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Patients' perceptions of the value of PET in diagnosis and management of non-small call lung cancer

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Abstract
A randomized controlled trial comparing the use of PET versus no PET provided the opportunity to investigate the value patients placed on any additional information provided by the PET scan. Interviews were undertaken with patients after their diagnosis had been made and, in the case of those who had surgery, once they had returned home following the operation. Content analysis was used to describe and analyse the text of the interviews. The aims of the research were to explore with people receiving PET their perceptions of its impact on aspects of well being, acquire a better understanding of how patients understand and deal with the outcomes (both benefits and dis-benefits) of PET, and assess the decision making processes regarding PET and subsequent treatment (surgical and non-surgical) from the patients' perspectives with the aim of providing information which can be used by providers of care in improving the process of care. Interviews were conducted with a sub-sample of 59 trial participants between February 2000 and July 2001, between six and eight weeks post-surgery. Thirty-three, (56%) had received a PET scan and 26 (44%) had not. The majority of patients consulted a surgeon in the expectation of having surgery to remove their cancer. Participants viewed PET (along with the other tests) as being most likely to provide information and reassurance to the surgeon, rather than having any impact on their (patients') decisions. As far as these participants were concerned, there was only one important decision - whether to have surgery - and that decision was in the hands of the surgeon. All other decisions were subordinate to this major milestone and thus did not appear significant to patients. Thus, on its own, PET appeared to be of little additional value to this group of patients. Between 23%-45% of respondents reported some complications whilst in hospital or some difficulties at home but these were mostly of a relatively minor nature. Even though some patients reported that their health was worse than when they entered hospital, most participants reported that their health was improving at the time of the interview. Most participants had, at least briefly, discussed the issue of relapse with a doctor at a consultation subsequent to their surgery. The diagnosis of cancer is the key issue; all that happens to them subsequently seems to be determined by clinicians. It is important that clinicians explain the reasons for tests such as PET to patients and use diagnostic tests appropriately in the management of the disease. Understanding the experiences of patients provides useful information for clinicians in preparing patients for surgery for lung cancer and for cancer services in considering the level of ongoing support required for patients following surgery.

Introduction

PET has been proposed as a valuable tool for clinicians in the diagnosis and subsequent management of cancer, particularly those types that involve major surgery as a first line of treatment. Once an initial diagnosis is made, it is critical that the cancer be staged as accurately as possible to facilitate the most appropriate management of the disease. In particular, accurate staging is necessary to avoid unwarranted interventions (e.g. major surgery in the case of advanced cancer) and thus reduce unnecessary pain and suffering.

Positron emission tomography (PET) is a relatively new imaging technology with potential to improve pre-operative staging. Many malignant tumours show increased glucose utilisation when compared to normal tissues (1987). Whole body PET with ^{18}F-fluorodeoxyglucose (FDG) can identify regions of increased glucose metabolism in non-enlarged structures, allowing detection of tumour metastases earlier than with anatomic imaging methods. Non-small cell lung cancer (NSCLC) accounts for approximately 80% of all lung cancer. At presentation, approximately 25% of patients have disease suitable for surgical resection (Nesbitt, Putnam, Walsh, Roth et al 1995). Following surgical resection, up to 40% of patients with clinical stage I disease and 60% of patients with clinical stage II disease ultimately relapse, implying that they had occult metastatic disease at the time of presentation. Such patients do not benefit from surgery, and the ability to identify them could save an unnecessary thoracotomy.

Data suggest PET may improve the accuracy of pre-operative staging of NSCLC, but, in general, these results are from small, retrospective, uncontrolled series (Saunders, Dussek, O'Doherty & Maisey 1999; Weder, Schmid, Bruchhaus, Hillinger et al 1998; Wahl, Quint, Greenough, Meyer et al 1994). A recent prospective uncontrolled study reported sensitivity and specificity of PET for detection of mediastinal and distant metastatic disease of 95 per cent and 83 per cent, respectively (Pieterman, van Putten, Meuzelaar, Mooyaart et al 2000). PET is costly, and resource implications of its widespread use in staging NSCLC are significant. There is increasing pressure for PET to be included in the standard diagnostic work-up prior to decisions about surgical management of NSCLC (Berlangieri & Scott 2000; Robert & Milne 1999).

