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Home symptom management training programme: carer evaluation

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Received 17 February 2022

Accepted 16 May 2022

Published Online First

3 June 2022

ABSTRACT

Objectives Most people say if they had a terminal illness, they would prefer to be cared for at home and, if possible, to die there. Often this is not possible without a carer to assist with on-going practical care and symptom management. If breakthrough symptoms are not treated in a timely manner, symptoms can escalate quickly causing increased suffering resulting in unwanted hospital transfers. Many carers report feeling motivated but uneducated for the task of medicine management, especially if it involves preparation and/or administration of subcutaneous medicines. This study assesses the impact of an education and resource package, *caring@home*, on carers' confidence, knowledge, and skills in managing palliative symptoms at home using subcutaneous medicines.

Methods Nurses trained volunteer carers on the use of the package. Carers were invited to complete a 10 min written evaluation survey and to consider consenting to a 30 min semistructured phone interview.

Results Fifty carers returned surveys and 12 were interviewed. Most carers agreed or strongly agreed that the package provided them with the necessary knowledge, skills and confidence to safely and confidently manage breakthrough symptoms using subcutaneous medicines, further, they would recommend the package to others. Interview analysis revealed three main themes: (1) hesitation and motivation to adopt expanded carer role; (2) the importance of a layered approach to support; and (3) avoiding perceived unnecessary contact with nurses.

Conclusion The programme can be used by clinical services to empower carers to help enable a person to be cared for, and to die at home.

INTRODUCTION

Collaboration between health professionals and carers is essential to ensure best-practice palliative and end-of-life care.¹ Carers report feeling unprepared for caring and have unmet information

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Carers are motivated but initially hesitant to take on expanded caring role involving medicine management for fear of making mistakes.

WHAT THIS STUDY ADDS

⇒ Adequate support and the desire to keep the palliative patient at home offset these concerns.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ The success of the programme was attributed to its layered approach to support: (1) face-to-face training; (2) resources to refer to at any time and; (3) 24-hour telephone support.

and support needs, particularly relating to medicine and symptom management.^{2–6} Caring for a person at the end of life is physically and emotionally demanding,⁷ however, studies have shown that carers are motivated to take on care responsibilities, desire active involvement in care,^{8–11} and feel empowered in their ability to help alleviate suffering and facilitate the palliative patient's wishes to die at home.^{8–11}

An important part of providing care at home and to facilitate home death is to manage breakthrough symptoms—the primary reason is home-based palliative patients are admitted to hospital.¹² Despite optimal background medicines, breakthrough symptoms can emerge at any time and require rapid access to medicines to alleviate suffering. In Australia, access to face-to-face 24-hour professional support to manage breakthrough symptoms is uncommon. A previous local study has shown that carers are able to manage breakthrough symptoms using subcutaneous medicines successfully if adequate professional support, information, and resources are available.¹³

The *caring@home* initiative was a national Australian project aiming to



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To cite: Parker D, Reymond L, Cooper K, et al. *BMJ Supportive & Palliative Care* 2023;**13**:e1390–e1397.

increase palliative care capacity of community services by providing resources to support healthcare professionals to teach carers to safely administer subcutaneous medicines to manage breakthrough symptoms. Nurses who completed *caring@home* online education modules trained carers using the *caring@home* resources. The *caring@home* resources were provided to carers in a package at the time of training to ensure they had multimodal information that could be referred back to at any time. The package for carers included: practice demonstration kit and sharps container; practical handbook with explanations; illustrated step-by-step guides; colour-coded syringe labels; colour-coded fridge chart; medicine diary for recording medicines; short training videos; and an information brochure for carers.

This article reports results of the evaluation of the *caring@home* programme from the perspective of carers who provided end-of-life symptom management at home using subcutaneous medicines.

METHODS

Study design

This study employed mixed-methods to evaluate *caring@home* through surveys and semi-structured interviews.

