

Title: Palliative care patients' and families' experiences of participating in a 'Patient-Centred Family Meeting': A qualitative study

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ABSTRACT

Context

Family meetings are used in palliative care to facilitate discussion between palliative patients, their families and the clinical team. However, few studies have undertaken qualitative assessment of the impact of family meetings on patients and their families.

Objectives

The study objective was to assess palliative inpatients' and their families' experiences of participation in a Patient-Centered Family Meeting ('Meeting') conducted as part of a clinical trial.

Methods

A qualitative study used semi-structured interviews to evaluate the patients' and families' experiences of the Meeting. Grounded theory provided theoretical and procedural direction. Thematic content analysis utilized the constant comparative method.

The setting was a specialist palliative care inpatient unit. Nine palliative care inpatients and a corresponding family member (n=18) were interviewed.

Results

Three overarching themes emerged. A patient-focused family meeting: (i) provides a safe space for palliative inpatients to speak candidly about their end-of-life concerns in the presence of significant others; (ii) ensures that the family member has a voice, is heard and has their needs addressed; and (iii) helps to ensure that everyone is "on the same page".

Conclusion

The Meeting model provided patients and their families with the forum to discuss psychosocial and relationship issues, and concerns related to preparation at the end-of-life. For some patients, the multi-disciplinary team provided the support necessary to initiate the difficult conversations they wished to have with families prior to their death. It is imperative to undertake further research to identify which patients and families this type of Meeting would provide the most benefit.

KEY WORDS

Palliative care, family conference, family meeting, patient-centered, qualitative study

RUNNING TITLE

Family meetings impact on palliative patients

KEY MESSAGE

This article describes the qualitative experiences of palliative patients and their families participating in a planned Patient-Centered Family Meeting ('Meeting'). The results indicate this Meeting model provides a potentially effective means of supporting palliative patients and their families to articulate, confront and address end-of-life issues with the multidisciplinary team.

INTRODUCTION

Optimal communication in palliative care is essential so that the concerns and needs of patients and families are identified and addressed (1-3) . Meetings involving the palliative patient, their family and the specialist multidisciplinary team (MDT) have been variously referred to as ‘family meetings’ or ‘family conferences’ (4-6). These terms are used interchangeably in both the clinical and research setting. Regardless of the terminology, these meetings in the specialist palliative care setting aim to improve patient-family-team communication (4, 7-9). They are also designed to facilitate discussion between palliative patients, their families and the MDT about care options and decisions, end-of-life issues and individual needs and concerns (10-11). In this context ‘family’ may refer to whomever the patient nominates as ‘family’, or a family equivalent, such as a close friend and/or carer (10).

In clinical practice, meetings between clinicians and patients have occurred traditionally on an ‘ad hoc’ basis, with little reference to relevant guidelines. Despite some evidence to support the appropriateness of family meetings in palliative care (6, 12) only a limited number of studies have been undertaken to examine the impact of family meetings on families in the inpatient palliative care setting (5, 13-17). Of these studies, four used validated outcome measures to evaluate family outcomes: (i) the Family Inventory of Needs assessment (5, 13, 15) (ii) the CARE measure (15) and (iii) the Distress Thermometer (16). There have been no studies that demonstrate benefits for patients attending family meetings using validated outcome measures (12), and a paucity of studies have undertaken qualitative assessment of the family meeting effect on patients (17, 18).

Patient-centered family meetings

A pilot project conducted in a specialist inpatient palliative care unit provided qualitative findings that patient-centered family meetings enhanced the patient's active participation. Patients and families focused on end-of-life issues and articulated their concerns and demonstrated their care for each other (17).

Family meetings involve considerable use of clinical resources and time. However, there is minimal evidence to demonstrate their utility. To enhance the body of knowledge related to family meetings in palliative care, the Valuing Opinions, Individual Communication and Experience (VOICE) Study was developed. This study (19) was designed to assess the acceptability and feasibility of providing *planned* Patient-Centered Family Meetings ('Meetings') in specialist inpatient palliative care. This Meeting model contrasts with the traditional 'ad-hoc' approach to family meetings in the palliative care context. Textbox 1 summarizes the key 'Meeting' components at the intervention site.

