

Lung cancer patients' perceptions of access to financial benefits: a qualitative study

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SUMMARY

Background: Financial worries may add to the stress experienced by patients and their families, but they are often not discussed with health professionals. People with lung cancer usually have to give up work, and many are terminally ill.

Aim: To explore the financial concerns, perceptions and experiences of claiming benefits of people with lung cancer.

Design of study: Qualitative study using narrative interviews.

Setting: United Kingdom.

Method: Interviews with a maximum variation sample of 45 people with lung cancer, recruited through general practitioners, consultants, nurses and support groups.

Results: Some people did not know that they could claim financial benefits, others found claim forms complicated, or were unaware that they had no legal right for important allowances to be backdated. Some people had to 'struggle' to obtain much-needed benefits to which they were entitled. Patients below retirement age said that they would prefer to be working, and many were shocked by how hard it was to obtain the information needed to make claims. There was some evidence that even those who are seriously ill, and life-time tax payers, feel stigma in claiming financial help. Nurses, doctors and other patients sometimes offered valuable guidance, but many patients did not receive timely advice. The special social security rules (and DS1500 report form), which might have allowed them to claim benefits more rapidly than usual and at a higher rate, were not always understood.

Conclusion: Many reasons were found as to why people with lung cancer have difficulty getting the benefits that they are entitled to. Hospital and primary care staff who handle the issue sensitively and help set claims in motion provide a valuable service that should be replicated throughout the National Health Service.

Keywords: DIPEX; financial support; lung cancer; qualitative research; stigmatisation.

Introduction

RECENTLY, terminal care and ways of planning for a 'good death' have been much debated,¹ but relatively little is known about the last few months of life from the patients' perspective.² Among patients' concerns is the fear that they will be a financial burden to their family.^{3,4} Financial worries may cause stress and lead to psychological and emotional problems.⁵ However, patients' financial needs are often forgotten and it is not common practice for health professionals to consider economic hardship in families.⁶ Research has found that people who are seriously ill often lack information about sources of much-needed financial help.⁷

Evidence suggests that only 40–60% of eligible claimants take up their disability living allowance and attendance allowance,⁸ and those who most need financial benefits may be least likely to obtain them.⁹ This may be due to fear of stigmatisation, ignorance about the benefits system, difficulty with forms, and previous failure to obtain benefits.^{10,11} Issues associated with having a terminal illness also need to be considered when trying to explain why certain benefits have not been claimed. Patients may not realise they have a terminal illness or, if they have been told, may not accept the situation.¹²

People under the age of 65 years who need care and attention can claim disability living allowance (care component), those aged 65 years or over can claim attendance allowance. Lung cancer progresses rapidly and prognosis is usually poor,¹³ so many people with lung cancer, especially small cell lung cancer, will qualify for benefits under special social security rules because they have a terminal illness and are unlikely to live for 6 months. If the doctor completes a DS1500 report form, and if the relevant sections of the claim form for disability living allowance (DLA1A) or attendance allowance (DS2A) are completed, these benefits can be obtained *immediately*. Under 'special rules', incapacity benefit at the *highest* rate can also be obtained after only 28 weeks of sickness (see Box 1 for an example of how a claim may be made).

Although much research has been done into new treatments to relieve the symptoms of lung cancer, relatively little is known about the practical difficulties faced by people with lung cancer, and how people identify the financial benefits that they are entitled to. Two small local studies have indicated that people with lung cancer may have inadequate support with financial matters.^{14,15} Our study builds on this work, exploring the financial concerns, and the perceptions and experiences of patients with lung cancer in many parts of the United Kingdom (UK). It also considers what can be done in primary care to help with these problems.

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HOW THIS FITS IN

What do we know?

People do not always obtain the benefits that they are entitled to, and stigma is attached to claiming benefits. People with lung cancer are often terminally ill and frequently qualify for benefits under special social security rules if a doctor completes a DS1500 report form.

What does this paper add?

Many people with lung cancer receive no information about their full entitlement to benefits. They often miss out on benefits that cannot be backdated and may not recognise the consequences of delayed claims. Patients may be reluctant to pursue claims or lack the information or energy to overcome the bureaucracy involved. This can cause much hardship in the last weeks of life. Those working in primary care are well placed to ensure that people do not 'fall through the net' and lose financial benefits.