Recruitment and data collection

Registered nurses from services across Australia identified carers eligible for training. Paid carers were excluded. Carers trained by registered nurses were invited to evaluate the *caring@home* training and package. The package included all carer training resources, an evaluation survey, participant information sheet and reply-paid envelope. The 10-min survey assessed knowledge and confidence in providing subcutaneous medicines and satisfaction with the *caring@home* package using Likert scale items. Carers willing to participate in a 30-min phone interview provided contact details on the final page of the survey (detached on receipt of survey). These carers were contacted and invited to participate in a telephone semistructured interview to discuss how the *caring@home* package and training impacted their experience of managing breakthrough symptoms using subcutaneous medicines. Full information sheet and consent form was provided via email. Consenting participants were asked to consent over the phone at the start of the interview.

Interviews ranged from 17 to 40 min (average duration 30 min), and were conducted by an experienced researcher employed for the project who had no prior relationship with study participants. Interviews began with broad open-ended questions about adopting medication responsibilities, and became more specific to the training and resources received (figure 1). Carers were prompted with open-ended probes and asked to clarify interpretations as interviews progressed.

Interviews were audiotaped, deidentified and transcribed verbatim by a professional transcription service. This study was conducted within the principles of the Declaration of Helsinki.¹⁴

Data analysis

Quantitative survey data were analysed using IBM SPSS V.26 (IBM Corporation, Somers, New York, USA). Descriptive statistics were used to analyse quantitative survey feedback. Open-ended responses (two items) were coded and grouped into categories to ascertain the most useful part of training, and further feedback about the experience.

Qualitative content analysis¹⁵ was undertaken to determine latent themes within the data. Initial codes were generated separately for each interview and grouped into categories by the researcher who conducted the interviews. This researcher has a background in symptom management in chronic illness and experience conducting interviews with consumers. Categories were then synthesised into larger themes in collaboration with coauthors who, with their background and expertise in palliative and end-of-life care, provided further insight and helped contextualise findings. Themes and related subthemes were discussed and disagreements were resolved by consensus to achieve analytical triangulation.

Results

Fifty carers returned feedback surveys, of which 30 expressed interest in participating in interview. One was not eligible for interview (did not administer subcutaneous medicines), 13 were lost to follow-up and 1 declined. Three carers who expressed interest were thanked for their time but notified that interviews had been ceased (saturation had been reached prior to these carers expressing their interest). Twelve carers returned a signed consent form and participated in a telephone interview.

Survey findings

Since receiving the training and *caring@home* package, the majority of carers (74%) had administered subcutaneous medicines more than five times, 12% had administered 2–5 times, 2% once, and 12% had not administered subcutaneous medicines.

Satisfaction with resources and training

As seen in table 1, the majority of carers were satisfied with the content of the resources and with the training provided.

Using the *caring@home* package to give subcutaneous medicines at home

Carers who had administered medicines at least once provided feedback on how the training impacted their experience of giving subcutaneous medicines at home when needed (table 2).

Qualitative & mixed methods

1. Prior to the training were there any particular concerns you had about giving subcutaneous medicines?
Prompts
Can you tell me about your experiences of helping to manage breakthrough symptoms using subcutaneous medicines for a person at home?
2. You would have received the training some months ago...can you tell me about how the training delivered by the nurse impacted your experience of giving subcutaneous medicines for a person at home?
Prompts
In what way did the training impact your understanding?
In what way did the training impact your confidence?
In what way did the training impact your skills?
3. Was there any particular aspect of the training that positively impacted your experience of giving subcutaneous medicines?
Prompts
Which parts were the most useful?
In what way were these useful?
Which parts were the least useful?
In what way were these not useful?
4. Can you tell me about how the *caring@home* package impacted your experience of giving subcutaneous medicines for a person at home?
Prompts
In what way did the resources impact your understanding?
In what way did the resources impact your confidence?
In what way did the resources impact your skills?
5. Was there any particular aspect of the *caring@home* package that positively impacted your experience of giving subcutaneous medicines?
Prompts
Which parts were the most useful?
In what way were these useful?
Which parts were the least useful?
In what way were these not useful?
6. Did you pre-prepare any syringes? If yes, please tell me about that experience.
7. Is there anything you would have liked more information about, or anything you would have wanted done differently?

Figure 1 Interview guide.

The majority of carers agreed that the training gave them skills such as being able to safely prepare subcutaneous medicines and help manage breakthrough symptoms. Carers strongly agreed that the training increased confidence to give subcutaneous medicines safely, manage the cannula safely and manage breakthrough symptoms. Two carers disagreed.