TEXTBOX 1

Patient-Centered Family Meeting at the intervention site

1. The Meeting was offered to eligible patients during the first 10 days of an inpatient admission at a specialist palliative care service in metropolitan Sydney, New South Wales (NSW), Australia.
2. The patient identified the family member(s) they wished to attend the Meeting.
3. Prior to the Meeting; the patient formulated with the researcher on-site (PJC) an agenda based on three key questions: (i) How do you see your health problems at the moment?; (ii) What do you expect from this admission?; (iii) Do you have any concerns about what is happening to you for which you would like help?
4. The patient-set agenda was provided to MDT participants prior to the Meeting.
5. The palliative care consultant and social worker routinely attended and facilitated the Meeting. Other clinicians participated if their specific expertise was required based on the patient-set agenda.

The study also sought to understand the benefits and burden of participating in this new Meeting model from the perspectives of patients, families and clinicians. This paper reports on the experiences of patients and families, utilizing the COnsolidated criteria for REporting Qualitative (COREQ) research Guidelines (20). The clinician data are reported elsewhere.

METHODS

The VOICE study is registered with the Australian New Zealand Clinical Trials Registry (www.anzctr.org.au - ACTRN12616001083482).

Design

This component of the VOICE study used a seven-question semi-structured interview schedule (Textbox 2) at the intervention site. The questions were designed to assess and gain an understanding of the patients' and families' experience of the Meetings (Textbox 2).

TEXTBOX 2

Participant interview schedule

1. What was the family meeting like for you?
2. Was anything that was talked about upsetting or distressing for you?
3. Were there other things you would like to have talked about at the meeting?
4. Why do you think you didn't talk about them?
5. Were you able to talk about how you were feeling at the family meeting?
6. Were you able to talk about your relationship and interactions with your family member at the family meeting?
7. Do you think the family meeting was helpful or not helpful for the family members who attended? Please tell me why...

Setting

Prior to patient recruitment commencing, two research team members (PJC, CRS) provided clinicians with education and a Meeting Manual that outlined the significant elements of the Meeting intervention. The researcher (PJC) had not previously worked with the clinicians at the participating sites.

Recruitment/participants

Consented patients and family members who had participated in a Meeting were approached face-to-face for an individual interview (n=18). All patients agreed to an interview, except one patient who became too unwell. All family members approached completed an interview except one case when the patient became increasingly unwell post-discharge and died, and the family member declined an interview.

Research Team

The research team comprised: the Director of a Research Center (JLP) that focuses on aged and chronic disease and palliative care research; an experienced qualitative and palliative care researcher (EAL); and a senior palliative care specialist and researcher (CRS). The main researcher (PJC) was a PhD student who had completed qualitative and quantitative research methods at a tertiary level.

Data collection process

All interviews were conducted onsite by the researcher (PJC) between December 2017 and December 2018. Patients and family members were consulted about their availability, and their current physical and emotional ability to undertake an interview. An appropriate time was negotiated. Interviews were conducted in a quiet space to ensure the minimal disruption and accurate recording. Prompts were used to elicit further information, if suggested by the interviewee's response(s), being mindful

of the interviewee's physical and emotional vulnerability. Most interviews were digitally recorded and transcribed verbatim. However, two patients and one family member for whom English was not their first language declined an interview recording and requested that the researcher (PJC) record their answers manually. Another family member interview was also recorded manually. The researcher (PJC) listened to the original recordings to check all transcripts, and completed field notes. As the patient and family populations were vulnerable in terms of their physical, emotional and psychological status and facing end-of-life issues, transcripts were not returned for comment.

Data analysis

Procedural direction from grounded theory informed data analysis. Key elements of thematic analysis (21, 22) guided the development of themes using the coded datasets. Blinded coding of 22% of the intervention site transcripts was undertaken by three of the researchers (PJC, EAL, CRS) to classify initial codes. The researchers (PJC, EAL, CRS) discussed these codes and reached consensus. The main researcher (PJC) coded the other transcripts based on the initial codes. Constant comparative method (23) guided the development of themes derived from the data. These themes were discussed and agreed to by the three researchers (PJC, EAL, CRS). Data management did not include a coding tree or software. Data saturation was attained with conclusive categories identified for the coded data (24). Quotes to exemplify themes are de-identified.

