Prospective comparative effectiveness cohort study comparing two models of advance care planning provision for Australian community aged care clients

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ABSTRACT
Objectives Conduct a prospective comparative effectiveness cohort study comparing two models of advance care planning (ACP) provision in community aged care: ACP conducted by the client’s case manager (CM) (‘Facilitator’) and ACP conducted by an external ACP service (‘Referral’) over a 6-month period.

Methods This Australian study involved CMs and their clients. Eligible CM were English speaking, ≥18 years, had expected availability for the trial and worked ≥3 days per week. CMs were recruited via their organisations, sequentially allocated to a group and received education based on the group allocation. They were expected to initiate ACP with all clients and to facilitate ACP or refer for ACP. Outcomes were quantity of new ACP conversations and quantity and quality of new advance care directives (ACDs).

Results 30 CMs (16 Facilitator, 14 Referral) completed the study; all 784 client’s files (427 Facilitator, 357 Referral) were audited. ACP was initiated with 508 (65%) clients (293 Facilitator, 215 Referral; p<0.05); 89 (18%) of these (53 Facilitator, 36 Referral) and 41 (46%) (13 Facilitator, 28 Referral; p<0.005) completed ACDs. Most ACDs (71%) were of poor quality/not valid. A further 167 clients (facilitator 124; referral 43; p<0.005) reported ACP was in progress at study completion.

Conclusions While there were some differences, overall, models achieved similar outcomes. ACP was initiated with 65% of clients. However, fewer clients completed ACP, there was low numbers of ACDs and document quality was generally poor. The findings raise questions for future implementation and research into community ACP provision.

INTRODUCTION
Advance care planning (ACP) is a coordinated communication process between a person, their family/carer(s) and healthcare providers and aims to clarify the person’s values, treatment preferences and goals of medical treatment should the person lose capacity to make or communicate such decisions in the future.1 In Australia, formal ACP programmes usually operate within health, institutional or aged care settings and involve trained staff.1 These programmes are often located at public health services. While discussions are the main focus, an important and often desirable outcome of ACP is the completion of a written advance care directive (ACD) that documents the person’s preferences and/or the appointment of a substitute decision maker.1 ACP has been shown to improve care, including end-of-life care,2 3 to improve the likelihood that a person’s preferences will be known and respected2–4 and to improve the psychological outcomes in surviving relatives.2 4

The Australian Government Home Care Package (HCP) programme provides funding for personal/health/nursing support to frail or unwell Australians to assist them to remain at home rather than enter residential care.3 HCPs assisted 60 000 people in 2013; this number is expected to increase to 100 000 by
2016/2017, with predictions that 80% of aged care services will be delivered in this form by 2050. Each client is assigned a case manager who, in partnership with the client, coordinates the services that the client receives. There are four levels of HCP support based on needs ranging from level 1 (basic) to level 4 (high).

ACP may be both beneficial and achievable for HCP clients. Older people believe ACP is important, and they are enthusiastic about participation. Although most HCP clients are elderly, frail and have chronic illnesses, they are more likely to have decision-making capacity than residential care residents and thus more able to participate in ACP. Additionally, care providers visit clients in their homes, possibly a more amenable environment for ACP conversations than either aged care facilities or hospitals. It is hypothesised that ACP discussions while the client is at home and likely to be stable is more appropriate and timely than during hospital admissions, when the person may be too unwell to undertake ACP. Evidence shows that preferences for life-sustaining treatments are dependent on the context in which they are made, with a ‘hospitalisation dip’ during and immediately following admission, and return of preferences to their prehospitalisation status after some time, thus supporting the notion of conducting ACP when clinically stable.

Despite the perceived value of ACP for HCP clients, limited international and Australian research has shown that generally the uptake of ACP within community care is low, and that case managers vary in their ACP practice, knowledge and attitudes. These studies show lack of a systematic approach to ACP within services that most services do not provide ACP training for staff, that minimal resources are allocated to ACP and that the quality and prevalence of ACP varies between service providers.

