The role of the genetic counsellor: a systematic review of research evidence

Running title: Genetic counsellor role

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Abstract

In Europe, genetic counsellors are employed in specialist genetic centres or other specialist units. According to the European Board of Medical Genetics, the genetic counsellor must fulfil a range of roles, including provision of information and facilitation of psychosocial adjustment of the client to their genetic status and situation. To evaluate the extent to which genetic counsellors fulfil their prescribed roles, we conducted a systematic review of the published relevant scientific evidence. We searched five relevant electronic databases (Medline, CINAHL, SocIndex, AMED and PsychInfo) using relevant search terms and handsearched four subject-specific journals for research-based papers published in English between 1 January 2000 and 30 June 2013. Of 419 potential papers identified initially, seven satisfied the inclusion criteria for the review. Themes derived from the thematic analysis of the data were: i) rationale for genetic counsellors to provide care, ii) appropriate roles and responsibilities and iii) the types of conditions included in the genetic counsellor caseload. The findings of this systematic review indicate that where genetic counsellors are utilised in specialist genetic settings, they undertake a significant workload associated with direct patient care and this appears to be acceptable to patients. With the burden on genetic services, there is an argument for the increased use of genetic counsellors in countries where they are under-utilised. In addition, roles undertaken by genetic counsellors in specialist genetic settings could be adapted to integrate genetic counsellors into multi-disciplinary teams in other specialisms.

Keywords: genetic counsellor; role; profession; systematic review.

Introduction

Although the term 'genetic counselling' was coined by Sheldon Reed in 1947 [1], the genetic counselling profession is relatively young in comparison to medicine and nursing. While genetic counselling can be undertaken by trained professionals from a range of disciplines, those describing themselves as genetic counsellors are specifically trained for the work. A definition of genetic counselling as an activity was produced by the NSGC Taskforce in 2006 and states that 'genetic counselling is the process of helping people understand and adapt to the medical, psychological and familial implications of the genetic contributions to disease. The process includes interpretation, risk assessment, education and counselling [2]. However, the members of that Task Force deliberately sought to define the activity, rather than the professional role of genetic counsellors. In Europe, the Ad Hoc Genetic Nurse and Counsellor Committee of the European Society of Human Genetics (ESHG) suggested that 'genetic counsellor' should be a protected professional title referring to a health professional who had been educated and trained at Master's level to enable them to develop the core competence defined for the role and to practice according to the Code of Ethics[3]. This definition has been adopted by the European Board of Medical Genetics (EBMG), which is responsible for registration of genetic counsellors in Europe[4]. The key aspects of the role of the European genetic counsellor are presented in Figure 1.

Genetic counsellors may be employed in specialist genetic centres or within other specialist units. Frequently they contribute to patient care as one member of a multi-disciplinary team for example in oncology[5], ophthalmology[6], cardiology[7], metabolic clinics[8] or obstetrics [9]. The roles of the genetic counsellor (Fig 1) include both information giving and exploration of the client's circumstances and needs[3]. However, it is not clear whether genetic counsellors fulfil all of the roles ascribed to them, in either specialist genetic clinics or in more

mainstream healthcare settings. For example, there has long been discussion around whether genetic counsellors adhere to a teaching or counselling model of practice. The 'teaching model' relies far more on information provision to support decision making than exploration of the client's emotional and social needs, while use of the 'counselling model' may enhance the exploration of the context of decisions to be made and support adaptation to risk or diagnosis. It could be argued that use of the teaching model reinforces the position of the counsellor as expert; however those who adhere to this model see information as empowering to clients, while those using the counselling model emphasise the relationship between client and counsellor and positive regard for the client as being the tools of empowerment. Meiser et al[10] undertook a systematic review of studies that involved analysis of actual genetic counselling sessions by genetic healthcare providers, including genetic counsellors. The authors concluded that the teaching model appeared to predominate, with counsellors spending much more time speaking during the consultation than clients. However, more positive outcomes for clients were associated with those consultations in which clients were given more opportunities to speak and the counsellor was less dominant. It therefore appears that both information provision and sensitive counselling are required to fulfil the role appropriately and maximise benefit to patients.

