AND WHAT IF THERE IS NO ADVANCE CARE PLANNING? A REVIEW OF THE LITERATURE IN SHARED DECISION MAKING WITH FAMILY AS PROXY IN DYING HOSPITAL PATIENTS

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Background Advance care planning (ACP) is an example of Shared Decision Making (SDM). Of particular concern in palliative care is the significance of both family and non-family
relationships and the patient’s social environment. Together, these influence the patients decisions and can significantly impact the direction of care. Proxies can be all that healthcare professionals (HCP) have to guide them in a patient with insufficient capacity or where (ACP) discussions have not happened. The place of SDM outside of the classical HCP-individual patient consultation is being increasingly explored to address these additional factors behind decision-making.

Aims To appraise and evaluate the literature on SDM with family as proxy in dying adult patients.

Methods A literature search was done using MEDLINE, EMBASE, CINAHL and SDM internet resources up to 7th December 2012. Studies were identified using inclusion & exclusion criteria and study quality appraised using Popay et al’s “Rationale and Standards for the Systematic Review of Qualitative Literature in Health Care”. Summary themes were then identified using content analysis.

Results Fifteen research studies fulfilled inclusion criteria. Nine predominantly researched family experience and six the HCPs experience. There was a paucity of studies from the UK and non-intensive care wards and no studies met Popay’s standards. Themes that arose from these studies included the disagreement on what constituted SDM in this context, difficulty of conversations about dying and family and HCP reported burden on families who had been involved in decisions.

Conclusions The findings are similar to studies examining difficulties in communication about a dying patient. There is no consensus on what decisions can be shared by families and this will differ between different healthcare settings, cultural and legal systems. Therefore there is insufficient evidence in the literature to show how we can incorporate SDM with family as proxy in dying patients into clinical practice.