Given the increase in community-based aged care programmes such as HCP, and the recognised value of undertaking ACP earlier and prior to loss of decision-making capacity, there is a strong impetus to provide ACP in this setting. However, how best to provide ACP in this setting is unknown. We conducted a prospective comparative effectiveness cohort study comparing two models of ACP provision to HCP clients:

1. ACP conducted by the client’s case manager (‘Facilitator’ model), based on previous ACP implementation in other settings.
2. ACP provided by referral to external ACP services (‘Referral’ model). This model is based on Australian research showing current practice within HCP services includes ACP initiation, followed by referral to complete ACP.

The aim of this study was to compare the effectiveness of these two distinct models of ACP provision, in terms of quantity of ACP discussions and quality of ACP completion, over a 6-month intervention period.

**METHODS**

**Study design**

This study was conducted in Victoria, Australia. Eligible participants were case managers. HCP services were recruited via an information session and invited their case managers to participate. Eligible case managers were ≥18 years, English speaking and expected to be available ≥3 days per week for the 6-month intervention period. Participants, provided consent, were stratified by site and sequentially allocated to Facilitator or Referral groups. No data were collected regarding the number of case managers not invited to participate.

Recruitment occurred in August 2014, the intervention period was 1 September 2014 to 28 February 2015, and data collection occurred during March 2015.

**Models of ACP provision**

Two models of ACP provision were utilised: the Facilitator model, based on previous ACP implementation in other health settings, and the Referral model, based on the findings from Australian research showing current practice includes initiation of ACP and then referral for ACP completion. Details of these models are outlined in table 1.

The expectations of the Facilitator case managers were that they would initiate and conduct ACP with their clients including ACD completion. These case managers received training based on Austin Health’s model of ACP facilitator training. (table 1) The expectations of the Referral case managers were that they would initiate ACP with clients, and then refer them to a specialist service for ACP discussions and ACD completion.

HCP services received remuneration for the case manager’s time as follows:

- **Facilitator group**: $A5000 per full-time case manager for time required for initiating and conducting ACP and providing study data.
- **Referral group**: $A2500 per full-time case manager for time required for initiating ACP, referral to a specialist service, and providing study data.

Case managers in both groups were asked to initiate ACP with all clients during the intervention period. ACP initiation was defined as raising the topic and explaining what it is and possible benefits. Case managers provide written information about ACP and assessed interest in further ACP discussions. Where the client was interested, the case manager would facilitate ACP or refer the person to a specialist service depending on the group allocation. Where clients had previously undertaken ACP, a review of ACP was offered and either conducted or referred.

Case managers recorded details, including duration, of all ACP activity during the intervention period.
Telephone mentoring by project staff was provided to case managers in both groups.

Audit of client files
At study completion, all client files of the participating case managers were audited. This included clients who had commenced or ceased receiving services during the period. Using a specifically designed template, researchers and case managers, or another HCP organisational representative, examined the files together to extract the required information. Data collected included demographics, detail of pre-existing (prior to intervention) ACP/ACDs and detail of new ACP discussions and ACDs. Researchers did not directly contact clients or have access to client identifying information.

A completed conversation was defined as one or more discussions (with/without completion of ACD) with no wish from the client for further discussion.

Document audit
Deidentified copies of all newly completed ACDs were assessed for quality and validity. These ACDs included statutory documents for appointing substitute decision makers (medical enduring power of attorney) and documents outlining preferences, either statutory (Refusal of Treatment Certificate (RTC)) or common law ACDs (CL-ACD).

Two researchers independently assessed ACDs for compliance with best practice and validity, using a specifically developed tool, based on previous research. Disagreement was resolved by discussion until consensus was achieved. Parameters included whether: the client’s name was clearly documented; only one cardiopulmonary resuscitation (CPR) preference was chosen (where relevant); only one life-prolonging treatment option was selected (where relevant) and this was compatible with the CPR option; that the document was signed by the client (or substitute decision maker if client was non-competent); and that witnessing requirements were met.

Outcome measures
These were the quantity of ACP discussions and the outcomes of these discussions including quantity and quality of ACDs completed and reported pre-existing ACP activity.

Statistical methods
Continuous data were assessed for normal distribution using a Kolmogorov-Smirnov statistic with a Lilliefors significance level for testing normality. Normally distributed data are reported as mean±SD and where appropriate hypothesis testing was performed using Student’s t-test. Continuous data not normally distributed are reported as median±IQR and where appropriate hypothesis testing was performed using a Mann-Whitney U test. Categorical data are reported as median±IQR or frequency plus percentage. Statistical testing was performed using Pearson χ² test. A p value of ≤0.05 was considered statistically significant.

