

Table 45: Nolan 2008³⁵⁰

Study (ref id)	Nolan 2008 ³⁵⁰
Aim	The study compared the preferences of people with amyotrophic lateral sclerosis (who normally maintain capacity for decision making until close to death) for involving family in healthcare decisions at the end of life with the actual involvement reported by the family after death
Population	People recently (within 8 weeks) diagnosed with ALS. They were excluded if they had an altered mental state. (n=16) The person's identified family members who might participate in healthcare decisions with them. (n=16)
Setting	USA
Study design and methodology	The patients were interviewed every 3 months prior to death <i>or</i> 2 years have elapsed, and the final interview (0 to 3 months prior to death) was included. The patients were asked to think of the most important decision that they had recently made or were about to make regarding their healthcare. Using a modified version of the Control Preferences scale (using picture cards) they were asked to rate how they preferred to make this decision with their family as either independent, through shared decision making, or through surrogate decision making. After death, the researchers interviewed the family member identified by the patient using the Family Member Decision Making Survey, a 30 items comprised of open questions and multiple choice questions. Asking the family member to think about the most important healthcare decision made near death, they were asked to indicate whether the person had made this decision independently, through shared decision making with family, or through decision making that was reliant on family. Using an in-depth qualitative interview they asked whether they had previous experience in decision making with or for another family member at the time of death, whether they had observed another person making decisions with or for a family member or whether they had received positive feedback from anyone about their ability to participate in these types of decisions. They were also asked to rate how satisfied they were with the decision making experience.
Analysis methods	Descriptive statistics used a Cohen's kappa to measure agreement between the patient and the family member's ratings for involvement in decision making. The qualitative data were analysed using content analysis. The investigator who conducted the interview and another independent investigator reviewed the transcript separately and then together. They stopped when theme saturation was reached.
Themes with findings	The actual involvement of the family was concordant with the patients preference in 78% of cases if the person preferred and independent style (n=9), 50% if the person preferred shared decision making (n=6), and 0% if the person preferred to rely on the families judgement (n=0).

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	Facilitators for family members decision making.	Barriers for family members decision making.
	Confidence in decision making usually brought by prior experience in making end of life care decisions.	Lack of support from family or healthcare professionals.
Limitations	Serious limitations. No quotes from the qualitative interviews provided, but summaries. No information from the descriptive elements (the Family Member Decision Making survey) were provided although listed in the methods.	
Applicability of evidence	Direct evidence from the family members as this occurred after the patients died. The information from the dying people is indirect given it could of occurred up to 3 months prior to death. Indirect setting outside of the UK.	