In order to evaluate the extent to which genetic counsellors fulfil the roles adopted by the European Board of Medical Genetics, we conducted a systematic review of the published relevant scientific evidence.

Materials and Methods

Conducting a systematic review enables the evidence on a particular topic to be gathered, analysed and synthesised. Adherence to a rigorous set of guidelines is essential to ensure rigour and objectivity. We followed the process for systematic reviews developed by the

Centre for Reviews and Dissemination[11], which involves identification of relevant search terms, selection of studies based on explicit inclusion and exclusion criteria and quality assessment of papers. The research question was 'What is the role of the genetic counsellor?'.

Search strategy

We initially conducted a search of five relevant electronic databases: Medline, CINAHL, SocIndex, AMED and PsychInfo. Following an initial ad hoc search to determine the relevant search terms, we used the following search terms: 'genetic counsellor' OR 'genetic counselor' AND 'role' OR 'task' OR 'responsibility' OR activity' OR 'job' OR 'profession' AND 'service' OR 'clinic' OR 'hospital' OR 'community' (within any part of the text). The search focussed on papers published in English between 1 January 2000 and 30 June 2013 and the search was limited to published articles.

Papers were eligible for inclusion if they: i) were based on research using qualitative, quantitative or mixed methods designs, ii) included data on roles or clinical responsibilities of genetic counsellors (where the paper reported roles of multiple professions, they were included if data related to genetic counsellors could be extracted from data on other professions) and iii) focussed on the role of the genetic counsellor in specialist genetic or other clinical settings in any country.

Papers were excluded if they: i) focussed on patient perceptions of the service, rather than analysis of the genetic counsellor role, ii) related to comparison of delivery modes for genetic counselling, e.g. telephone versus face to face counselling, iii) related to *styles* of counselling rather than *roles* or iv) *w*ere focussed on genetic counsellor education.

As a result of the initial search, we identified 419 potential papers for inclusion. Of these, 63 were duplicates, leaving 356 papers for examination. Further to this process, a handsearch of the indexes of four highly relevant journals for papers published between the relevant dates

was undertaken, these were: *Journal of Genetic Counseling, American Journal of Medical Genetics, European Journal of Human Genetics* and *Clinical Genetics.* No further papers were identified. After reading the titles of all papers, a further 299 were excluded, leaving a total of 57 papers. The abstracts of these papers were read by two researchers, and a further 40 were excluded on the grounds that they did not fit the exclusion criteria (see Figure 2). All 17 remaining papers were read in full by two researchers, of these seven fitted the criteria for the review. This process is illustrated in the PRISMA flow diagram in Figure 2.

Quality assessment

Assessment of the quality of studies was undertaken using the tool developed by Kmet et al[12] . This tool facilitates evaluation of both quantitative and qualitative studies, using two lists of relevant questions. Each paper is scored against each question, a score of 2 is assigned if the quality criterion is met, 1 if partially met and 0 if not met. The total score is then converted to a percentage. Each paper was assessed independently by two researchers and any areas of disagreement were discussed until consensus was reached. The tool developers[12] do not specify a cut-off point below which papers should be discarded; we decided that a cut-off point of 60% was appropriate to enable us to exclude poor quality papers. The range of scores for the included papers was 60% - 89%, therefore all were included.

Data abstraction

Original data from the included studies were abstracted and presented in a table. As there was a diversity of studies and populations, a meta-analysis of the data was not feasible. We therefore conducted a thematic analysis of the data[13] and present this in narrative form. At least two of the authors were involved in data selection and abstraction at every stage in the review.

