go into the ward and what I found really hard was nobody drew their curtains at all so I never got to look out the window the whole week, everybody had their curtains drawn” (69 year old woman with cancer)*

The physical environment of the hospital also impacted on social relationships. For one participant being in a multi-bedded room was an opportunity to interact with other patients however constantly having the curtains closed around bed spaces prevented her from doing so.

*“...and there was a nice lady across from me I would have liked to have talked to but curtains shut all the time.” (69 year old woman with cancer)*

Being alone with little opportunity to interact with others including other patients resulted in feelings of boredom for some participants. One participant described how when he was left with nothing to do he could find no reprieve from reminders of his illness.

*“If the patient has nothing to do then you start to think....I feel uncomfortable, I feel this, I feel that. If your mind is not thinking you are sick it’s much better. If you think about your illness then you think about what is happening. It’s too much negative thinking.” (61 year old man with cancer)*

Many participants reported a negative impact on their relationships with family as a result of being in hospital. The hospital environment was often not conducive to staying connected with friends and family and this was distressing for some participants leaving them feeling lonely and isolated.

*“I would spend the day with Tracey (his wife) and then she would go home. I would walk out to the door with her and I would watch her going down the corridor. I found that difficult staying there, not going with her but she was there again the next day.” (77 Year old man with cardiac disease)*

While some participants did not like being away from friends and family, attempts by staff to accommodate family out of normal visiting hours when a patient was dying was very distressing for one participant.

*“There were people around the next bed. I kept thinking they would go and then they stayed and they would read their bible and the preacher would come and pray with them. I found it so distressing.” (69 year old woman with cancer)*

For one participant saying goodbye to his father was that much harder from his hospital bed. Not being part of family activities as his father prepared to travel overseas was distressing for them both.

*“My Dad is a bit concerned. He flew out to Samoa today and I wasn’t there today. My partner said that when they came to visit last night, he didn’t want to go and leave me here.” (47 year old man with cancer)*

Staff appearing too busy to care was a key factor in participants making positive relationships with hospital staff. Participants reported that staff were often very busy which left them feeling anonymous and an inconvenience.

*“In the hospital you are an inconvenience and they have always got another person to move on to. It’s just too busy, people are too busy. You are an inconvenience. You are a number. You know they are not really interested in you.” (57 year old woman with cancer)*

The way in which staff worked within the hospital environment also influenced the way in which participants interacted with clinicians. One participant reported that repeated assessments by clinicians who asked the same questions over and over again were difficult. Added distress occurred when there was a lack of continuity with new staff coming and going.

*“Always someone new is coming, new one is coming, new one is coming, new one is coming and they ask you so many same questions. I can’t understand after minute, after minute, after minute and a new one and you didn’t see him again. I don’t know why?” (61 year old man with cancer)*

Those participants who reported positive relationships with hospital staff experienced a level of continuity with individual staff. One participant had repeated admissions to the same ward and had got to know the staff well and for another participant, an admission that lasted for several weeks gave him an opportunity to establish a good relationship with ward staff.

*“The nurses and the doctors were marvellous, I could not say anything against them they were absolutely wonderful and the nurses having been there for so long, they sort of like adopt you to a degree and they make a fuss of you, you know. You got to the stage where you started to know everybody like Tracey (his wife) was part of it as well because she would come and spend the whole day with me and they were giving her a meal at night times which was great you know.” (77 year old man with cardiac disease)*

When staff were busy participants felt they were not important and these feelings were exacerbated when they were left waiting for long periods.

*“You are left just sort of sitting there and I have to go and complain to the senior nurse because I have been sitting in the waiting room for hours. I always go and ask how long will it take? Because there is always someone who is far more important than you.” (57 year old woman with cancer)*

While the way in which staff behaved in the hospital setting impacted on the social relationships that form between participants and health professionals, these socialised behaviours are often a component of hospital culture. For the purposes of this paper “cultural milieu” encompasses the shared beliefs, attitudes, values and norms of staff behaviour that contribute to a certain way of working within a hospital setting<sup>26</sup>. They include the ‘rules’ of the hospital setting (both spoken and unspoken) and the perception that health professionals have the power to make decisions with and/or for the patient.

Restrictions imposed by staff reduced participants ability to maintain autonomy and independence. Participants reported a lack of freedom being in hospital, feeling like they were trapped and unable to “get out”. This loss of freedom to do what they wanted was difficult for some participants.