1. The patient (or their representative, who may be a social worker or other health professional) must fill in section 1 of the claim form for attendance allowance (DS2A). It is important to tick the box to say the claim is being made under special rules.
2. The doctor or specialist completes a DS1500 report form. This can be given to the patient (in a sealed envelope if preferred). Both forms have to be sent to the Department for Work and Pensions in the envelope provided. If for any reason the DS1500 report form cannot be sent straight away, the patient should send the DS2A claim form immediately and send the DS1500 as soon as possible afterwards.

Box 1. Claiming attendance allowance under special rules.

not want to reveal how much he had been paid in compensation). Having studied the transcripts we developed 'categories' or 'themes'.¹⁷ Using the computer program NUD*IST,¹⁸ sections of text from interviews were marked, and linked to sections of text from other interviews about similar issues or experiences. Then each theme was considered in the light of the context of the whole set of interviews.^{19,20} Inter-rater reliability scores were not developed as the interviews had very little structure. Such scores are not appropriate to data that have little or no pre-defined coding.²¹ However, two of the authors regularly discussed the coding and the interpretation of the data.

Method

The sample and the interviews

Having obtained multiple research ethics committee approval, we interviewed 45 people throughout the UK with confirmed lung cancer for a qualitative research study of people's entire experience of lung cancer. Interviews contributed to the website, DIPEX (Personal Experiences of Health and Illness) www.dipex.org. To look at all stages of the lung cancer experience, we chose a maximum variation sample to include younger and older people from various social backgrounds, people diagnosed with small cell lung cancer, non-small cell lung cancer, and mesothelioma, and those who had been treated in different ways.¹⁶ Of the 18 people under retirement age (65 years for men, 60 years for women) eight were still working, five of them part time. Most people that we interviewed had retired or had had to stop work for health reasons. People were invited to volunteer through general practitioners (GPs), nurses, oncologists, chest physicians, and support groups. A few volunteered, having read about the website (Table 1).

With informed consent, one of the authors, a medical sociologist, interviewed people in their homes between October 2002 and August 2003. People were asked to tell their story from when they first suspected that they had a problem. Among other things, we were interested in people's accounts of the benefits system and the financial help they had received. Some people brought up the subject spontaneously, others were asked to comment on the financial implications of having lung cancer. The interviews lasted 1–3 hours and were audio taped.

Analysis

The interviews were transcribed, and each transcript returned to the responder to read and revise if necessary. Four people asked to have a section of the comments they made about their financial situation removed from the transcript (these included someone who had great difficulty gaining income support, one who did not think he would qualify for benefits if means tested, and another who did

Results

Barriers to obtaining financial benefits

Threat to moral identity and fear of stigma may make people reluctant to seek help. The stigma attached to claiming benefits seems to affect even those who have a serious illness. A threat to moral identity is apparent in accounts where people stress that they would rather be working than claiming benefits, or point out that they were lifelong tax and national insurance payers and were claiming entitlements, not hand-outs. For example, a man with mesothelioma commented:

'I suppose in a way it's only money that I'm not going to get in my old age pension, so instead of paying me an old age pension they're paying me the money now I suppose. So in some ways it's the money that you would've got paid anyway.' (LC18, aged 55 years, diagnosed in 2002, died 2003, ex-welder.)

In our culture the diagnosis of cancer itself can be associated with stigma.²² One man was diagnosed many years ago but still felt ashamed that he had the disease:

LC15, aged 56 years, diagnosed in 1989, ex-joiner:
'I was ashamed I had cancer.'

Interviewer (I): *'But why did you feel it was something shameful?'*

LC15: *'Because I was a man, because I, as a young man I'd boxed, I'd run marathons, I'd played rugby, at the time I was taken ill I was in an advanced swimming club and I just felt, I was at that time in work, you know I was the*

Table 1. Characteristics of 45 people interviewed about their lung cancer.