Interview findings

From the 12 semistructured interviews, three main themes emerged: (1) hesitation and motivation to adopt expanded carer role; (2) the importance of a layered approach to support; and (3) avoiding perceived unnecessary contact with nurses.

Table 1 Carer satisfaction with training and resources (n=50)

	0 Strongly disagree	1	2	3	4	5	6 strongly agree
I think the content of the <i>caring@home</i> package is easy to understand					1 (2%)	11 (22%)	38 (78%)
Overall, I was satisfied with the information in the <i>caring@home</i> package				2 (4%)		7 (14%)	40 (82%)
The nurse pitched the training at my level	1 (2%)			1 (2%)		6 (12%)	41 (84%)
The training delivered by the nurse was very easy to understand	1 (2%)			1 (2%)	1 (2%)	6 (12%)	40 (82%)
The training made me feel more comfortable to be able to give subcutaneous medicines	1 (2%)				1 (2%)	6 (12%)	41 (84%)

Table 2 Perceived impact of training and resources on carers' experience of giving subcutaneous medicines at home (n=44)

	0 Strongly disagree	1	2	3	4	5	6 strongly agree
The training was relevant to my needs when giving subcutaneous medicine		1 (2%)			2 (5%)	6 (14%)	35 (80%)
The <i>caring@home</i> package helped to reduce the stress I felt in relation to giving subcutaneous medicines	1 (2%)				4 (9%)	7 (16%)	31 (72%)
The training gave me the skills I needed to give subcutaneous medicines		1 (2%)	2 (2%)			7 (16%)	35 (80%)
I feel the training enabled me to safely prepare and give subcutaneous medicines			1 (3%)	1 (3%)	1 (3%)	5 (13%)	32 (80%)
I feel the training helped me to manage breakthrough symptoms as soon as it was required			1 (2%)		3 (7%)	6 (14%)	34 (77%)
Overall I am satisfied that I am able to give subcutaneous medicines to help manage breakthrough symptoms					1 (2%)	7 (16%)	36 (82%)
I feel that the training increased my confidence to give subcutaneous medicines safely			2 (5%)		1 (2%)	7 (16%)	34 (77%)
I feel that the training increased my confidence to manage the subcutaneous cannula safely			2 (5%)	1 (2%)		9 (21%)	31 (72%)
I feel that the training increased my confidence to help manage breakthrough symptoms	1 (2%)				2 (5%)	10 (23%)	31 (71%)
I would recommend this training and the <i>caring@home</i> package to other carers				1 (2%)	2 (5%)	5 (11%)	36 (82%)

Hesitation and motivation to adopt expanded carer role

Carers spoke about attitudes and confidence in adopting the expanded carer role involving medicine management, how responsibility was shared within caring experiences, and how feedback appraisal and 24-hour telephone support provided reassurance. Three subthemes illustrated this theme.

Attitudes and confidence in caring role

Some carers expressed initial hesitation to accept medicine responsibility because it was a daunting task or because of fear of making mistakes that would lead to adverse outcomes.

I'm sure it's the same when somebody says we're going to be climbing Mount Everest - I'm sure I would be apprehensive and anxious about it until I got the training. (Participant 7)
 I just didn't want to feel after it all like I contributed to his death. (Participant 6)

The majority of carers, however, expressed that the desire to keep the person at home outweighed concerns about administering medicines.

We didn't have a lot of chance to think about it or worry about it, it just became what was necessary... We were prepared to do anything to keep mum at home. (Participant 1)

Shared responsibility within caring experience

Although some participants were sole carers, caring was often a shared responsibility between family members.

Fran and I did the medications...inserting the medications et cetera doing the top-ups. Kim chose not to; it was something that she just said no, Fran and I knew what we're doing and so she took other roles. (Participant 1)

The resources were used to facilitate collective understanding among family members should they need to step in.

I even asked my brother to actually watch the DVD and everything as well, in case there was a family member that we needed to swap over to make sure that we would both be comfortable. (Participant 8)

Facilitators of managing subcutaneous medicines at home

Feedback appraisal and 24-hour nurse support were noted as major facilitators of managing breakthrough palliative symptoms at home.