*“You can’t go home at night. You can’t do this and you can’t do that. You see I have always been very active. I’m an active person and you are captured you know.” (78 year old man with COPD)*

Staff were perceived as having control over one participant’s freedom to leave hospital, with him reporting that he would do whatever he was told to do if it meant he would get out of hospital.

*“I had no option. At the same time I had this worry about the virus and if this was going to fix it. I’m one of those people that whilst in hospital to get out again if they suggested go into the corner and stand on my head, I would go and stand on my head you know.” (77 year old man with cardiac disease)*

Some participants described difficulties in being an active participant in their care and this was exacerbated by examples of poor communication by health professionals. A belief that clinicians did not think he would understand details of his illness left one participant feeling disempowered and unable to actively participate in decisions regarding his treatment.

*“Some...like these people have been good, they tell me but on other occasions you ask and you just get a roundabout answer sort of thing you know, you don’t really get....it’s almost as if they think well, what does he know about it anyhow” (77 year old man with cardiac disease)*

Another participant described how the doctors would stand around her bed talking amongst themselves making decisions about her care.

*“...I’m not used to it...when everybody is sort of not talking at you and you are sitting there like this (indicating that she has to look up above her) and there’s the doctor and she’s saying this that and the other...” (89 year old woman with chronic obstructive pulmonary disease (COPD))*

When participants reported positive communication with staff they felt empowered and this helped to create a positive relationship with staff and enabled them to be involved in decision making about their care.

*“This is the whole thing...if they couldn’t get rid of this infection they would have to replace the valve again and the condition of my heart as it is placed me at great risk but they had my family come in and we had a meeting with B and he explained it all to us...to everybody and it was a decision that we had to make as to whether I would have an operation with the risk or else carry on with this damn virus but there was really no decision to be made because the virus would have killed me anyhow.” (77 year old man with cardiac disease)*

## **Discussion**

This study provides a key contribution to the literature regarding the impact of the hospital environment from the perspectives of patients with palliative care needs. The findings suggest that the social environment of a hospital that encompasses the physical surroundings, social relationships and cultural milieu can impact negatively on the experiences of patients with palliative care needs. However, there is a paucity of research regarding the ideal environment for those with palliative care needs. A study by Gardiner *et al.*<sup>7</sup> regarding the optimum physical environment for palliative care in acute hospitals from the perspective of health professionals found that while health professionals assumed patients would prefer single rooms in order to maintain privacy, staff valued an environment that was conducive to observing and monitoring patients which was not always compatible with single rooms. The findings from our study suggest that there is a need for flexibility in regards to providing an appropriate physical



environment for patients. Meeting patient preferences whilst ensuring that individual care needs are met are factors that should guide the allocation of an appropriate bed configuration and this may even change over the hospital admission. While most patients who are feeling unwell may express a preference for single bedded rooms, when feeling well enough to interact with other patients they may prefer to be in a multi-bedded room.<sup>27</sup>

As a result of growing pressure to deliver care for patients with complex health care needs, the hospital environment is becoming increasingly busy. Studies have shown that patients and families perceive busy staff as being unavailable<sup>28</sup> and this can impact on the quality of the relationships patients form with their care providers. The findings from our study suggest that when patients perceive staff as being busy or when they are left waiting for care, they feel like they are an inconvenience, invisible and forgotten.

Health professional behaviours can impact on relationships with patients. When families feel cared for, it is often in response to staff who are attentive to their needs, appear approachable and friendly and check in regularly to make sure they have what they need.<sup>29</sup> Furthermore, attitude and helpfulness of staff has been shown to influence the atmosphere of the environment regardless of physical factors such as layout and furnishings. Staff who demonstrate a positive attitude, appear competent and are helpful impact positively on patient's mood and well-being.<sup>27</sup> Understanding the impact of appearing busy to patients and families is an important component of finding ways to improve the quality of palliative care in the hospital setting.