RESULTS
Case manager and client demographics
Thirty-five case managers were recruited and trained; 19 were allocated to Facilitator group and 16 to Referral group. Five case managers subsequently withdrew (four changed jobs, one went on extended leave). Thus, data for 30 case managers (16 Facilitator, 14 Referral), and their clients, are included.

There were no significant demographic differences between Facilitator and Referral case managers (table 2), and they are similar to that of Australian case managers in that their median age was 47 years; most were female, were born in Australia, New...
Zealand or UK and they had a median client case load of 25. One included Referral group case manager’s hours changed after recruitment and training, and therefore did not meet inclusion criteria in that they did not work 3 or more days per week.

Client data for all 784 clients of the 30 case managers are included: 427 (54%) from the Facilitator, and 357 (46%) from the Referral groups. Clients had a median age of 83 years, most spoke English (89%) and most (73%) were on low level (one or two) packages (table 3). Client demographic data were similar in the two groups, apart from a slightly higher proportion of females in the referral group. Client demographics were representative of Australian HCP clients, where two-thirds are female, 90% are ≥70 years and three-quarters receive level one or two packages.

**ACP activity**

Table 2 presents a flow chart depicting the baseline and 6-month intervention ACP activity for the entire group of clients.

| Case managers | Overall n=30, n (%) | Facilitator n=16, n (%) | Referral n=14, n (%) | p= |
|---------------|---------------------|-------------------------|---------------------|----|
| Gender: female | 27 (90) | 14 (88) | 13 (93) | 0.63 |
| Age (years), median (IQR) | 47 (38–55) | 48 (39–55) | 45 (36–56) | 0.69 |
| Country of birth | | | | 0.62 |
| Australia or New Zealand | 16 (53) | 8 (50) | 8 (57) | |
| UK | 6 (20) | 4 (25) | 2 (14) | |
| Other | 8 (27) | 4 (25) | 4 (29) | |
| Work classification | | | | 0.26 |
| Full-time | 17 (57) | 11 (69) | 6 (43) | |
| Part-time (0.6–0.9 EFT) | 12 (40) | 5 (31) | 7 (50) | |
| Part-time (0.1–0.5 EFT)* | 1 (3) | 0 (0) | 1 (7) | |
| Training classification – multiple responses possible | | | | |
| Nursing | 9 (30) | 5 (31) | 4 (29) | |
| Social work | 9 (30) | 5 (31) | 4 (29) | |
| Occupational therapy | 3 (10) | 1 (6) | 2 (14) | |
| Community services | 7 (23) | 4 (25) | 3 (21) | |
| Disability services | 2 (7) | 1 (6) | 1 (7) | |
| Aged care/care coordination | 9 (10) | 5 (31) | 4 (29) | |
| Case management | 14 (47) | 7 (44) | 7 (50) | |
| Other† | 3 (10) | 3 (21) | | |
| Years worked as case manager | | | | 0.48 |
| Less than 1 year | 3 (10) | 2 (13) | 1 (7) | |
| 1–5 years | 14 (47) | 9 (56) | 5 (36) | |
| 5.1–10 years | 9 (30) | 4 (25) | 5 (36) | |
| >10 years | 4 (13) | 1 (6) | 3 (21) | |
| Clients in case load, median (IQR) | 25 (20–28) | 26 (21–29) | 23 (19–28) | 0.66 |
| Full-time CM | 26 (20–37) | 26 (20–36) | 29 (23–42) | 0.54 |
| Part-time CM | 23 (20–26) | 26 (24–27) | 20 (18–23) | 0.52 |

*One CM only worked 2 days per week (0.4 EFT).†Other: health promotion, counselling, master of law.

ACP activity during the intervention period

Overall, case managers initiated ACP with 508 (65%) clients during the intervention period, with a higher proportion in Facilitator compared with the Referral groups (69% vs 60%, p<0.05). Of the remaining 276 clients, reasons for not initiating ACP were documented in 193 (70%) of files (figure 1).

