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Receiving A DIagnosis Of MESOthelioma (RADIO Meso): recommendations for practice to improve the patient experience.

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(399 words. Max = 400)

Background

Communicating a diagnosis of mesothelioma is complex and highly skilled[1, 2]. If done badly, 'it can cause long lasting distress, confusion and resentment'[1]. Receiving A DIagnosis Of MESOthelioma (RADIO Meso) is a qualitative research project designed to identify ways to improve patient and family carer experience of receiving a mesothelioma diagnosis by generating evidence based recommendations for practice. This abstract provides an overview of the findings and a summary of ~~final~~ recommendations.

Methods

The study utilised a descriptive qualitative approach. Individual telephone interviews were conducted with people who had experience of giving or receiving a diagnosis of mesothelioma. This included patients, family carers (N=16) and health care professionals (N=16). Two separate focus groups were also carried out with patients and carers (N=27) and mesothelioma nurse specialists (N=15). A national web-based consultation with staff and patients/ family carers was then undertaken. Interview recruitment and the consultation were conducted via electronic mailshots and social media run by Mesothelioma UK, the National Lung Cancer Forum for Nurses and British Thoracic Oncology Group. Interview data was collected between January and December 2017. Consultation data was collected between January and March 2018. Framework analysis methods were used[3].

Results

The findings provide an in-depth understanding of patient, family carer and staff experiences of receiving a mesothelioma diagnosis. A number of patient centred requirements to improve this experience were identified. These requirements form the basis of the recommendations developed and refined through consultation. The recommendations highlight the importance of providing consistency and continuity in terms of who the patient sees and what is said on the diagnostic journey. The recommendations also emphasise the value in health professions having the following: specialist knowledge and skills of both mesothelioma and communication, a patient-centred approach, a quiet and private environment to facilitate communication, sufficient time to address patient and family concerns, access to good quality information resources, and effective partnerships for timely referrals to specialist services. Participants indicated that the involvement of the Clinical Nurse Specialist enhanced diagnostic experience.

Conclusion

The study provides unique insight into the mesothelioma diagnostic experience. The recommendations will be launched by Mesothelioma UK on 1st May 2018. These recommendations will help to inform health professional's decisions and practice regarding the communication of a mesothelioma diagnosis and improve patient experience. The goal is to make the patient feel like the most important person in the room, and at the centre of the communication process.

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