Results

Original data from the included studies are presented in Table 1. Of the seven studies, three were conducted in the United States (US), three in Australia and one in South Africa. Two studies were undertaken using qualitative methods[14,15]. Of the other five studies, two involved both analysis of secondary data and a survey[16,17], one was based on a retrospective case series[18] and two were survey-based[19,20] . Cohort sizes ranged from 10 to 76 participants. The themes extracted from the papers were: 1) rationale for using genetic counsellors to provide clinical care, 2) appropriate roles and responsibilities for genetic counsellors and 3) types of conditions that could be included in the genetic counsellor caseload.

The education and training of the genetic counsellors who were the focus of the studies was not mentioned in all papers. In the US papers, Hannig et al[16] stated that genetic counsellors were licensed in the US state in which the study took place, while Powell et al[20] and Hines et al[15] studied members of the NSGC. It can therefore be assumed that the majority of the genetic counsellors in those studies were educated via a Master's programme in genetic counselling. Hodgson et al[14] explained that in Australia genetic counsellors undertook a postgraduate diploma in genetic counselling and could be certified by submitting a portfolio of cases to the Board of Censors of the Human Genetic Society of Australasia (HGSA). In that study, five participants were trained as genetic counsellors and one was certified. Similarly, in another Australian study James et al[19] recruited certified genetic counsellors and associate genetic counsellors. All ten counsellors in Kromberg et al's Australian study[18] were HGSA certified but had a range of backgrounds; five were nurses. Kromberg et al[17] described the education of genetic counsellors in South Africa: all undertake a Master's degree in genetic counselling and are able to apply for registration as a genetic counsellor with the Health Professionals Council of South Africa (HPCSA).

Rationale for genetic counsellors to provide clinical care

Authors stated that there was a need for genetic counsellors to be utilised to provide care because the number of patients seeking genetic healthcare was growing rapidly and the numbers of available medical geneticists could not cope with the demand[16]; the increased demand for genetic counsellors was also related to increase in the complexity of cases and the number of laboratory test that were available, for which informed consent was necessary[16]. Related to this point, Kromberg et al[17] suggested that the role of the genetic counsellor would expand further, as pre and post-test counselling was essential to accompany the increasing number of tests available, particularly for pre-symptomatic tests. It was claimed that genetic counsellors had more available clinical time than medical geneticists and consultations with genetic counsellors were therefore less pressured[16]. Powell et al[20] stated that the skills of the genetic counsellor were useful in public health settings, citing involvement in administering newborn screening programmes as an example. However, with regard to the value placed on genetic counsellors in some settings, it may be significant that the genetic counsellors in the study by Hannig et al [16] were only allocated clinical space on a day it was not required by others and were unable to charge for their services. This could be important in a healthcare system placed on insurance, such as the US where that study was set.

Appropriate roles and responsibilities for genetic counsellors

Some authors described the activities undertaken by genetic counsellors in the clinical environment. These included family history taking[16,19], pedigree drawing[19], risk assessment [16,19], discussion of natural history of the condition[16], psychosocial impact of the diagnosis[19], provision of patient education[15,18,19], discussion of options[16], addressing ethical issues[15], making a psychosocial assessment[16] and providing psychosocial support[15] . Other responsibilities perceived to be appropriate for genetic counsellors included providing professional and public education[18,20] and conducting newborn screening programmes[20]

Some authors mentioned roles that were not considered appropriate for genetic counsellor to undertake: Hannig et al[16] expressly stated that examination and management of complex cases was outside the role. However, James et al[19] found that some respondents did appear to be conducting clinical examinations. The extent to which this happened varied according to the work setting, as 9% of those working in main units, 20% of those in metro outreach clinics and 42% of those in rural outreach communities said they did clinical examinations, but this depended upon the condition or was performed in consultation with a medical geneticist. In an Australian study[18], the authors did not explicitly state that diagnosis was not undertaken by genetic counsellors, but did say that the reason that 20% of cases were seen by medical geneticists alone was because those cases required diagnostic input. Kromberg et al[17] did not indicate that there were roles that should not be undertaken by genetic counsellors in South Africa, but did stress that emphasis that the prior experience of the counsellor should be considered.