Of those where ACP was initiated, 89 clients (11% of total 784 clients; 18% of the 508 clients where ACP was initiated) completed ACP conversations, with no significant difference between groups (figure 1, table 4). A further 167 clients (Facilitator 124, Referral 43; p<0.005) were interested in progressing ACP further, with 40 stating they would do this themselves without further assistance, and 127 clients noted to be progressing with but not completed ACP by the end of the study. The remaining 252 clients (Facilitator 116, Referral 136) either declined ACP discussion (173) or stated they had previously undertaken ACP (79) and did not wish further discussion (figure 1).
Research

Completed ACP conversations
Where initiated (n=508), ACP was completed in 89 (18%) clients, with 55 (66%) taking 60 min or less (table 4). Significantly more time was required when case managers facilitated conversations than when the clients were referred (p<0.05). However, the total time taken at the ACP service was not recorded. Thus, total time required (HCP case manager and referral staff) for the Referral group clients is unknown. Clients in both groups required a median of 2 discussions.

Completed advance care directives
Of the 89 people completing ACP, 41 (46%) completed ACDs (table 4), with a higher proportion in the Referral (75%), compared with the Facilitator group (25%) (p<0.005).

Overall quality of documentation was poor. Only 12 (5 Facilitator, 7 Referral) of the 41 clients (29%) had all completed documents being valid (table 5). The substitute decision-maker documents were more likely to be correctly completed than either the RTC or the common law ACDs (60% vs 33% vs 29% respectively). The most common errors were absent, incomplete or inappropriate document signing or witnessing and inconsistencies within documents regarding treatments (eg, person indicating they did not want life-prolonging treatment but did want CPR performed, which is life prolonging).

Prior levels of ACP
Of the 784 clients, 322 clients (41%) had evidence in their records of prior ACP (table 6), with no difference between groups. The majority of these involved substitute decision-maker appointments. Only a minority of these documents were present in the files (24 decision-maker appointments, 4 ACDs).

DISCUSSION
This is the first known study evaluating the effectiveness of models of ACP implementation in community aged care. During the 6-month intervention period, case managers initiated ACP with 65% of their clients. Although some differences between the two models were observed, that approximately two-thirds of clients in both groups achieved this result is a positive indicator for the implementation of both models, especially considering the minimal scope of the training interventions. However, a much smaller proportion of clients went on to complete ACP discussions and ACDs. Thus, it is important to consider why those where ACP was initiated did not complete it.

ACP may be considered a health behaviour where individuals have varied motivations, barriers, enablers and self-efficacy.23 24 ACP consists of multiple components including identifying values, and treatment goals, choosing substitute decision makers, discussions with family and health providers and completion of ACDs. Theories of behaviour change25 recognise the importance of a stepped approach (precontemplation, contemplation, preparation, action and maintenance) towards target behaviours. In this study, the principal outcomes were the completed ACP discussions and ACDs. Interestingly, of clients where ACP was initiated but incomplete, one-third reported they were in progress. Similar observations over the same time period have been made elsewhere.26 It is reasonable to suppose that over time ACP completion rates might

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Table 3 Client demographics

| Package level | Overall n=784, n (%) | Facilitator n=427, n (%) | Referral n=357, n (%) | p= |
|---------------|----------------------|--------------------------|-----------------------|---|
| 1–2           | 572 (73)             | 321 (75)                 | 251 (70)              | 0.26 |
| 3–4           | 212 (27)             | 106 (25)                 | 106 (30)              |     |
| Gender: female | 512 (65)             | 264 (62)                 | 248 (70)              | 0.03 |
| Marital status| 0.15                 |                          |                       |     |
| Married/long-term partner | 291 (37) | 175 (41) | 116 (33) |     |
| Widowed       | 380 (49)             | 192 (45)                 | 188 (53)              |     |
| Divorced/separated/single | 112 (14) | 60 (14)  | 52 (15)  |     |
| Can communicate in English | 694 (89) | 384 (90) | 310 (87) | 0.22 |
| Age           | 83 (77–88)           | 84 (77–89)               | 83 (77–88)            | 0.18 |
| Medical conditions* – Multiple responses possible | 466 (59) | 245 (57) | 221 (62) |
| Circulatory system | 411 (52) | 218 (51) | 193 (54) |
| Musculoskeletal and connective tissue | 212 (27) | 107 (25) | 105 (29) |
| Endocrine, nutritional and metabolic disorders | 181 (23) | 105 (25) | 76 (21) |
| Dementia      | 160 (20)             | 88 (21)                  | 72 (20)               |     |

*Up to three medical conditions (coded according to the Aged Care Assessment Service classifications) per client, only conditions occurring for more than 20% of clients are listed.