Seeing the effect of medicines motivated carers to continue managing symptoms despite hesitations. This feedback appraisal enhanced confidence in undertaking the task. Being able to alleviate symptoms made carers feel powerful rather than helpless.

To know that you're able to treat something, at any kind of level, to fix either discomfort or anxiety, is a really big thing. To feel in charge of, I guess, lessening someone's suffering is a really big thing and it's really quite a privilege to be able to do that (Participant 4)

The 24-hour phone support was crucial in making carers feel well-prepared to take on the role and was

particularly useful in instances where carers needed to prepare medicines.

At the end of the day, what really helps is that you know that you're not alone and you can contact them and ask a question. Even at night, when they're off, they give a phone number...so you've even got after hours support. (Participant 4)

One point raised by multiple participants was the importance of stressing to carers that the dose of medicines was not enough to be lethal. Reassurance about this was critical in reducing carer stress and anxiety around potentially harming patients.

One of the fundamental things that needs to be reiterated over and over again, that you're not killing the patient by giving them the medication. It's a worm that gets buried under the skin and just wriggles away. (Participant 3)

It was noted that, with practice and adequate professional support, all carers should be able to feel comfortable and competent in providing symptom relief at home using subcutaneous medicines.

Any carer should feel like they can handle the situation if they've got practice. It's not a matter of just saying, oh, I couldn't do that... So, there's no reason why people shouldn't be able to do it. (Participant 2)

The importance of a layered approach to support

This theme highlighted the importance of the combination of the training, resources and 24-hour phone support to the success of the programme. These three layers of support ensured carers had practical experience, could refer back to resources after the training that catered to different learning styles, supported good protocol and acted as a helpful prompt, and could call for support at any time if any uncertainties remained. Four sub-themes illustrated this theme.

Therapeutic relationship with nurse

The relationship with the nurse was fundamental to the success of the training. Nurses were described as personable, enthusiastic and encouraging, which collectively contributed to a positive training experience.

Her (the nurse's) excitement also helped us engage as well. (Participant 3)

Carers felt the nurses delivering the training were empathetic, treated them as equals, and tailored training to their specific caring scenario.

She understood her job so the way she delivered it, the way she showed us each component like she was training another nurse. Also she had taken into account our different roles. (Participant 3)

Positive attitudes, empathy, and patience were key in reducing carer stress and anxiety. A number of carers described the demeanour of the nurse as calming.

She did it at our pace, and it made caring for him so much easier and so much less stressful. (The nurse's) calm, relaxed nature helped keep us calm and relaxed about what we were doing. (Participant 5)

Face-to-face tailored demonstration perceived as most important

Face-to-face demonstration was perceived as the most important part of the training. Step-by-step demonstration accompanied by clear communication, extensive practice and seeing no needles were involved enhanced carers' confidence and eased anxiety.

When we could see that it didn't involve needles, that it was just basically having the correct dose and then unscrewing - screwing it on, it gave us a lot of confidence. (Participant 1)

I mean, in training, it is repetition is going to bring on the good actions later on, and people do things over and over and over and over again. Repetition is one of the major factors of people learning what they have to do properly (Participant 2)

Resources were perceived to be useful, but face-to-face training was perceived to be the most important given the hands-on nature of the task being learnt.

You can read as much as you like...but because this involved much more than that, it (hands-on training) gave me the confidence to put into practice what I'd read. (Participant 11).

Resources seen as adjunct to training and provided reassurance

The *caring@home* resources were described as visually appealing, easy to understand, well presented and helped facilitate comprehension. They were a useful adjunct to the training, helping to reinforce what was learnt. Participants noted that the resources were particularly helpful as a reference to facilitate information retention at a time when strong emotions and stress were likely to impact health literacy.

You could only take in so much (at the time of training)...particularly when you are dealing with the emotions and to be able to go back and look at it at whatever time of day, it was good to do that. (Participant 1)

The training was great, but then when you're at home and you're a bit sleepless, and a bit stressed, those resources were the adjunct that made it all work. (Participant 5)

Resources facilitated care continuity

Resources helped to facilitate information and management continuity among family members (carers and non-carers) and the formal care team. The resources enabled collective understanding among family members, including those not in a caring role.