Characteristic	Number of people
Age at interview (years)	
40–50	9
51–60	20
61–70	11
71–80	4
81–90	1
Ethnicity	
White British	44
Indian	1
Type of work ^a	
Professional or higher managerial	14
Other non-manual	15
Skilled manual	9
Manual	7
Type of cancer	
Non-small cell lung cancer	14
Small cell lung cancer	10
Mesothelioma	4
Not known by patient	17
Source of recruitment	
Support group	24
Chest physician, oncologist or nurse specialist	9
General practitioner	7
Other ^b	5

^aIncludes those retired for medical reasons. ^bFor example, volunteered after reading about DIPEX.

provider and I just felt ashamed that this disease had come and, come to me. I found that very hard to cope with; even now after all this time.'

Later in the interview he explained that he could have obtained relief from payment of tax that was due, but he refused to tell tribunal judges that he had had lung cancer and so suffered financially:

'I was given no money, nothing from no-one, it was just buttons we lived on, how my wife coped with it I just don't know. We never had hardly any savings. And then suddenly I had money for tax which I had to pay, which we had spent, we had had to live on. And then later on the tax [man] wanted that and I had to go and see them; to a couple of tribunals, it wasn't a lot of money but I never had it to pay, but they questioned me, it was like a court. And to get me off it I knew if I had told them I had lung cancer they would have just discharged it then, the case. But I refused to tell 'em that, because I wanted to be normal you know so I wanted to be treated normal, I didn't wanna be treated any different than anyone else ... I didn't want them to know that I had cancer. It seems to categorise me down and make me less than them you know and I didn't want the sympathy I suppose neither you know.' (LC15.)

Barriers imposed by the illness itself. People with lung cancer must claim disability living allowance as soon as possible after diagnosis because this benefit cannot be backdated as a matter of legal right.²³ The illness itself may make this

difficult. For example, one man was too preoccupied with his illness to think about applying for benefits, and so suffered financially:

'The problem is that you have all this information coming in [while in hospital] and to actually take it all in and deal with it is very difficult ... they give you a booklet, or several booklets about different things and so forth and so on about benefits, but I just don't think you take that kind of information in. It's later when you start to need it more, but then of course it's too late because it's very difficult if, if you have surgery and you go through all of this stuff, may be a month, 2 months down the line you suddenly realise that, ah hang on, at the moment I should be doing this or that, any claim for any benefit will start from that point onwards whereas you should really be hooked into that system from the day of your diagnosis. I would like to see someone say, "Okay, irrespective of your situation we'll book you into a set of benefits now, and we can take you off them later if they're not applicable".' (LC12, aged 43 years, diagnosed 2002, ex-rigger.)

This man went on say that he found the benefits system difficult and confusing:

'We claimed for two or three benefits before I was actually told which one I should be claiming for, only to be refused those three benefits, having filled out this huge information pack ... There should be specialist advisers and I've been told that there are; however I wasn't able to access them so it obviously needs addressing.' (LC12.)

Barriers due to failure on the part of professional staff. Some people were not aware that financial benefits were available, and depended on professional staff for information. For example, one man lost benefits because of lack of help at the right time. While in hospital, a nurse told him that a social worker would be along to discuss benefits. However, she never appeared, and he only obtained benefits much later when a community nurse discovered what had happened:

LC13, aged 67 years, diagnosed 2002, retired electrician: *'I received the allowance that the nurse looked for. It wasn't a retrospective payment or anything, it was just from the time that she filled the form in, they never paid me for the amount of time I was off.'*

I: *'So what's your view about the sort of support that you got on that side from the hospital?'*

LC13: *'Dismal, I can't expand on that, it's dismal, that's how I would call that.'*

Barriers owing to bureaucracy and confusion about the DS1500 report form. Many people found the claim forms long and complicated or were not sure which benefits were available in their circumstances. For example, one man, diagnosed too late for surgery, had been misinformed about the DS1500 report form, and it seems that no one had told him whether or not he qualified for benefits under special rules:

'I've been trying to get on a disability allowance for people under 65, but I was given the wrong information when I filled out the form. So I filled out the form, sent it away and I got it back saying, "no, you're not getting it". So I appealed, the appeal was rejected so I phoned them up and asked them, "why has it been rejected?" She said, "well, you didn't have a certain form". I said, "well who's got these forms?" I said, "I'll fill it out and send it in", she said "well it's not your job to fill it out, it's the Macmillan nurse or your consultant [']s job] to fill it out". The form is a DS1500 ... You get very little help off social security ... you've got to have a degree in higher English to be able to understand them because I don't know who makes these forms out but they are not user-friendly, to man or beast.' (LC07, aged 56 years, diagnosed in 2002, ex-offshore medic.)