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be higher. Also, similar to previous studies, almost half of those who completed ACP discussions also completed ACDs.

The HCP population is heterogeneous. It is therefore reasonable to expect clients to be at differing stages of readiness for each of the ACP components. Despite being mostly an elderly, frail population, as other studies have postulated, many of this group and their families may not have viewed ACP as relevant. They may not have considered themselves sick enough, may have lacked information regarding their illness and prognosis, may not have wished to discuss their likely future worsening health state or death, may have been occupied with other priorities or assigned a low priority to ACP without clear triggers or health crises. Previous research has shown that illness severity is not necessarily associated with ACD completion. Other elements of ACP, such as values clarification and communication with family/carer(s), may have occurred but were not measured here. The findings in this study therefore may not be surprising. Supporting case managers to use tools to assist with prognosis, such as the Supportive and Palliative Care Indicator Tool or the ‘surprise question’ may help prioritise clients for ACP. Furthermore, incorporating ACP into routine assessments, such as on commencement of an aged-care package, following hospital admission and during specific assessments (health assessment for people aged 75 and older, chronic disease assessment), may help to overcome the perceived lack of a trigger or health crisis.

ACP activity prior to the intervention in this study found that a third of the group reported having already appointed substitute decision maker(s), and 5% had completed ACDs. These reported levels of existing
Research

Table 4  Outcomes of advance care planning (ACP), including documentation

|                           | Overall n (%) | Facilitator n (%) | Referral n (%) | P=*
|---------------------------|---------------|-------------------|----------------|--------
| Total clients in group    | 784           | 427               | 357            |        |
| Clients with whom ACP was initiated | 508 (65) | 293 (69) | 215 (60) | 0.01   |
| Clients completing ACP (% clients where ACP was initiated) | 89 (18%) | 53 (18%) | 36 (17%) | 0.31   |
| Time taken               |               |                   |                |        |
| ≤30 min                  | 31            | 15                | 16             | 0.02   |
| 31–60 min                | 24            | 9                 | 15             |        |
| 61–90 min                | 7             | 5                 | 2              |        |
| 90–120 min               | 6             | 6                 | 0              |        |
| >120 min                 | 15            | 13                | 2              |        |
| Missing data             | 6             | 5                 | 1              |        |
| All documents n (% who completed ACP) | 41 (46) | 13 (25) | 28 (78) | <0.005 |
| Medical enduring power of attorney |         |                   |                |        |
| Total                    | 15            | 5                 | 10             | 0.30   |
| Alone                    | 3             | 2                 | 1              |        |
| Plus CL-ACD              | 9             | 2                 | 6              |        |
| Plus CL-ACD and RTC      | 4             | 1                 | 3              |        |
| Common law advance care directives (CL-ACD) |         |                   |                |        |
| Total                    | 38            | 11                | 27             | 0.10   |
| Alone                    | 23            | 6                 | 17             |        |
| Plus MEPOA               | 9             | 3                 | 6              |        |
| Plus MEPOA and RTC       | 4             | 1                 | 1              |        |
| Plus RTC                 | 2             | 1                 | 1              |        |

*For facilitator compared with referral.

MEPOA, medical enduring power of attorney (substitute decision maker); RTC, Refusal of Treatment Certificate.

appointments of substitute decision makers are higher than other studies have found.27 31 The majority of these pre-existing documents were absent from the client’s file, and therefore it is unclear as to their existence and validity. Anecdotally, our experience has found people wrongly believe that they have already completed them, confusing ACDs with wills and financial powers of attorney.

