

'Missing' data complicate picture of where patients choose to die

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An NIHR-funded study from the University of Cambridge has raised questions about the widely-held assumption that most patients at the end of their lives prefer to die at home rather than a hospice or hospital.

End-of-life care policy in the UK has a focus on enabling patients to die in their preferred place, believed for most people to be home, although whether home is always the best and preferred place of death is of increasing debate.

A systematic review of 61 studies, published today in the open access journal *PLOS ONE*, which looked at adult preferences for place of death, found that when missing preferences - where the views of participants with no clear preference, or who were unwilling or unable to express or communicate a preference - are taken into consideration, the picture becomes far less clear.

Researchers at the Primary Care Unit and Cambridge Institute of Public Health found that when missing data were excluded, the majority of those questioned preferred to die at home.

However, when the large amount of missing data were included in the analysis, it was no longer clear whether home was where most participants with cancer or other conditions preferred to die.

In many reports a large proportion of participants' preferences were missing. The missing preferences are likely to represent preferences that were not asked or not expressed. Preferences may have been missing because participants were not given the opportunity to state their preference, and so could reflect the difficulty healthcare professionals have in holding conversations about end of life care. Preferences could also be absent because participants did not have a preference to share, which may suggest that place of death is less important to patients than other end of life care issues. Regardless of the reasons, the study authors argue that the exclusion of missing preferences inflates the significance of recorded preferences.

Sarah Hoare, a PhD student at the Cambridge Institute of Public Health, first author of the study, says: "Our review has shown that there is a substantial amount of missing data on UK participants' preferences for place of death. We do not know what locations, if any, these 'missing' preferences are for and so we need to be careful about claiming that the majority of patients wish to die at home."

While surveys of the general public, even with missing data included, tended to show a strong majority preference for dying at home, there was more variability amongst patients and [family members](#) reporting patient preferences. For these groups the extent of missing data meant it was not known what proportion preferred home.

The researchers believe that the variance found between the preferences of the general public and patients could in part be explained by differences in data collection. For example, information provided

about the general public was often drawn from large surveys while patient preferences were often collected from patient records. The differences between public and patient preferences may also in part be attributed to the different meanings given by respondents to questions about preferred place of death.

Dr Stephen Barclay, the study's senior author, adds: "The extent of missing data has major implications for clinical practice. We need to know why patients' preferences have not been recorded. Is it because they do not have a preference, which in itself needs to be recognised as a legitimate opinion? Or does it reflect the difficulty that healthcare professionals have in holding conversations on this sensitive issue, and so patients have not been given a clear opportunity to state a preference?"

"Surveys of the general public are valuable in assessing public opinion, but they do not appear to reflect dying patient preferences," adds Ms Hoare. "Likewise, family members do not appear to necessarily reflect [patients](#)' views. This has implications for UK health policy which relies on next-of-kin reports for assessing quality in end-of-life care."

More information: Hoare, S et al. Do patients want to die at home? A systematic review of the UK literature, focused on missing preferences for place of death. *PLOS ONE*; 10 November 2015

Provided by University of Cambridge

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