Effective communication skills have been shown to impact positively on patients' forming positive relationships with hospital staff.<sup>30</sup> Furthermore, interactions that demonstrate a willingness to find out who the patient is as a person, is an important component to establishing a positive relationship with patients. Initiating simple strategies, such as health

professionals introducing themselves, can make a significant difference to this process.<sup>31</sup> With an increasing workload in hospitals, care staff may become more focused on the tasks at hand rather than on the patient. Using a patient centred approach to care showing empathy and kindness whilst attending to tasks and interacting with patients, whilst do not require more time, have been shown to leave patients feeling reassured, safe and cared for as an individual.<sup>32</sup>

Professional and organisational values, beliefs and norms within the hospital setting may influence the way in which care is provided. Organisational rules around how patients should act in this setting can be a burden for patients. For example, there is an implicit understanding that once admitted the patient will largely remain at their bedside, ensuring they are readily available for any health professional that needs to meet with them. This restriction on their sense of freedom and independence can be a burden for patients. A study exploring the experiences of patients with advanced cancer found that although patients accepted being in hospital as a “temporary necessity”, factors such as being unable to make their own decisions, a loss of independence and the effects of the physical environment all contributed to a sense of imprisonment at times during the admission.<sup>33</sup> Similarly, findings from our study suggest that when patients feel they are unable to leave hospital and are isolated from friends and family they feel as if they are “captive” within that environment. Identifying opportunities to challenge the restrictions traditionally seen within the hospital environment to empower and enhance patient’s sense of freedom and independence may be an important component of providing palliative care in this setting.

Professional culture influences the way in which health professionals interact with patients. Health professionals have traditionally adopted a paternalistic position as the sole decision maker in patient management. A move towards a shared decision-making process involving

the patient and family has been promoted as a more effective approach to ensure that patient's preferences for treatment are taken into consideration however a lack of knowledge about their illness as a result of poor communication with health professionals can result in patients being unable to participate in this process. Furthermore, the development of relationships with health professionals has shown to an important component to patients feeling they are able to participate in decisions about their palliative care.<sup>34</sup> Examples of poor communication were evident in our findings and some patients perceived hospital staff as the sole decision makers regarding their care. This was particularly in relation to when they could leave the ward or indeed when they might be discharged home, with little evidence that they felt they could influence these decisions. A patient's ability to be an active participant in health care decision making is dependent on a number of factors including the information they receive from health professionals and their ability to build positive relationships with staff.<sup>34, 35</sup> In our study despite attempts to engage with health professionals about their illness, some participants were unable to get the information they required and staff behaviours limited their ability to participate in care decisions.

### **Strengths and Limitations**

The process of purposive sampling was used to maximise the diversity of the sample of patients with palliative care needs. A mix of age, diagnoses and ethnicities was captured within the selected sample. Furthermore participants represented a range of prognoses, with 64% of participants having died within 12 months of being interviewed. By using serial, semi-structured interviewing, participants were able to speak freely about their expectations and experiences of being in hospital. This method is considered to be useful in providing opportunities for rich and contextualised accounts of individual experiences over time.<sup>15</sup>

Moreover, the evolving researcher-participant relationship creates an environment of trust enabling the participant to share a more personal account of their experience.

However some limitations to the study must be acknowledged. Recruitment was confined to one urban hospital in New Zealand and recruitment was limited to four specialty services and therefore the findings may not be applicable to other countries or services. Participants were questioned about their experiences of one particular admission to hospital and assumptions cannot be made that they had similar experiences during previous or subsequent admissions; however many participants drew upon past experiences of having been in hospital during the interviews. Furthermore participants' experiences may have been influenced by the length of time they spent in hospital. Family members were present in a small number of interviews and this may have influenced participants' responses.

## **Conclusion**

The limitations of the hospital environment impacts on patients experiences of hospitalisation resulting in significant burden for patients with palliative care needs. Emulating the 'ideal' environment for palliative care such as that provided in a hospice setting is an unrealistic goal for acute hospitals. Further research is needed looking at how changing attitudes and behaviours of busy hospital staff can relieve some of the burden of being in hospital for this patient group. Paying attention to the things that can be changed, such as enabling family to stay and improving the flexibility of the physical environment whilst improving the social interplay between patients and health professionals, may be a more realistic approach than replicating the hospice environment in order to reduce the burden of hospitalizations for patients with palliative care needs.

**Acknowledgements**

The authors would like to thank the patients and families who so willingly gave their time to participate in this research.

**Contributions**

All authors were involved in the conception, design and implementation of the research including data analysis and drafting of the paper. All authors have reviewed and approved the final version for publication.

**Funding**

There was no funding provided for this research.

**Competing interest**

None

**Ethics approval**

Research ethics approval was obtained from the University of Auckland's Human Ethics Committee (No: UAHPEC 9499).

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