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**EXPLORING THE PROCESS OF DECISION MAKING
BETWEEN PATIENTS, FAMILIES AND COMMUNITY
HEALTHCARE PROFESSIONALS AT END OF LIFE**

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Background Many studies in palliative care report that the majority of people would prefer to die at home.¹ It is recognised that the delivery of this care often requires the involvement of many different health care professionals and groups of family members. International evidence highlights the importance of patient choice and the notion of shared decision making in end of life care. However, little is known about how decisions are made.

Aim The aim of this study is to identify what happens in the process of decision-making at end of life (EOL); to uncover participant experience of that process and contribute understanding the issues for patients, families and professionals.

Methods A multiple case study design using a qualitative approach was used. The sample included palliative patients living at home in the last 12 months of life (N=9); their family carers (N=10) and community based healthcare professionals, (general practitioners, nurses, social workers, allied healthcare practitioners) providing palliative care (N=56). Data collection included individual interviews (N=45), observation of interactions between participants, documentary review and focus groups (N=8) of professionals. Drawing on a shared decision making model, within and across case analysis was conducted using the Framework approach to identify themes and match patterns.

Results Decisions are understood among the group via numerous one to one interactions. Subject to assumption and interpretation, decisions are often not explicitly stated and preferred place of death is avoided. Family are central to the process but marginalised from information. The process of death and the implications of dying at home are not explicitly discussed with patient or family.

Conclusions Findings suggest that shared decision making process at end of life is complex. Greater understanding of decision-making in this setting is required to improve care for patients approaching end of life.