While in hospital, a patient asked to see someone from Social Services to discuss financial benefits. He was referred to a Macmillan nurse, who gave him useful advice, but he still had to see a welfare rights officer, who helped him fill in the necessary forms, before he finally obtained benefits:

'But it did take a long time and it did seem to be a bureaucratic process to get it, but I got the welfare rights officer from the city council came to see me, and one or two pestering phone calls and some close family members who fought my corner. But it was a tussle; it was a tussle to get all the benefits acknowledged.' (LC10, aged 48 years, diagnosed 2002, ex-merchandise.)

A man, who was dying of mesothelioma, had to 'tackle' the benefits agencies for nearly 6 months. He emphasised that he did not want to be off work claiming benefits and spoke bitterly about his experience:

'And of course, all you want to do is to get back to work, but when you're diagnosed with cancer you can't go back to work and then you've got to tackle the Benefits Agency. And to be honest it takes months, it takes months, it's one long worry. You can sit on the phone for days and days on end, for months on end just to get what you're entitled to.' (LC18, aged 55 years, diagnosed 2002, died 2003, ex-welder.)

He went on to describe how his family had suffered because of the slow bureaucratic process, and he explained that it was hard to cope with financial problems when he was feeling so ill:

'But it took me nearly 6 months to get my benefits sorted out and in that time I had the television licence people round knocking on the door telling me my television licence was out of date, I got fined for that. The gas board was going to cut my gas off, the electric people was hammering on the door. We went from a quarter meter onto a payment card and that is very difficult when you're not well and you really don't feel well enough to cope with all that.' (LC18.)

Occasionally benefits are backdated. The man quoted below applied for a disability allowance and was turned down. He was encouraged to reapply by another patient and the same thing happened. His struggle was eventually rewarded when a tribunal unanimously awarded and backdated the money:

'So I applied for it [disability allowance] again and I was turned down. I then asked them to re-look at it, they did do and I was turned down again. So I finally took them to a tribunal. When I got to the tribunal I was awarded it by every member of the tribunal and it was backdated a whole year. So I was quite lucky, but there's an awful lot of people out there miss out on benefits because they don't apply for them at the right time.' (LC28, aged 58 years, diagnosed 2000, ex-fire-fighter.)

Better access to benefits

When looking for examples of less difficult experiences we found that some patients had received timely financial advice. Both doctors and nurses had played an important part in helping people to obtain benefits. One woman explained how a nurse had helped on the day she received the diagnosis, even though finances were 'the last thing' on her mind:

'And then I spent some time with a Macmillan nurse who actually got me disability living allowance. I mention that because there's a lot of people that get cancer that don't know that they're entitled to it and it's quite a help. I know finances are the last thing on your mind but it's enabled me not to worry too much about not working. And it's a benefit that you get whether you're working or not, it's, you know it's not taxable so whatever you get it's all for you.' (LC09, aged 55 years, diagnosed 1997, ex-accounts assistant.)

Another man was grateful for a specific grant he received from Macmillan:

'But the Macmillan organisation can open doors that you don't realise are there [discusses benefits] ... and they will give you a one-off small grant that can help you to catch up or help you in your quality of life. For example, one of the consequences of cancer can be an enormous weight change and your wardrobe is inappropriate so they will help you restock your wardrobe. I got a grant of about £600 from them as a one off, very early on, and it was very helpful.' (LC10.)

Others received invaluable help from their GPs, as this patient explained:

I: 'Can you say a bit more about benefits?'

LC05, aged 55 years, diagnosed 1997, ex-paint sprayer: *'Oh right, actually the doctor got a form and, saying that, at my age I couldn't go back to work and he called us down, filled in the forms and all that and the claim went into the benefit offices and they sorted everything out. I got an allowance for not working and I also get*

a "mobility" [allowance], which you can either keep the money or get a car. And that's really what it's all about is getting out and about and just get back to normal life as much as you can.'

These experiences highlight how much easier it is for patients if the doctor or nurse takes the initiative about benefits, rather than waiting to be asked for help, or assuming that someone else is dealing with it.