RESULTS

Eighteen participants were interviewed: nine patients (three males and eight females) and nine family members (four females and five males). The mean patient age was

71 years (SD = 7.16) and the median family age group was 55-64 years. The mean recorded interview duration was 15.86 minutes (SD = 9.54).

Three overarching themes emerged. A patient-focused family meeting: (i) provides a safe space for the palliative inpatient to speak candidly about their end-of-life concerns in the presence of significant others; (ii) ensures that the family member has a voice, is heard and has their needs addressed; and (iii) helps to ensure that everyone is “on the same page”.

Patient cohort

(i) provides a safe space for the palliative inpatient to speak candidly about their end-of-life concerns in the presence of significant others

Patients reported that the Meeting provided an opportunity to clarify what was happening to them at this time:

... you know, we all had a chance to ask and anything that we sort of didn't quite understand, it was clarified. I thought the meeting was excellent.

(Patient 1)

They also recounted being able to ask questions and being provided with the answers or information that they were wanting:

I wanted to know the answer to my three questions and they were answered satisfactorily. (Patient 3)

The Meeting venue and number of attendees was significant for some patients:

Good to have in the (patient's) room; not too many people ... able to say and ask the questions you wanted to ask. (Patient 2)

Fewer attendees was also important for patients to feel comfortable to articulate their concerns and issues:

... I thought it was good, ... I had the doctor there and well you (Researcher - PJC) were sort of the recorder and 'X' [social worker]. I thought 'X' just struck the right tone actually... like (with) a crowd of people I can sort of "jam up" ... so I didn't even think twice about whether I should say that, shouldn't say that, or anything else. (Patient 6)

When several MDT members attended, there remained for the patient a sense of the team focusing on the patient and family member:

... Very good (the) way you were treated; good to have a friendly team ... attention to us ... there was privacy for them (the patient and her husband) ... at the meeting. (Patient 4)

As a result of speaking honestly about their concerns, patients experienced an enhanced sense of peace:

I would say I'm more at peace than I was ... I think just the whole process of having the questions asked and being heard and raising stuff. I honestly think it helps. (Patient 9)

Furthermore it seemed important for patients that the Meeting provided 'agency' to their family:

... I did believe I had some agency, more agency than before.....And I think my boys would say the same, that they had agency and that's really important for them as well in this current situation. (Patient 9)

The opportunity to talk with the clinicians about their individual issues provided patient benefits:

I always feel good after I talk to the doctors and you know clarify some of the things that you know I might have been thinking about over the last couple of

days ... I feel comforted after the meeting... I do feel like I've got the right team... (Patient 7)

However this patient and two others noted that a future meeting may be worthwhile to enable further opportunity for discussion:

... the family meeting was good because it consolidated a lot of things but ... I would say ... that you would probably need a follow-up family meeting ... because the priorities change ... (Patient 7)

One patient described the reassuring impact that the Meeting provided to raise specific end-of-life issues:

I tell you one thing that was really ... mind-settling ... knowing that (the patient's son) is not going to have to be racing around all over (name of city) trying to sort ... funerals, that really sort of ... detailed end-of-life sort of stuff. And that there is a morgue ... I mean that sounds a bit weird but that's how I felt. (Patient 6)

Patients also identified that the Meeting model provided a forum where open and honest communication could occur between them and their significant family member:

... And I didn't want to open up the subject, in case, you know, it upset him (son) and you know we're both afraid (of) treading on one another's toes I s'pose, so ... I thought it might have been rather harsh for him to hear it from me so because I was really facing facts about the whole illness and I thought well that might come across as a bit, you know, tough. (Patient 6)

This patient was able to raise end-of-life concerns at the Meeting with the son and as a result:

... he had to process it in a fairly formal way and I think that was probably helpful for him and me ... it started the ball rolling. And now that topic is open for, you know, discussion. (Patient 6)

The Meeting was a forum for open discussion about end-of-life issues for the family which were at times confronting:

It's like there's this really interesting interplay because you have a meeting with a doctor and they know, they can answer any question that you're brave enough to ask. I think a discussion around prognosis is important as much as you don't want to; I didn't find the prognosis shocking, ... I found, it was confronting. It was just the fact that it was open and being talked about and being confirmed by someone who knows what they're talking about, rather than just my guesstimating. (Son of patient 9)

There was a level of honesty in these exchanges, which was reflective of close personal relationships between both the patient and family member:

... you know I'm really close to mum. And I'm getting married soon and you can tell from how determined she is that she's not really ready to keel over any time soon either, so it's hard ... (Son of patient 9)

For this family the acknowledgement of prognosis and the impending wedding of the patient's son enabled the MDT members to forward plan the patient's care to facilitate the patient's attendance at the wedding:

... super useful ... having ... all the relative specialists ... that was really useful and yes 'X' (has) been amazing, the social worker ... just formulating a plan, yeah on how that'll work. (Son of patient 9)

The presence of the MDT members listening to the patient and indicating that they would continue to care for the patient during the end-of-life phase, was also comforting for the family member who attended and witnessed this discussion:

They were the same questions coming up time and time again... except this time, 'X' [Palliative Care Physician] just sat there and just said, "Well this is what it is, this is where we can help, you know where we can guide you or whatever." So yes it was ... probably a more controlled environment too, because people weren't rushing, to get to the next person, ... they had time just to sit and listen to her ... it was positive that it was all about what she was about ... And all about addressing her fears and problems.... You know that they're not going to abandon her, and just pass her on to somebody else.

(Cousin of patient 7)

Family cohort

(ii) ensures the family member has a voice, is heard and has their needs addressed

Family members indicated that the Meeting provided them with a voice to ask questions and express their concerns:

If I have question I want to ask I will raise it during the meeting ... I feel free, so free to have my say... I think it's good to have our say and to participate in the family meeting so that the doctor can explain to us clearly about the outcome, what is their plan for the patient. (Wife of patient 2)

Family members also acknowledged that being able to contribute to the Meeting resulted in a balance between patient and family discussion:

I mean I was almost thinking, "Alright good, that's enough air time for me guys" just focus on the patient now. Yeah it was well balanced I think. But yeah I certainly got a voice in that meeting which was good. (Son of patient 6)

Furthermore the Meeting provided an opportunity for this family member to be heard by the patient:

I just don't get listened to, most of the time...

Interviewer: Did you feel like you were listened to the other day?

By the staff absolutely, yeah

Interviewer: You're not sure how much your mum heard what you were saying?

... I think in that situation (the Meeting) it stood a better chance of being heard than any, than anything else (Son of patient 6)

Patients acknowledged that the Meeting met the family's need to express their concerns:

It was good for him to talk about all the things that he's been thinking about... all those pressures and stresses and strains that he's been under ... It just got it 'out in the open' for him. (Patient 5)

Patients were comforted and grateful that family members were able to raise their issues and receive worthwhile responses from the MDT team members present:

... the family meeting was just brilliant because for [daughter's name], she couldn't get answers but also for me, the anxiety about, you know, what if I get home and I can't cope? And each time with something like that, it just puts more stress on 'X' [daughter], so both [daughter], and myself, we thought

the meeting was just fabulous and 'X' [social worker] was just wonderful.

(Patient 1)

Families were also appreciative that the Meeting discussion with the patient and the team, allayed their concerns and provided them a sense of equilibrium at a challenging time:

... it's much easier on her and on us too because we know where to go to or who to go to if we've got a problem. It was helpful because in answering (patient's) question we got off that 'turntable' that we've been on. I think just having herself heard and answered in a way that she could cope with ... was very calming. (Cousin of patient 7)

Attendance by MDT team members was considered essential for a positive experience for family members:

I thought it was interesting, just to have all the heads together. I think I learnt more from 'X' [physiotherapist] in that meeting ... the physio. side of the world, about what was necessary, in order to go forward and (the patient) get ... improved. (Husband of patient 5)

The MDT members' attendance at the Meeting also provided the family with a clear understanding of the different disciplines and their role in the care of the patient. In the palliative care setting this was reassuring and informative for the family member:

And (it) was the opportunity to see all of the professionals in one room at the time. And I think we came away with a clear understanding of what everybody does, who has the authority over particular areas and that seems clear-cut, and how decisions are made. (Husband of patient 10)

While the majority of patients expressed that the Meeting provided them with a voice, a minority of family members indicated that the focus of the Meeting wasn't necessarily on them:

I just thought it was for (the patient)... she doesn't need to know how we are feeling. She's got enough to concentrate on. (Cousin of patient 7)