Whilst the results of PET scans may be valuable to clinicians, no information is available about patients' perceptions of their usefulness or value. For example, a PET scan result indicating that the cancer has not spread beyond the lung may be reassuring to patients and be valued positively. On the other hand, if the PET scan indicates that the cancer has spread, patients may perceive a trade-off between the positive aspect of such a result (ie surgery may be avoided) and the negative one (ie more widespread disease probably means a poorer prognosis). The trial described below provided an opportunity to investigate these issues.

A randomized controlled trial was undertaken comparing the use of PET versus no PET in 183 people with a clinical diagnosis of Stage I-II non-small cell lung cancer. The recommended treatment for these patients is surgery to remove the affected lung or part thereof. The overall research question was "to what extent does a "positive" PET scan result (ie a result which indicates that the cancer is at a more advanced stage than Stage 1) change the management of the disease?" Following exclusion of one ineligible patient, 92 patients were assigned to no-PET and 91 to PET. Compared with conventional staging

PET upstaged 22 patients, confirmed staging in 61 and staged two patients as benign. Stage IV disease was rarely detected (2 patients).PET led to further investigation or a change in clinical management in 13% of cases, and provided information that could potentially have affected management in a further 13% of cases. There was no significant difference between the trial arms in the number of thoracotomies avoided (p=0.2). It was concluded that for patients who are carefully and appropriately staged as having stage I-II disease, PET provides potential for more appropriate stage-specific therapy, but may not lead to a significant reduction in the number of thoracotomies avoided. Details of the trial and results have been reported elsewhere (Viney, Boyer, King, Kenny et al 2004).

In addition to answering this question, the trial also provided the opportunity to investigate of a number of related issues such as the costs and quality of life associated with this group of patients and the value patients placed on any additional information provided by the PET scan. In this paper, the latter issue is addressed through qualitative analysis of interviews undertaken with patients after their diagnosis had been made and, in the case of those who had surgery, once they had returned home following the operation.

Qualitative research methods in health care

Qualitative research has become increasingly popular in the evaluation of health care and health services. This type of research answers questions that cannot be addressed using quantitative methods. The types of issues that are often investigated using qualitative research include the emotions, perceptions and actions of people with a particular disease or condition and the interactions between users and providers of health care services.

There are numerous paradigms within the discipline of qualitative research; at one end of the spectrum are the use of techniques of data production and analysis as they relate to textual or non-numerical data whilst at the other is the explicit use of specific theories derived from, for example, grounded theory, sociology, ethnology or anthropology to investigate individual's understanding and experiences of their lives and the social context in which events (such as exposure to health care) occur. The research reported here falls into the first category of qualitative research as it employs content analysis to describe and analyse text.

The aims of this research were to:

- explore with people receiving PET their perceptions of its impact on aspects of well being. In particular, to investigate the potential impacts of information, reassurance and the morbidity associated with the surgery itself;
- acquire a better understanding of how patients understand and deal with the outcomes (both benefits and dis-benefits) of PET, in particular the trade-offs between earlier knowledge of metastatic disease and avoidance of (unnecessary) surgery;
- assess the decision making processes regarding PET and subsequent treatment (surgical and non-surgical) from the patients' perspectives; and
- provide information which can be used by providers of care in improving the process of care (e.g. the type and amount of information required by patients).

Methods

Data collection

Interviews were conducted with a sub-sample of trial participants between February 2000 and July 2001. Interviews occurred between six and eight weeks post-surgery, so that most patients would have largely recovered from the effects of the operation. Arrangements were made by phone to interview patients in their home and, when telephone contact was made, it was explained that, if possible, the interviewer would like to tape the conversation. All participants read an information sheet and consent form and all consented to have the interview audiotaped. Consecutive participants in the trial were approached about their willingness to be visited and interviewed. Most participants lived in or near Sydney and the interviewer traveled to the Central Coast and Wollongong as a significant proportion of participants lived in these areas. Two participants declined to participate and three were not approached because they did not speak and/or understand English well enough to be interviewed. Two researchers undertook alternate interviews with the first ten participants. The resulting interviews were transcribed and read by both researchers, each of whom produced a simple summary of the interview and highlighted issues raised by it. Based on these initial results, additional questions and/or probes were formulated. One researcher completed the remainder of the interviews. Data collection was completed when the interviews ceased to yield new information – i.e. when saturation was reached.