Some patients attended support groups where they received help and financial advice:

'They tell you all what's best to claim, how is the best way to claim unemployment benefit or incapacity benefit. We have a different person come now each month, it's one day a month for an hour and a half, we have a lady come from the pensions bureau that tells you about pensions or one that tells you the best things to claim, what you can claim according to your age and your sex and all that sort of thing.' (LC41, aged 57 years, diagnosed 2002, ex-furniture retail manager.)

One man, whose wife worked in the 'Benefits Agency', found it easy to obtain his benefits because his wife obtained the relevant forms, and another man — uniquely — asserted that the situation had improved. However, he was a lecturer in social work, which might explain this unusual or 'deviant' case.²⁴

I: 'Did you find the forms difficult to fill in or was it easy?'

LC44, aged 54 years, diagnosed 2003, part-time university lecturer: *'No, they're very straightforward. I mean I think that's one of the things that's improved with social security forms is they, they might be very lengthy sometimes but generally they, they're very clear and easy to follow ... I know some people find them confusing um, but then there's usually somebody who will give you some help and advice to complete them.'*

Discussion

Summary of main findings

Although some patients benefited from financial advice offered by doctors, nurses and support groups, others (including those who had been in and out of hospital several times) had missed out on the benefits to which they were entitled. Some were not aware of relevant benefits, others applied too late, and others found claim forms difficult to complete. There is particular stigma associated with lung cancer,²⁵ and it appears that fear of stigma affected some people's attitudes to seeking help. Our findings probably also apply to other patients with terminal illnesses — who are likely to have similar financial needs and experience similar difficulties when trying to get financial benefits.

The strengths and limitations of this study

It is not possible to use this study (which is based on a maximum variation, not random, sample) to estimate the relative frequencies with which people miss out on certain

benefits. However, we interviewed people from many different parts of the UK, and their accounts illustrate the distress and frustration experienced by people from a wide range of social backgrounds. We only managed to interview one person from a minority ethnic group. People who have a poor command of English, or who come from other cultures, may have additional difficulties when trying to obtain financial benefits. More research is needed to explore the financial needs of people with terminal illness who come from various minority ethnic groups.

Implications for clinical practice

A number of lessons can be learnt from our findings. Later problems might be averted if a member of the hospital healthcare team were to help the patient to initiate a claim. Patients need to know that disability living allowance or attendance allowance is not means tested, and that claims should be made quickly so that patients do not miss out on those benefits that are not backdated. Many patients with lung cancer (those identified as terminally ill) will qualify for benefits under special rules, and thus can obtain benefits especially quickly. However, patients may not get timely advice while they are in hospital and so we believe that finance is an important issue for GPs to raise with patients when they return home. Patients may be reluctant to admit to financial difficulties, or to become a 'claimant'. We suggest, therefore, that health professionals should start the discussion and encourage the patient to regard an early claim as both an entitlement and responsible financial behaviour.

Some patients are not aware that they are terminally ill, and so the subject of benefits and special rules has to be raised in a tactful manner. Doctors tend to avoid talking about death,²⁶ but some patients will benefit financially (and in other ways) from an honest and open approach.²⁷ When caring for patients, doctors tend to overestimate survival time,^{27,28} and it may be hard to predict whether or not those with lung cancer are going to die within 6 months, but doctors need to realise that completion of the DS1500 form can hugely affect the type and level of benefit that patients receive.

GPs may not feel that it is part of their role to provide sociolegal help, especially in view of the increasing risk of litigation for inaccurate advice. However, some general practices have weekly visits from benefits advisers, who counsel patients about benefits.²⁹ Advisers may be managed by the Citizens' Advice Bureau but funded by the primary care trust. There are also useful websites that provide information about benefits; for example, www.nacab.org.uk, run by the Citizens' Advice Bureau.

People with lung cancer, or other terminal illnesses, may be reluctant or lack the energy or facility with forms, to pursue a claim for the benefits they need to end their lives without unnecessary financial hardship. We hope that the difficulties that we have highlighted here will encourage primary care workers to recognise their important role in ensuring that patients receive the benefits they deserve without an exhausting and humiliating struggle.

References

1. Saunders Y, Ross J, Riley J. Planning for a good death: responding to unexpected events. *BMJ* 2003; **327**: 204-207.

