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"The right choice for you." How descriptions of treatment options in information resources may influence patient understanding and decision-making

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INTRODUCTION

Only 1% of people with kidney failure in Europe age 75+ receiving dialysis progress to transplant[1]. Most will decide between dialysis or conservative kidney management (CKM) options. This process can be complex, involving weighing risks, benefits and effects on quality and quantity of life. Information resources from renal units support people with their decision-making[2].

AIM

To describe how information resources about CKM and dialysis present living with and dying of kidney failure.

METHOD

- **When & where:** Physical and digital information resources from four UK renal units with varying CKM treatment rates, collected between 06/2021 and 01/2023.
- **Inclusion criteria:** Resources focussing on CKM and/or dialysis options individually or in comparison, or broader contextual information related to treatment options, e.g. lifestyle information.
- **Critical discourse analysis** examined how documents describe and explain living and dying with kidney failure in relation to CKM and dialysis.

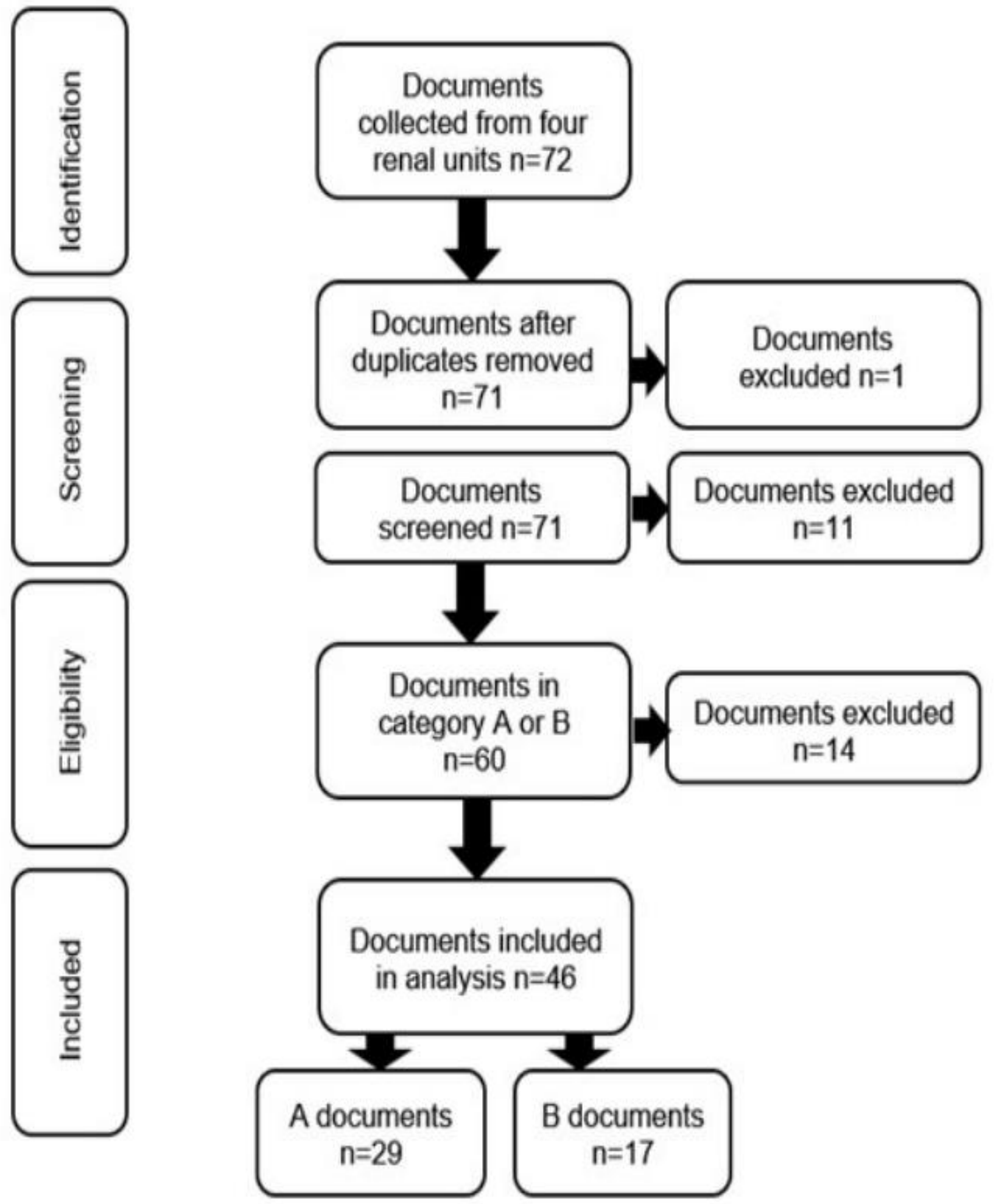
RESULTS

72 resources were identified across four renal units. 46 documents were included after deduplication and screening (see figure 1).

- Category A documents provide direct information about treatment options.
- Category B documents provide broader contextual information.

Analysis identified three global themes.

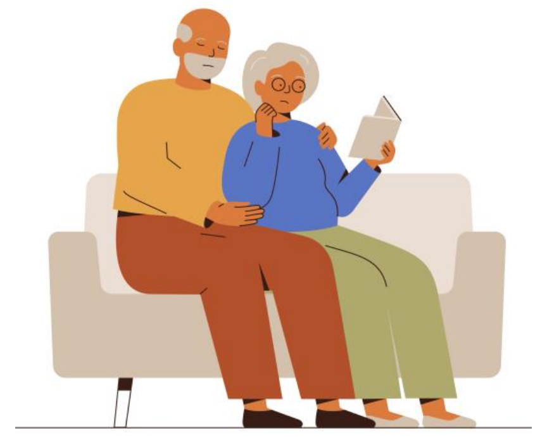
Figure 1. Documents screened and included



1) How treatment options are constructed: Dialysis was typically framed positively (e.g. as "life saving") and CKM negatively (e.g. "this will result in death"). Information about risk was often unclear or missing.

"Kidney failure, if left untreated, is fatal but modern medicine has provided us with a life saving treatment – DIALYSIS."
A-3-11

2) Deciding is challenging: Making a decision between treatment options was portrayed as a challenging process which might require emotional support. Resources emphasised shared and/or informed decision-making and the right to decide, however some resources presented-patients in a passive role.



"It is very difficult to know how to talk to my family and friends. Can you help?
Yes. Many people find it difficult to talk about such matters to those who are close to them."
A-1-18

3) End of life and dying: Advance care planning, palliative care and descriptions of dying were presented in the context of CKM, implying these were not relevant topics for people choosing dialysis.

"When these changes to people's health happen, kidney professionals offer treatments to relieve people's symptoms and give some comfort. These types of options are sometimes known as palliative care."
A-1-20

CONCLUSIONS

- UK information resources typically present unbalanced information about dialysis and CKM.
- Dialysis was framed as "treatment", and possible complications minimised.
- CKM was framed as "non-treatment" and linked to death, palliative care and advance care planning
- Despite the focus on patients' "right" to choose a treatment option, it may therefore be challenging for a person to choose CKM, even when this treatment choice is the best fit for their goals and values.
- For people who choose dialysis, information resources often exclude important end-of-life information, limiting their opportunity to consider and participate in advance care planning.

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