Table 5  Validity of completed advance care directives

|                        | Overall n (%) | Facilitator n (%) | Referral n (%) |
|------------------------|---------------|-------------------|----------------|
| Medical enduring power of attorney |               |                   |                |
| Valid as per legal requirements n (%) | 9 (60)   | 3 (60)            | 6 (60)         |
| Validity errors        |               |                   |                |
| Not signed by client   | 1             | –                 | 1              |
| Witnessing of document incomplete, incorrect* | 5        | 2                 | 2              |
| Refusal of Treatment Certificate | 6          | 2                 | 4              |
| Valid as per legal requirements |  2 (33)  | 0                 | 2 (50)         |
| Validity errors        |               |                   |                |
| Treatment refused option not indicated | 2        | 1                 | 1              |
| ‘Medical treatment generally’ chosen but specific treatment specified | 1      | 1                 | –              |
| Witnessing of document incomplete† | 1        | –                 | 1              |
| Advance care directive (common law) | 38       | 11                | 27             |
| Complies with best practice | 11(29) | 4 (36)            | 7 (26)         |
| Best practice non-compliance element (one or more) |         |                   |                |
| Incompatible CPR/LPT option‡ | 14        | 5                 | 9              |
| Not signed by client   | 14            | 2                 | 12             |
| Not signed by witness  | 20            | 4                 | 16             |
| Not signed by doctor   | 17            | 2                 | 15             |
| Number with both treatment inconsistencies and signing/witness issues | 11    | 3                 | 8              |

*Must be signed in the presence of two witnesses. Neither witness can be the agent/alternative agent. One witness must be authorised by law to witness the signing of statutory declarations.

†Must be signed in the presence of two witnesses, one must be a registered medical practitioner.
‡Person has selected that they do not want LPT, but want CPR, or have stated they want CPR, but have also stated they do not want to be resuscitated. CPR, cardiopulmonary resuscitation; LPT, life-prolonging treatment.
When ACDs were completed, they were generally of poor quality, with less than half being legally valid. The reasons for this are unclear and raise issues of how quality control of ACP and ACD should be managed and also raise concern that the ACD documents themselves are overly complicated or difficult to complete. Both groups experienced issues regarding signing and witnessing of documents, something that may be improved by embedding ACP into the broader healthcare system and including the clients’ usual doctors in the process. Neither model in this study addressed this issue specifically.

While ACP completion rates were similar in both groups, more Facilitator clients had ACP initiated (Facilitator 69%, Referral 60%; p<0.05) and more (Facilitator 124, Referral 43; p<0.005) reported that ACP was in progress at the end of the study. This finding raises the possibility that with longer follow-up, there might be differences in favour of the Facilitator group. This may be a reflection of the ‘Facilitator’ group receiving more extensive ACP training and, therefore, feeling more comfortable/skilled in ACP. Despite small numbers overall, there was a significantly higher percentage of document completion in the Referral group. Thus, while both models of ACP have potential advantages, this study has shown similar outcomes overall.

The client population and case manager characteristics were representative of Australian HCP services, and therefore results are likely to be generalisable to the Australian HCP population. However, this intervention was only of 6 months’ duration, and the outcomes measured were completion of ACP discussions and ACDs. While these measurements are consistent with existing ACP literature, recently there is ongoing interest as to how to best capture the efficacy of ACP interventions and indeed which ACP components are most critical to its success. This may be particularly important given the transtheoretical model of behavioural change theory and the relevance to ACP. Other steps in the ACP process were not measured in this study. Furthermore, this study did not look at whether ACP affected future decision making and end-of-life care—the ultimate aims of ACP. Although the HCP organisations received payment and case managers committed to the requirements of the study, it is unknown whether any additional time or funding was made available to case managers to conduct ACP discussions. Finally, this study did not actively source pre-existing ACDs, thus it is not possible to compare the quantity and quality of pre-existing documentation with those achieved in this study.

**CONCLUSION**

This study found that during a 6-month period, both Facilitator and Referral models of ACP provision achieved similar results, in terms of ACP initiation, completed conversations and ACD documentation. While ACP was initiated with many clients, there was low numbers of completed discussions and documents, and documentation quality was generally poor. Both models have merit, and how providers offer ACP services may depend on factors, such as access to a suitable referral service, access to training and support for case managers and preferences of the clients. The findings raise questions for future research into ACP practice in the community aged care, including when and how to offer and conduct ACP, what training is required to provide the necessary skills and what are the most useful outcome measures for determining whether an ACP intervention has been successful.

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Research

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