CONCEPTS OF INFORMATION PROVISION IN CANCER CARE – A CRITICAL INTERPRETIVE SYNTHESIS OF LITERATURE

Karolina A Kazimierczak, Zoë C Skea, Sara J MacLennan, James N’Dow

Academic Urology Unit, University of Aberdeen
Overview

• Background
• Methods
• Findings
• Conclusion
• Implications for practice
Background

• Information as an integral part of the delivery of healthcare services
• Crucial tool for the support of cancer patients
• Facilitating involvement in care management and decision-making, providing reassurance, enabling autonomy
• Growing emphasis on the individual nature of patients’ needs and experiences
• Move towards the development of tailored health information services
• Need for critical scrutiny of the concepts underlying approaches to information provision
Methods

Critical interpretive synthesis (CIS)  
(Dixon-Woods et al., 2006)

• Elements of conventional systematic reviews:
  – Formal search strategy
  – Inclusion and exclusion criteria
  – Data extraction and quality appraisal

• Interpretive approaches to analysis and synthesis typical for primary qualitative research:
  – Literature as an object of inquiry
  – All types of evidence included
  – Oriented towards generation of theory

Findings

• 4635 articles identified through formal database search (Medline, Embase, PsychInfo, CINAHL, Web of Knowledge), reference chaining, searching of websites and theoretical sampling

• 765 abstracts screened

• 138 publications retrieved in full text

• 57 publications included (qualitative and quantitative studies, reviews, theoretical and opinion pieces, reports, policy documents, books)

• Thematic analysis of the included publications
Findings

• Analysis of the evidence confirmed a significant diversity and individuality of patients’ needs and preferences related to information in cancer care.

• Synthesis of the evidence identified 2 concepts of information provision:
  – a vision of ‘personalisation through standardisation’ making standardised information available to patients.
  – a vision of ‘navigating the knowledge landscape’ supporting patients’ use of different information tools and their interpretation of their circumstances.
‘Personalisation through standardisation’

• Information provision as a process of “making available” resources
• Patient knowledge as a direct outcome of these inputs
• Patients “enabled” to “engage” in playing their proper role in making choices, managing their care, and exercising autonomy
• Paradoxical vision of the supposedly personalised services offering patients one “correct” way of engaging with healthcare: as passive learners and active consumers
‘Navigating the knowledge landscape’

• Adapted from Daniels et al. (2007)
• Information provision as an ongoing and iterative process unfolding alongside patients’ experiences of health and healthcare
• Part of a dynamic and dialogic practice in which patients are supported to navigate different resources relevant to them
• Patient knowledge as a social practice linked to the broader contexts of healthcare interaction
• Patients able to legitimately vary in what they do and want (rather than being acquiring a burden of rights and being enabled to “engage”)

Conclusion

- Static methods of providing information (i.e. making booklets or leaflets available to patients) insufficient to address the diversity and individuality of patients’ needs and experiences
- Supporting patients’ navigation of different information resources more useful
- Concept of “navigating the knowledge landscape” as a model for flexible and patient-driven information provision
- Importance of reflexivity and critical scrutiny in healthcare research and practice
Implications for practice

- Healthcare professionals responsive to the individuality of patients’ needs and experiences
- Information provision as an ongoing process unfolding alongside patient experience of illness and care
- Information tools (i.e. leaflets, booklets, interactive computer programmes or Internet resources) actively navigated and interpreted by patients with support from healthcare professionals
- Healthcare professionals adopting more flexible roles as supporters, facilitating patients’ use and interpretation of health information, and understanding of their circumstances
- Communication skills training for medical and nursing students and staff emphasises the value of a flexible approach to providing information embodied in the concept of “navigating the knowledge landscape”
Acknowledgements