One family member did not engage with the questions as he considered the patient (his wife) should answer and that the Meeting focus should be on her:

... if she wants to answer then she should be the one that answers so I tend to shut up and ... not look at the person asking the question because invariably that person turns to me expecting a response. (Husband of patient 10)

(iii) helps to ensure that everyone is “on the same page”

Patients reported that the Meeting contributed to the family's understanding of their current situation:

... she (patient's cousin) found it was helpful because it just showed that we were all on - we were all able to be “on the same page” when it came to, you know, what I wanted. (Patient 7)

The Meeting also provided an opportunity for family members to find out information, which they had not previously been given but which they needed:

Just because I didn't know what was happening with her, like where do we go from here, so 'X' [social worker] fixed all that up, so yes, he was really good. (Daughter of patient 1)

Family members recounted that as a result of the Meeting there was a clearly articulated care plan:

I mean, it was in the middle of a meeting we actually got a structure that says, 'Your next goal is to get up to the top floor' (Rehabilitation Ward), and then you've got ... a structured three-week program. And then you do a big assessment and if you haven't improved, then you've got to worry about where you're going to go from here, and that's where, I needed to know that. ... because when you walk in the door here ... no one actually sits down and says, now, "This is why you're here and this is where we're going." And so if the meeting was the only vehicle of getting that out and that was the purpose of it, that's fantastic. (Husband of patient 5)

The families' need for information about the future plan and consolidating this plan was often raised as an important outcome of the Meeting:

...it was helpful for my wife – my wife knows the future direction – I can go to a "good" nursing home - she wants me to be comfortable.

... it was helpful for my daughter – my daughter thought (the Meeting) was very good; she listened to everything (via mobile phone) and had more information. (Patient 2)

The Meeting also provided the forum for families to discuss difficult issues so they could begin to move towards being "on the same page":

Well I think he would not ask questions that I would - you know, because frightened, he would be a bit afraid that he'd be treading on my toes, especially the really detailed end of life stuff ... (Patient 6)

Interviewer: Yes, so the Meeting allowed you to ask those questions?

Yes and in front of him was I think very valuable because we're both now getting towards the same page on that, on those details ... (Patient 6)

DISCUSSION

At the outset, it should be noted that the current study, unlike previously-published studies, formalizes the concept of “family meetings” in palliative care. In contrast to the traditional “ad hoc” meeting between clinical staff, family members and patients, the VOICE Study focuses on outcomes of a patient-centered approach to care in family meetings. Conventional “ad-hoc” family meetings have often taken place in a ‘reactive’ fashion such as in response to some clinical incident (13), rather than being planned and structured as in our study. Furthermore, it may be argued that conventional family meetings have been more “service-focused” rather than being “patient-focused”. Therefore, our study provides a unique insight into the dynamic interactions between patients, families and clinicians in a patient-centered approach to family meetings.

The findings of this study support the findings of the original pilot project in which end-of-life issues were frequently (69%) raised in patient-centered meetings (17). Patients’ concerns about their families, noted in the pilot project were also evident in this study’s findings. It is interesting to note that patients reported they ‘felt better’ in various ways as a result of the patient-centered meeting in the pilot project (17). This too was evident in the responses of the patients in this study, one of whom referred to the “mind-settling” impact of being able to discuss at the Meeting specific end-of-life issues related to the management of her body. Another patient stated they felt an enhanced sense of peace post-Meeting. The process of the patient setting the agenda for the Meeting is in itself designed to give the patient ‘agency’ prior to the Meeting. It is likely that this sense of agency engendered courage in the patient to speak frankly and openly about their end-of-life concerns, knowing that they had prepared their questions and had nominated which family member they wished to attend, witness, and participate in the Meeting.

Family members also identified that they had a voice and their needs were addressed in the Meeting. This outcome, reflect the results of a study which examined the factors important to the quality of the family's experience when a family member died in a hospital setting (25). The key domains which contributed to the quality of the family's experience included: (i) the relationship with the healthcare provider such as where the family member could obtain answers to their concerns, and (ii) what to expect about the course of the patient's disease. Another essential factor was decision-making, which included the need to understand what was happening to the patient and the aims of the care provision. Families interviewed in the current study reported similar issues to those previously reported (25), such as knowing who to go to with a problem and having a clear plan and explanation of potential outcomes for their family member.