If there were other family members that were wanting to understand, then we would show them the book and that it was reassuring for them too. (Participant 1)

Participants noted that the medication diary was particularly helpful in facilitating management continuity and better communication between the informal and formal care team.

So I like the fact that I could record it, I could write why you'd given it and I could write later what happened, so I could then feed back to the nurses what had been happening at what stage of the day or night. (Participant 12)

Avoiding perceived unnecessary contact with nurses

This theme explores the experience of carers preparing and administering medicines, including their motivations to maintain this responsibility, and the challenges they faced.

Experience of medicine preparation

Carers did not prepare medicines in all instances, in some services nurses routinely prepared syringes for later use by the carer.

We make sure that we've always got plenty of medication on hand and the needles and everything, to make sure that we're never going to be left without things. (Participant 2)

Carers who did prepare medicines themselves learnt by watching the nurses and initially did so with nurse supervision. Carers often established a routine for pre-preparing medicines so that nurses could check pre-prepared syringes.

I would draw up the medication in the morning, before the Palliative Care Nurse would come and I would make sure that I would have enough for the night and a little left over, just so that I wasn't having to think about drawing up medication in the early hours of the morning, or at night. (Participant 4)

Many carers noted that avoiding unnecessary contact with the nurses was important to them and motivated them to take responsibility for this task.

There's no sense jumping on the phone in the middle of the night, getting someone out of bed, when really all you have a to do is draw a little bit of product into a syringe. It's not that hard. (Participant 6)
 We had a lot of human resources to support mum when we knew that there were a lot of people out there that didn't have that. We wanted the nurse to be actually available for them. (Participant 3)

Feedback appraisal—pros and cons

Immediate symptom relief provided reassurance that the correct procedures were being followed. On the other hand, carers would question whether they were managing symptoms appropriately if they did not see rapid symptom relief after administration of medicines. Deterioration caused additional stress to carers.

The importance of telephone support was highlighted in these cases.

...it was full on. It was me phoning to get permission to change doses and everything. I probably think I went into shock that night or the next morning, because I just needed the assurance that I had done everything I possibly could, due to not getting the results for the medication that I thought I would be getting.... (Participant 8)

Standing challenges

Carers described two key areas amenable to further education and training: (1) managing multiple medicines and (2) deciding when to provide symptom relief.

We had a range of medications, I think five or six by memory...for different symptoms. That was the part that took a little bit more understanding. (Participant 6)

The majority of participants noted that more information was needed to help with symptom appraisal and clinical decision-making.

Look it would be nice to understand how or when you know that the patient requires medication. (Participant 11)

I didn't know how accurate I was, because I had never seen my father in pain or agitated. So I just don't know - that would be my only query is gauging that. You would get used to it after a period of time, but I really didn't have that opportunity. (Participant 8)

DISCUSSION

Across Australia, carers reported high satisfaction with the *caring@home* training and resources package and recommended it to others in their situation. Carers identified that the major motivator for managing subcutaneous medicines was to keep the person they were caring for at home. They described the importance of the hands-on training and in particular the therapeutic relationship with the nurse providing the training. The *caring@home* resources were perceived as a useful adjunct to training, providing reassurance. Resources were used as a reference point and facilitator of information continuity between carer and non-carer members of family and the formal healthcare team.

Prior to the training, carers were hesitant to take on medication responsibility, however, they were motivated to adopt the role because they did not want the alternative—for the patient to experience uncontrolled symptoms or to not be at home. This is in keeping with findings of international studies.¹⁶ Providing symptom relief and facilitating home death was empowering for carers. This has also been described in a similar Irish study, where participants stressed the value of being able to give medications as needed for symptom control.¹¹ While challenging, studies have shown that many carers describe the caring experience

as rewarding and describe a sense of relief in being able to help and be with the patient at the end of life.⁷ Caring for a person at home can thus facilitate coping and meaning-making at the end of life.⁷

