Journal Watch

What do palliative care patients and their relatives think about research in palliative care? – a systematic review.

White C, Hardy J. Support Care Cancer (2010); 18:905-911.

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Abstract:

Introduction: Research in palliative care patients has been controversial and is often challenging. It is important to know the views of potentially eligible patients themselves in order to determine the appropriateness of research in the palliative care population and to develop realistic studies that are practical and achievable in this population. This systematic review aims to identify the views of palliative care patients and their families towards research, the factors that are important when considering participation, and the types of research trial they would support or reject.\ Methods: A systematic literature review was undertaken to identify what is known to date regarding the views of palliative care patients and their relatives towards research participation. Eight relevant studies were identified.

Conclusion: Research to date in the palliative care setting has suggested that patients are interested in participating in research and may actually benefit from doing so.

Comments:

Strengths/ Uniqueness:

- This is one of a very few systematic reviews to identify the views of palliative care patients and their relatives towards research participation, (only eight studies were identified through a literature search from 1950 to May 2008).
- Although no consistent theme was identified through all studies, the
 authors of this review identified 7 common themes. It is useful to be aware
 of themes that are related to barriers for patients/proxies to enroll into
 studies, such as trial-related factors (e.g. invasiveness, potential sideeffects, financial burden).

Weaknesses:

Due to the low number of studies included in this review, the themes that were extracted still suffer from limited generalizability.

Relevance to Palliative Care

This study provides guidance in designing and conducting studies in palliative care settings, and heightens awareness of how to improve study participation for patients and proxies.