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Review

Analyzing communication in genetic consultations—A systematic review

Jean Paul [a,b,c], Sylvia Metcalfe [a,b], Lesley Stirling [c], Brenda Wilson [d], Jan Hodgson [a,b,*]

[a] Genetics Education and Health Research, Murdoch Childrens Research Institute, Melbourne, Australia
[b] Department of Paediatrics, The University of Melbourne, Melbourne, Australia
[c] School of Languages and Linguistics, The University of Melbourne, Melbourne, Australia
[d] Department of Epidemiology and Community Medicine, University of Ottawa, Ottawa, Canada

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ABSTRACT

Objective: To systematically review studies that have analyzed communication within medical consultations involving genetic specialists and report on their findings and design.
Methods: Drawing from PRISMA and appropriate guidelines for reviewing qualitative research, a systematic search of seven databases was conducted, followed by selection of studies for inclusion based on a set of criteria. Three authors conducted data extraction and narrative synthesis.
Results: Twenty-two studies were identified and were heterogeneous in setting, design, and methods, with many including limited descriptions of health professionals involved. Despite this variability, studies generally pursued the following three main objectives: searching for structural patterns within consultations, investigating communication and genetic counseling concepts, and linking process with input- and outcome-measures. Structural patterns identified included clinician dialog dominating consultations, and talk being mostly biomedical. Counseling and communication concepts investigated were: risk communication, the negotiation of power and knowledge, and adherence to genetic counseling ideals. Attempts to link consultation data to input- or outcome-measures were often unsuccessful.
Conclusion: More interdisciplinary research, grounded in appropriate theoretical frameworks, is needed to explore inherent complexities in this setting.
Practice implications: Findings from this review can be used to guide the design of future research into the process of genetic consultations.

Contents

* Corresponding author at: Genetics Education and Health Research, Murdoch Childrens Research Institute, The Royal Children's Hospital, Flemington Road, Parkville, Victoria 3052, Australia. Tel.: +61 3 8341 6308; fax: +61 3 8341 6207.
E-mail address: jan.hodgson@mcri.edu.au (J. Hodgson).

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1. Introduction

1.1. Rationale

For almost 35 years senior figures in genetic medicine have called for more studies investigating the content and process of genetic consultations, describing consultations as a 'black box' [1–4]. Clarke argued that assessing outcome-measures alone will not allow for adequate description and evaluation of genetic consultations [3]. While there have been previous reviews of process studies in genetics [5,6] none have systematically reviewed their methods or findings. This paper aims to address that gap.

1.2. Healthcare consultations in genetics

Clients are referred to genetic counseling (GC) for diagnosis, management, support and treatment of genetic conditions [7]. Genetic healthcare covers a range of services including population screening, prenatal diagnosis, and genetic testing for conditions affecting a range of life-stages such as infant or pediatric, adult-onset such as cancer, and susceptibility testing. GC has been described as a 'hybrid activity' combining traditional aspects of medical consultations with those from counseling disciplines [8]. GC involves communicating complex and abstract information while supporting clients to make informed decisions about possible testing and adjust to their genetic identity [7,9,10]. Clarke describes GC as different to other medical interactions where instead of providing treatments, specialists provide information and support [3]. Debate exists around GC ideals, particularly the principle of 'non-directiveness' [11–13] where clinicians "*promote and enhance the autonomy and self-directedness of clients*" [14, p. 164]. In Australia, genetic services are mostly offered through tertiary hospitals by a multidisciplinary team that may include clinical geneticists, genetic counselors and social workers. In various countries, these specialists may be referred to with different titles; for the purpose of this review they will all be referred to as clinicians.

With the introduction of new genomic technologies, clinicians may now provide answers to more clients than previously possible [15]. Although increasing diagnostic yield, these technologies introduce novel challenges relating to incidental and uncertain test results [16], particularly how and what to communicate to clients [15,17–19].

1.3. Approaches to analyzing healthcare interactions

Complexities of clinician–client relationships can be explored through analyzing medical interactions [20] where a better understanding of this relationship may increase the 'therapeutic potential' of medical visits [21, p. 6].

One approach to researching communication processes utilizes quantitative methodologies where 'talk' is broadly coded and classified, investigating communication behaviors and patterns. Byrne and Long classified consultations into phases [22] adapting Bales' coding system, interaction process analysis (IPA), for use in coding medical interactions [23]. Another method is the Roter Interaction Analysis System (RIAS), a widely used tool in medical interaction assessment [24], where speech is 'unitized' and 'categorized' following a systematic pre-determined coding schedule [21, p. 51–2].

An alternative approach involves a microanalysis using qualitative techniques. Qualitative research generally uses an inductive approach to asks questions such as 'why?' and 'how?' thereby allowing the researcher to delve deeply into the data and allow meanings to 'emerge', often with no preconceived hypothesis [25–28]. Researchers undertaking this approach are typically sociologists, linguists, and anthropologists. Examples of particular analytical designs include: discourse analysis (DA), conversation analysis (CA), interactional sociolinguistics (IS), pragmatics, and ethnography. Sarangi and Roberts describe this approach as a 'thick' description, which "*reaches down to the level of fine-grained linguistic analysis and up and out to broader ethnographic description and wider political and ideological accounts...*" [29, p. 1]. Qualitative approaches acknowledge the importance of context in understanding complexities and nuances in interactions.

Although debate exists around which approach is most suitable, it has been argued that a combination of qualitative and quantitative approaches can enable a 'thick' description to be assessed across larger data sets and potentially become generalizable [20].

1.4. Exploring the 'black box' of genetic consultations

Since 1996, three articles have reviewed studies analyzing genetic interactions [3,5,6], although these were not systematic reviews.

In 1996, Clarke et al. reviewed GC process- and outcome-based studies, of which only a few had been conducted [3]. The authors