With adequate support, carers can confidently manage breakthrough symptoms at home. Adequate support was perceived to be the combination of face-to-face training, resources and 24-hour telephone support. Findings from this national programme mirror those from the original Queensland initiative,¹³ providing evidence for its success in increasing carer confidence to adopt the expanded caring role. Carers stressed the importance of the 24-hour telephone support and ongoing encouragement in facilitating effective symptom management and managing self-doubt. The therapeutic relationship with the nurse was highlighted as key to the success of the training, where carers felt included and treated as part of the care team, addressing the need for effective collaboration between health professionals and carers to provide best-practice care.¹

Not all carers prepared medicines depending on healthcare service procedures and carer preference. Interestingly, carers who chose to were motivated to prepare medicines to avoid overburdening community palliative care nurses. Despite the sometimes-hesitant attitudes of nurses with regard to carers preparing medicines themselves, carers perceived this task as just another part of caring, and noted that with adequate support '*it wasn't that hard*'.

Further training in relation to symptom appraisal could be useful, as many carers described this as a major challenge requiring a level of interpretation they did not always feel confident with. This was one aspect of care that participants felt a trained nurse would be better equipped to manage. Knowing what to do was perceived as easy in comparison to making decisions about when it was appropriate to administer subcutaneous medicines. This was particularly challenging in cases where the palliative patient deteriorated rapidly and carers did not have enough time with the patient to understand patterns of symptom onset. To reduce anxiety in decision-making, a number of carers described the importance of highlighting the fact that if medicines were prepared and administered as ordered, overdose was not a possibility. Several carers reported that nurses did stress this point, however, it is unknown whether this was consistently relayed despite its effectiveness in reducing carer stress. Given its impact on carers, this message could be highlighted in the resources to help reduce anxiety for all concerned.

As the population ages and public acceptance of palliative care grows, it is becoming progressively more difficult for healthcare services to meet the increasing demand for home-based palliative care. This is largely due to workforce, financial and other resourcing constraints. One way that services could increase capacity to care for community patients is by

welcoming and appropriately integrating volunteer carers into the healthcare team who could help manage emergent breakthrough symptoms in the person for whom they are caring.

Limitations

There are important limitations to this study. The sample size is small, yet the findings provide valuable information about managing end-of-life symptoms at home from the perspective of carers who are often hard to reach. The participant response rate was unable to be calculated, as only the numbers of resource packs ordered by individual services were known to the researchers, not the numbers of carers subsequently approached by services to participate.

Importantly, all participants were subjectively triaged by nurses as being suitable to be offered the extended carer role and the carer evaluation participants were a self-selected subgroup of that population. To ensure confidentiality of participants, the demographics of the carer respondents were not collected. These considerations must impact the generalisability of the findings. Regardless, they provide important insights into the acceptability of the intervention.

Carers who agreed to participate in this evaluation may not be representative of all carers who participated in the *caring@home* programme. Participants were a selected sample, referred by nurses as suitable, therefore limits our understanding of widespread acceptability of the intervention. To minimise responder burden, the evaluation survey included feedback items only. Demographic information was not collected, affecting the generalisability of findings. The number of carers approached to participate is unknown, thus the response rate was unable to be calculated. Sample size is small, yet findings provide valuable information about managing end of life symptoms at home from the perspective of carers who are often hard to reach.

Conclusion

The *caring@home* training and resources are useful tools to support carers in providing breakthrough symptom management using subcutaneous medicines for palliative patients at home. The combination of training, resources and 24-hour telephone support were the three layers of support that facilitated carers' confidence and skills to prepare and administer subcutaneous medicines as needed. Findings show that volunteer carers are motivated to adopt an expanded caring role that includes medicine management. Resource-stretched community palliative care services may be advantaged by incorporating volunteer carers as part of the healthcare team, without compromising quality patient care.

Acknowledgements This work was supported by the Australian Government Department of Health and Ageing, National Palliative Care Projects.

Contributors DP, ER, KC and JT contributed to the planning, design and implementation of the research. DP and SI contributed to the collection and analysis of the results, and all authors to the writing and critical revision of the manuscript. DP will act as guarantor.

Funding This work was supported by the Australian Government Department of Health and Ageing, National Palliative Care Projects.

Competing interests None declared.

Patient consent for publication Not applicable.

Ethics approval This study involves human participants and was approved by University of Technology Sydney Human Research Ethics Committee (ETH19-4472). Participants gave informed consent to participate in the study before taking part.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement No data are available.

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