The taped interviews were transcribed verbatim by a commercial secretarial firm. Written instructions were provided to the firm asking them not to transcribe the names of individuals but to use the first letter of names used by the interviewer and interviewee to preserve anonymity.

Data analysis

The transcribed interviews were analysed using a content analysis technique. Content analysis involves breaking text into relatively small units of content and submitting them to descriptive and/or statistical analysis (Lieblich, Tuval-Mashiach & Tamar-Zilber 1998). This is generally accomplished by selecting sections of text or single words belonging to a defined category, describing the categories and counting the number of times each appears. Categories may be based on words, phrases or ideas (Kellehear 1993). Aspects of text which may be quantified include: time or space measures (e.g. the space devoted to a topic in the media or the time devoted to it on television); appearances (e.g. how many times did a particular issue or person or type of person appear in the text); and intensity (the importance or prominence given to the topic).

To be viewed as credible (reliable and valid), content analysis must be comprehensive, that is, all relevant sources of data should be examined. In addition, the categories must be clearly defined and specific, that is, be able to be used by a non-expert, and not be overlapping (Scott 1990). Content analysis is a widely used form of analysis and has some well-described advantages: using categories makes it clear what has been searched for and from where the information has come; others are easily able to check the data and method of classification; the connection between the data and subsequent interpretations is precise and explicit and; using categories in a systematic way avoids the tendency of researchers to analyse and interpret according to preconceived notions and/or intuition.

Content analysis was judged to be an appropriate analytic tool because it is able to use the stages of diagnosis, treatment, recovery etc experienced by participants as categories. The categories used were those defined by the stage of management of NSCLC (ie diagnosis and treatment) and the three main issues discussed with respondents: their health (before and after treatment), relapse and life expectancy.

Results

A total of 59 individuals were interviewed following their diagnosis and treatment. Of these, 33 (56%) had received a PET scan and 26 (44%) had not. That is, 32% of trial participants also received a follow-up interview, 36% of those in the PET arm of the trial and 28% of those in the non-PET arm. One (control) patient's status had changed between the initial treatment and the time of the interview – in this case the cancer had re-occurred.

Diagnosis

Having a PET scan did not appear to influence individual's experience of or perception of the time taken to make a diagnosis or the results of that diagnosis – all participants had multiple diagnostic tests (e.g. blood tests, X-Rays, CT scans, broncoscopy) so the addition of a PET scan did not loom large in the overall scheme of things. Of the 33 people who had a PET scan, 28 remembered having the scan and 8 stated that they were explicitly told the scan was to "check for the spread of cancer". There were 28 "positive" responses to a question about the results of the PET scan[1]. These ranged from being told the results were good (1) to having no other cancer (12) and that the results did not change the planned treatment (15). Participants who received good news from the PET scan results gave only positive responses to the question – that is, they had no negative perceptions regarding the value of PET. Five respondents volunteered that having the PET scan gave them peace of mind or reassurance.

The 8 "negative" responses included one respondent who stated that s/he didn't know the results of the tests as her/his daughter was told the cancer had spread, 2 who stated that the planned treatment was changed as a result of the PET scan and 5 who reported that the PET scan revealed the cancer had spread. In addition to the "negative" responses reported above, participants whose results indicated that treatment needed to be changed or that the cancer had spread also indicated that they felt positively about the PET scan; for example, that, although the results were not as good as they had hoped, it was better to know than not. That is, they recognized the trade-off between information and bad news and generally preferred information because they believed that treatment outcomes would, overall, be better with full information.