Other authors took a different approach to analysis of roles. For example in the study of prenatal genetic counselling, Hodgson et al[14] described the counsellors providing information on the screening test, diagnostic testing, test procedure, risk of miscarriage, possible results and the nature of the decisions to be made by parents. In the same study the interactions between client and counsellor were designated as: risk communication, decision making dialogue and discourse on abortion. Somewhat similarly, Hines et al[15] organised the responses of their participants into domains labelled information provision, reproductive decision making, psychosocial support and addressing ethical issues. The counsellors in that study offered presymptomatic testing for Huntington disease, and did express the view that in some ways their service differed from other genetic counselling, for example they felt that they were at times more directive in the context of counselling for Huntington disease.

Types of conditions that could be included in the genetic counsellor caseload

It was stated that genetic counsellors could provide care for families affected by or concerned about the following conditions: familial cancer[16-20], neurodegenerative conditions[16] (including offering presymptomatic testing), chromosomal abnormalities[16-20] (including of the sex chromosomes[18,20]), multiple miscarriage[16,17], and single gene disorders[18,20] including haemoglobinopathy [16, 17], cystic fibrosis [16-19], metabolic disorders[17,19] neurofibromatosis[17,18], muscular dystrophy[17,18], haemachromatosis [19] and Huntington disease[15, 17,19]. Counselling for neural tube defect[18,19], advanced maternal age[17,18,20] or abnormal prenatal screening results[17,20] were also explicitly mentioned by several authors.

Of interest, Hannig et al[16] stated that the diagnosis should be known in cases of cystic fibrosis, neurogenetic conditions, endocrine disorders and sex chromosome abnormalities. This seems to contradict the claims of Powell et al[20], who cite cases of developmental delay as suitable for counselling by genetic counsellors and Kromberg et al[17] who cite general 'fetal abnormality' cases as suitable for genetic counsellor management.

Discussion

To ensure rigour, this review was conducted according to the stringent criteria recommended by the Centre for Reviews and Dissemination[11]. The selection of material for inclusion and the quality assessment were conducted independently by at least two authors. However, we did not search for studies that had not been published in peer-reviewed journals and there may be unpublished data that could have contributed to our understanding of this topic.

Both the Council of Europe[21] and the Organiasation for Economic Co-operation and Development (OECD)[22] recommendations on genetic testing emphasise that those considering testing must be provided with relevant information to enable them to give informed consent, and that people providing genetic counselling to accompany testing must have the required educational preparation and training. These points are consistent with the

recommendations made by the Kariainen et al[23] in a document produced as part of the EuroGentest project that genetic counselling within the context of genetic testing must be delivered by a person trained to provide it. In a recent survey of members of the NSGC [24] 73% of the members who responded had completed a Master's degree in genetic counselling, while the majority of respondents to a similar survey for the Australasian Society of Genetic Counsellors[25] had a graduate diploma (41%) or a Master's degree (31%). The majority of genetic counsellors in the studies included in this review therefore appear to have been educated at postgraduate level via a specific genetic counselling programme and all worked in countries where the opportunity for professional registration or certification existed. This confirms the European Board of Medical Genetics stance that education in genetic counselling or genetic nursing at Master's degree level is essential to prepare professionals for practice[4].

Hannig et al[16] suggested that the increases in genetic tests, the concurrent need for genetic counselling to accompany those tests and the limitation to the numbers of medical geneticists to see clients has emphasised the need for genetic counsellors to be included in the team providing specialist genetic healthcare services. This is in keeping with the standards of genetic counsellor practice in Europe[3] that have been adopted by the European Board of Medical Genetics and the recommendations for genetic testing practice[23] accepted by the ESHG, which state that genetic counselling should accompany genetic testing. However, it should be noted that none of the studies in this review were conducted in Europe, and this is an area where research is urgently needed to ensure that genetic counsellor roles are appropriate for this different cultural context.