2. Clark J. Patient centred death. *BMJ* 2003; **327**: 174-175.
3. Kuter J, Steiner J, Corbett K, *et al*. Information needs in terminal illness. *Soc Sci Med* 1999; **48**: 1341-1352.
4. Sheldon F. Social impact of advanced metastatic cancer. In: Lloyd-Williams M (ed). *Psychosocial issues in palliative care*. Oxford: Oxford University Press: 35-48.
5. Higginson I. Clinical implications. In: Addington-Hall J, Higginson I (eds). *Palliative care for non-cancer patients*. Oxford: Oxford University Press, 2001: 261-277.
6. McIntyre R. Support for family and carers. In: Lugton J, Kindlen M (eds). *Palliative care: the nursing role*. Edinburgh: Churchill Livingstone, 1999: 193-215.
7. Rozmovits L, Ziebland S. What do patients with prostate or breast cancer want from an Internet site? A qualitative study of information needs. *Patient Educ Couns* 2004; **53**: 57-64.
8. Hoskins R, Carter D. Welfare benefits' screening and referral: a new direction for community nurses? *Health Soc Care Community* 2000; **8**: 390-397.
9. Toeg D, Mercer L, Iliffe S, Lenihan P. Proactive, targeted benefits advice for older people in general practice: a feasibility study. *Health Soc Care Community* 2003; **11**: 124-128.
10. Daly M, Noble M. The reach of disability benefits: an examination of the disability living allowance. *Journal of Social Welfare and Family Law* 1996; **18**: 37-51.
11. Ettinger F. Ask and you might receive. *Nurs Stand* 2001; **15**: 20.
12. The A-M. *Palliative care and communication: experiences in the clinic*. Buckingham: Open University Press, 2002.
13. NHS Centre for Reviews and Dissemination, University of York. Management of lung cancer. *Eff Health Care* 1998; **4**: 1-12.
14. Hill K, Amir Z, Muers M, *et al*. Do newly diagnosed lung cancer patients feel their concerns are being met? *Eur J Cancer Care* 2003; **12**: 35-45.
15. Murray S, Kendall M, Boyd K, *et al*. *Improving care for people with advanced illness. A community-based prospective study of patients with lung-cancer or end-stage cardiac failure and their families from diagnosis to bereavement*. Edinburgh: Department of Community Health Sciences, Department of General Practice, University of Edinburgh, 2001.
16. Coyne I. Sampling in qualitative research. Purposeful and theoretical sampling; merging or clear boundaries? *J Adv Nurs* 1997; **26**: 623-630.
17. Pope C, Ziebland S, Mays N. Analysing qualitative data. *BMJ* 2000; **320**: 114-116.
18. Richards L, Richards T. The transformation of qualitative method: Computational paradigms and research processes. In: Fielding N, Lee R (eds). *Using computers in qualitative research*. London: Sage, 1993: 38-53.
19. Tesch R. *Qualitative research: analysis types and software tools*. New York: Falmer Press, 1991.
20. Malterud K. Qualitative research: standards, challenges, and guidelines. *Lancet* 2001; **358**: 483-488.
21. Morse JM. 'Perfectly healthy but dead': the myth of inter-rater reliability. *Qual Health Res* 1997; **7**: 445-447.
22. Muzzin L, Anderson N, Figueredo A, Gudelis S. The experience of cancer. *Soc Sci Med* 1994; **38**: 1201-1208.
23. Radcliffe C. *Injury or illness: welfare benefits in 2002*. Sheffield: Irwin Mitchell, 2002.
24. Silverman D. *Interpreting qualitative data*. London: Sage, 1993: 44.
25. Chapple A, Ziebland S, McPherson A. Stigma, shame, and blame experienced by patients with lung cancer: qualitative study. *BMJ* 2004; **328**: 1470.
26. Workman S. Doctors need to know when and how to say die [Letter]. *BMJ* 2003; **327**: 221.
27. Lamont E, Christakis N. Complexities in prognostication in advanced cancer. *JAMA* 2003; **290**: 98-104.
28. Glare P, Virik K, Jones M, *et al*. A systematic review of physicians' survival predictions in terminally ill cancer patients. *BMJ* 2003; **327**: 195-201.
29. Paris J, Player D. Citizens' advice in general practice. *BMJ* 1993; **306**: 1518-1520.

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