"if it wasn't for the PET scant they might have missed some…. I mean they were looking at taking the top lobe and then after the PET scan it was sorry we're going to have to go a bit more …and he got it all…he said to me we got it all, no chemo no radio" (ID 108)

Treatment

Approximately 80% of the respondents in both PET and non-PET groups provided information about their experience of surgery and post-surgery hospitalization. Most

[1] This does not mean that there were responses from 28 individuals as respondents could provide more than one response in the course of answering the question or discussing the issue of the results of the PET scan.

reported that they experienced little pain or that the pain was controllable. Fifteen people (45%) in the PET group and 14 (54%) in the control group reported that their surgery and hospitalisation went well and that they recovered well. However, 10 (30%) members of the PET group and 6 (23%) in the control group reported that they experienced some problems or complications following surgery, for example:

> *"I had an adverse reaction to morphine….. 48 hours after the operation I woke up in the middle of the night with the most dreadful abdominal pains and I had to rush out to the bathroom very quickly and, to be perfectly honest I was so violently sick - vomiting and the most dreadful diarrhea, and for the next four nights I was getting up 6 and 7 times a night and I knew this was doing something to me"* (Female aged 77 years)

> *"I had complications with the trachea or the oesophagus - it kinked and I had projectile vomiting…for a day and a half and then two days after it they put a tube down to try and straighten it…went back to nothing by mouth for three days"* (Male, aged 72 years)

> *"Yes I had some complications. I should've been home in 5 to 6 days but my bowels ceased to operate and I understand they didn't know why that happened ……and I had to go back up to surgery because I had a hole and it was leaking……and then they realised I had polyps in my bowels so I had to go back up to surgery for that"* (Female, aged 61 years)

Ten (30%) of those in the PET group and 7 (27%) of those in the control group reported that their stay in hospital was shorter than they had expected but only one person volunteered that they perceived they had been discharged too early from hospital.

Fifteen (45%) of the PET group reported experiencing some problems at home: of these 10 experienced physical problems, 2 emotional problems and 3 reported that they took longer than expected to recover. Of the 10 who reported physical problems, only 4 said they needed assistance for personal or daily activities. In the control group, 9 (35%) reported problems once they were home (5 physical, 1 emotional and 3 took longer to recover than expected). The majority (85% PET; 96% control) reported that they were having regular or further check-ups with a medical practitioner and 48% of the PET group and 42% of the control group reported that they needed no further treatment. A number reported that they had received additional treatment such as radiotherapy (9 PET; 10 control), chemotherapy (1 PET; 1 control) or other treatment (drug trial, herbologist, physiotherapy, as well as treatment for unrelated conditions – 3 PET; 3 control).

Health

Seventeen (52%) of the PET group and 11 (42%) of the control group commented on their general health status following surgery. Most perceived that it was much the same as previously, or returning to normal but 5 members of the PET group reported that their health was worse. Twelve (36%) in the PET group and 12 (46%) in the control group reported that problems with their breathing contributed to lower health status. Fourteen (8 PET; 6 control) reported pain, tightness or discomfort in the chest, related to the surgery, 13 (7 PET; 6 control) reported having less energy and 21 (14 PET; 7 control) reported being restricted in their activities or taking longer than previously to complete tasks.

Relapse

Twenty four (73%) of the PET group and 19 (73%) of the control group reported discussing the probability and consequences of relapse (ie recurrence or spread of the cancer) with their doctor. Of these, 12 (36%) of the PET group and 9 (35%) of the control group reported that the doctor indicated a relapse was possible whilst very few said it was probable (1 PET; 3 control) or unlikely (2 PET; 1 control). More than half of those who reported discussing the likelihood of relapse with the doctor reported that they, rather than the doctor brought up the subject (15 PET; 11 control). Fourteen (42%) members of the PET group and 8 (31%) in the control group reported that they continued to think about relapse whilst smaller numbers (9 PET; 10 control) reported that they did not think about it.

Life expectancy

More than 70% in each group indicated that they expected or hoped to live the same length of life as they would have without the cancer. A number of participants stated that the surgical removal of the cancer meant that they now had the same chance of living a "normal" length as if they had not been diagnosed with the disease. But when the interviewer asked about specific expectations, a more complex set of issues emerged. Seventeen (52%) of the PET group and 16 (61%) of the control group indicated that their expectations had not changed, saying that they were getting on with life, had faith they were cured or accepted that things often do not go to plan so did not have any particular expectations, for example:

> *"Well I do exactly the same things as I was doing a couple of years ago - no difference"* (Male, aged 73 years)

> *"We're still going to go away in our caravan next year"* (Female, aged 75 years)

Eight (24%) of the PET group and 5 (19%) of the control group indicated that their expectations had changed, explaining that their horizons had narrowed, they believed that they were getting older and needed to prepare their family for the worst and that they didn't plan too far ahead. The following quotations from four different participants illustrate this:

> *"I'm not getting any younger and my body obviously must be slowing down and, I might be able to swing the shovel but I can't swing the pick. See what I'm saying - you know I'm saying, -obviously you're not going to be going in the Olympics"* (Male, aged 81 years)

> *"Yes I do think differently…… I've come to accept that I may not live to a ripe old age but at least I'm not young. You know, if I was young I'd have a different attitude I suppose but I've had my life and let somebody else have a go now" ……My daughter won't let me talk about it because every time I say to her - you know I might not be here, she says don't talk like that mum, she gets really upset about it and so does my husband. I mean he's worse than she is"* (Female, aged 63 years)

" I got a boy and a girl, oh they're grown up married children and, I said to them you know what's going on here… of course you plant the seed in their brain, in their head" (Male, aged 77 years)

"Oh yes, I don't think very far ahead at all. I mean I don't plan something in the distant future, like when they went to sell the tickets for the Olympics there was no way I was going to buy one because that's a year away. We went on holidays in November and normally we'd have planned for that quite a bit longer and this time it's only about a month before we went we planned everything" (Male, aged 51 years)

An interesting finding was that 16 (48%) of the PET group reported having changed feelings about life – specifically, 12 said that they regarded each day they were alive as a bonus, whilst only 3 (12%) of the control group reported these feelings.

Discussion

The main aim of this research was to examine the perceptions and values of people with NSCLC regarding the use of PET as an additional diagnostic tool – in particular, its role in the provision of information, reassurance and the prevention of unnecessary surgery. In doing so, we expected to be able to assess how patients traded-off earlier knowledge of metastatic disease and the avoidance of painful surgery.

However, the results of the trial of PET for Stage I-II, which aimed to assess its role in the management of NSCLC, showed that while PET had the potential to indicate more appropriate stage-specific therapy, it did not lead to a significant reduction in the number of thoracotomies avoided. The results of this qualitative research support these findings. The majority of patients consulted a surgeon in the expectation of having surgery to remove their cancer and most were convinced, prior to PET or any diagnostic test performed after the consultation, that they were having surgery. Those who had a PET scan regarded it as one amongst many diagnostic tests which they perceived as aiding or confirming the clinical skills of the surgeon. Thus, participants in the trial viewed PET (along with the other tests) as being most likely to provide information and reassurance to the surgeon, rather than having any impact on their (patients') decisions. Whilst a number of individuals had their cancer upstaged as a result of PET, very few subsequently faced the trade-off between earlier diagnosis of metastatic disease and surgery. Thus, on its own, PET appeared to be of little additional value to this group of patients. Most recipients of PET understood it to be a more advanced version of a CAT scan and were grateful for the availability of such a sophisticated test. A number voiced the opinion that it should be more widely available.

The main reason that PET seems not to have been particularly valuable to participants appears to be related to the notion, apparently shared by both surgeons and patients, that the clinician was both ethically obliged and accountable for making this particular type of decision. This in turn is related to patients' perceptions of the clinical skills of the surgeons involved in the trial and their ability to inspire confidence in their patients. Because they understood the significance of their cancer being classified as stage I-II, (i.e. in terms of their capacity to have and benefit from surgery), patients relied on surgeons to provide them with information about the stage of the cancer and hence the chance of its being able to be treated by surgical removal. Overall, participants expressed

great faith in the competence of the surgeon they consulted, in terms of both diagnostic and surgical skills. Thus, their attitude to the results of the PET scan is a reflection of their faith and belief in the capacity of the surgeon to correctly stage the cancer. Being offered surgery was perceived as an indication that the diagnosis of cancer, while shocking, was not as great a threat as it might be and patients were very happy to be operated on.

Although there has been much discussion in the literature about the value of PET as a means of both diagnosing and staging lung cancer and its potential impact on clinical decision making (Weng, Tran, Rege, Safa et al 2000; Wren, Stijns & Srinivas 2002; Sachs & Bilfinger 2005), there has been little investigation of the importance of the technology from patients' perspectives. Papatheofanis (2000) obtained utilities for stage-dependent outcomes for NSCLC and found that patients valued the information from non-invasive PET and invasive mediastinoscopy equally. This result may indicate that, although patients responded to the utilities questionnaire in a similar vein to participants in the current study, they did not believe they had the skills to differentiate between the two diagnostic technologies as the information gained from them was primarily for the benefit of clinicians and clinical decision making.