The findings from the family members in the current study also replicate the findings of an Australian study evaluating the impact of family meetings on family members in an inpatient palliative care unit (15). Families in this study reported that as result of the family meeting: they felt heard, they obtained a better knowledge and relationship with the MDT members, and they were able to ask about prognosis and discuss this at the family meeting. Families in the current study report similar experiences.

For a minority of family members, however, the Meeting was seen pre-eminently as focusing on patient's issues and needs, rather than their own concerns. It would seem prudent to encourage family members to raise their concerns during the Meeting (where possible), so that these concerns are also identified and addressed openly.

Patients in this study reported that they were reassured when their family members were able to raise and discuss their issues or concerns during the Meeting. Clearly,

for the majority of family members, there was a strong sense that they too had a voice, and were an active participant in the Meeting discussion.

The experience of everyone being “on the same page” is illustrative of the pilot project (17) and published observations (2010) about family meetings in the palliative care context (26). Fineberg (2010) asserts that the power of the family meeting as a method of communication is due to the bringing together of the patient, the family (ideally nominated by the patient) and MDT members to discuss the patient’s issues and concerns, and to hear the same information contemporaneously (26). The result is that participants have the experience, as described in the current study, as being “on the same page”. The participants witness simultaneously during the Meeting the verbal and non-verbal exchanges, which are so important to all at this vulnerable time. The patient-set agenda guides the attendance and contributions that the MDT members provide. The participation of the relevant MDT members at the same time and in the same space, leads to a shared understanding of the current situation, and the issues and concerns for the patient and family. It appears that this shared knowledge and involvement is vital to adequately preparing for the end-of-life.

Strengths and limitations

To our knowledge, this is the first qualitative research study undertaken in an inpatient specialist palliative care context, to evaluate patients’ experiences of family meetings, using a semi-structured interview schedule.

A limitation was the small number of patients and family members interviewed. This was a result of the number of patients who consented to the VOICE Study. As these patients and families self-selected, the findings may not be necessarily applicable to the overall palliative care population.

Implications for research and practice

Patient-Centered Family Meetings are a potentially effective means of supporting palliative patients and their families to articulate, confront and address end-of-life issues in the presence of the MDT. The strength of family meetings in commencing and promoting a shared conversation and understanding of the patient's disease, prognosis and end-of-life concerns may also lead to ongoing productive discussion between the patients, families and the MDT as the end-of-life approaches. Additional research should be undertaken to delineate those patients and families for whom such Meetings would provide both short-term positive outcomes, and also longer-term family benefits post-bereavement. Furthermore, the potential risks and burdens of meetings should be considered.

Conclusion

This study has emphasized that a structured, pre-emptive Meeting model provides patients and their families with an effective forum to safely raise their end-of-life concerns. The patient-set agenda empowered the patients to identify and discuss psychosocial, emotional and relationship issues and concerns related to end-of-life preparation. For some patients these Meetings were critical for opening-up with their family the difficult conversations they wished to have prior to their death, in an attempt to resolve outstanding concerns. The presence of the relevant MDT members provided a scaffold for the patient and sometimes the family member to initiate or undertake and/or complete these important discussions. It is imperative to identify the patients and families who would provide the most benefit from this type of Meeting and any (potential) disadvantages of participating in these Meetings.

DISCLOSURES

Authorship

PJC contributed to data collection, data analysis, manuscript drafting and revisions. EAL contributed to study conceptualization, data analysis, manuscript review and revision. CRS contributed to study conceptualization, data analysis and manuscript review. JLP contributed substantially to the manuscript concept and planning, and review and revision of the manuscript. All authors approved the version to be published.

Conflict of interest Statement

The Authors declare that there is no conflict of interest.

Research Ethics and patient and family consent

St Vincent's Hospital Human Research and Ethics Committee approved the study (Reference Number 15/SVH/33 - SVH File Number:15/021) on 20 April 2015. All patients and families provided written informed consent for the VOICE Study including digital-taping and transcription of their interviews.

Data management and sharing

Raw data is included in the manuscript in the form of excerpts from the recorded interviews. All data were de-identified. The patient and family names, identification numbers, digital audio recordings and transcripts were saved on a password - protected computer at the sub-acute facility. The corresponding author may be contacted for further information.

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