Having reached the conclusion that the patients in our study perceived that the value of PET was primarily related to the provision of information for clinicians, the other aims of the research, (ie examining the decision making processes used by patients and the amount of information they required), seem somewhat redundant. As far as these participants were concerned, there was only one important decision - whether to have surgery - and that decision was in the hands of the surgeon. All other decisions were subordinate to this major milestone and thus did not appear significant to patients. A recent paper by Wirtz, Cribb and Barber (2006) highlights possible explanations for the lack of involvement or interest in decision making by some patients. Current models of doctor-patient decision making fail to address which decisions patients should be involved in and how they should be involved. Clearly, patients in this study did not feel they should be involved in the decision about whether surgery was appropriate and, thereafter, any involvement in the process was as a recipient of information rather than as equal partners in any reasoning-communication process. When the options for treatment are small and there is likely to be a strong preference on the part of the provider or patient (or both) for one, then shared decision making is not appropriate. Moreover, in the case of a risky procedure such as major chest surgery, ethical obligations on the part of the surgeon entail being accountable for the success of the procedure and therefore for the decision about whether to recommend it for individual patients.

In general, participants in this trial indicated that they had either sufficient or too much information. This appears to be because they had numerous, sometimes repeated diagnostic tests. Once the diagnosis of cancer was made and the Stage confirmed and they had been told the exact site of the cancer and the type of surgery they would have (e.g. lobectomy, removal of entire lung), most patients felt they had enough information. However, useful information has been obtained about participants' experiences of diagnosis, hospital care and surgery and their attitudes to issues regarding their health, including relapse and life expectancy.

One possible side-effect of the generally positive attitudes to major surgery may have been the low reported rate of major problems during hospitalisation and at home following surgery. Although 23%-45% of respondents reported some complications whilst in hospital or some difficulties at home, these were mostly of a relatively minor nature. Even though some patients reported that their health was worse than when they entered hospital, most participants reported that their health was improving at the time of the interview. These findings reinforce those of the associated investigation of health-related quality of life (HRQOL) of these patients (Kenny, King, Viney, Boyer et al 2007) Surgery substantially reduced HRQOL across all dimensions (i.e. physical, role, cognitive and social functioning) except emotional. HRQOL improved considerably in the first month following surgery and continued to improve for patients without recurrence. However, around half continued to experience symptoms and functional limitations two years after surgery (Kenny, King, Viney, Boyer et al 2007).

Most participants had, however briefly, discussed the issue of relapse with a doctor at a consultation subsequent to their surgery. Understandably, participants were less forthcoming about this issue and that of life expectancy than they were about their experiences before, during and after surgery. For some, this was due to the fact that they had little real information to go by- although a number spoke of knowing the probability of relapse for the average person in their position, most also understood that there was no way of knowing if they were, in fact, "typical". For others, not discussing these issues meant that they felt they were not worrying their family or were better able to cope by "getting on with life".

The fact that they were able to have surgery may also have contributed to respondents' positive responses to questions about how long they expected to live. A belief that a positive attitude would contribute to their chances of surviving into old age may also have influenced some responses. A number of participants indicated that they felt a need to remain positive for the sake of their family.

Limitations of the study

Whilst the results of qualitative research produce in-depth information about feelings, perceptions and experiences of health care, the extent to which they are generalisable to other groups or the wider population is limited. Hence the results reported here apply to this group of (mostly) men, with Stage I or II lung cancer treated by surgery either in a large tertiary hospital or a private hospital in Australia. Only 59 of a potential 173 participants were interviewed. However, there is no reason to expect that information supplied by other participants would have added to our knowledge as the sub-sample included in the qualitative study had a similar socio-demographic and clinical profile to study participants as a whole.

Conclusion

For those patients who participated in this study, the diagnosis of cancer is the key issue; all that happens to them following this seems to be determined by clinicians. Therefore, it is important that clinicians explain the reasons for tests such as PET to patients and use diagnostic tests appropriately in the management of the disease. The experiences of patients provides useful information for clinicians in preparing patients for surgery for lung cancer and for cancer services in considering the level of ongoing support required for patients following surgery.

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