While there is general agreement about the core component of the role of the genetic counsellor across studies, the inclusion of clinical examination of the consultand for diagnostic purposes is included in only one study[19]. This appears to be controversial, as

diagnosis or management of complex cases by genetic counsellors is specifically excluded in another study[16]. It is possible that conflicting views about clinical examination arise due to the differences in professional backgrounds of genetic counsellors: those who are also nurses may be trained in some examination skills and feel more confident in performing these. The study in which these skills were included was conducted in Australia, where a proportion of genetic counsellors have nursing backgrounds[18] and where those in rural or remote locations may be expected to perform examinations. Diagnostic activities based on clinical examination are not mentioned in the European core competencies for genetic counsellors, however it is clear that genetic counsellors utilise a range of documented evidence to make genetic diagnoses to inform counselling. For example, a genetic counsellor would use the family history and a report signifying a *BRCA1* mutation in an affected family member to make a diagnosis of familial breast and ovarian cancer and counsel the consultand accordingly.

The work of several authors in the area of health psychology has indicated that when an individual is faced with a health threat, adjustment to their circumstances is supported by expression of their emotional responses to the situation[26]. This would seem to be consistent with the aspect of the genetic counsellor role that states it is based on an empathic client-centred approach[3]. Enabling and inviting emotional expression could therefore facilitate adaptation and support effective decision making in the context of genetic risk. Roles included in this review include making a psychosocial risk assessment, offering psychosocial support. However, Roter et al[27] identified four general styles of counsellor behaviour. These were clinical teaching (used by 31%), psycho-educational teaching (27%), supportive counselling (33%) and psychosocial counselling (14.9%). Those who used the first three models spoke at least five times as frequently as clients during simulated genetic counselling sessions, while even counsellors who utilised a psychosocial counselling model spoke at least

four times as often as their clients, indicating that the consultation was highly counsellor oriented. One of the limitations of this study was the use of simulated, rather than genuine clients, and this may have affected both client and counsellor behaviour

The results of this review are interesting when compared with the findings of Ellington et al[28], who analysed the content and personal interaction of genetic counselling sessions concerning either prenatal diagnosis or familial cancer risk. The authors found that counsellors spent more time during the session focussed on enabling clients to express emotional responses (25.49% of the total time) than they did supporting cognitive processing of the information provided (4.23% of the total time). However, the authors conclude that both responsiveness to client emotion and enabling cognitive processing are necessary to enable clients to process information provided and enable them to use it effectively in decision making. The predominance of the 'teaching model' within genetic counselling is certainly confirmed by the studies described above[27,28]. This may indicate that genetic counsellors are more comfortable with the 'information giving' aspects of their role than they are with eliciting client concerns or providing psychological care. However, as indicated by authors such as Lepore et al[26], this focus on information giving may not be optimal in supporting patients to make decisions relevant to their healthcare.

While McCarthy Veach et al [29]have suggested that the model of healthcare offered by genetic counselling practice is somewhat unique, Smets et al [30] argue that genetics specialists have similar ethos to health professionals operating outside the genetic speciality, and face similar challenges in engaging clients, eliciting the client's agenda and facilitating understanding of relevant concepts. The authors conclude that rather than claim unique skills and approaches, genetic specialists could learn from research undertaken on shared decision making and client/professional communication outside the field.

The findings of this systematic review indicate that where genetic counsellors are utilised in specialist genetic settings, they undertake a significant workload associated with direct patient care and this appears to be acceptable to patients. Notwithstanding that limitation, with the increasing burden on genetic services generally, the results of this review could be used to argue for the increased use of genetic counsellors in countries where they are under-utilised. In addition, the roles undertaken by genetic counsellors in specialist genetic settings could be adapted to integrate genetic counsellors into multi-disciplinary teams in other specialisms.

Conflict of Interest: the authors declare no conflict of interest.

Table 1. Table of included papers

Authors and title (country of study)	Objective	Design and method	Participants	Data analysis	Main results	Quality assessment score and quality issues
Hannig VL et al. Expansion of Genetic Services Utilizing a General Genetic Counseling Clinic. (2013) (US)	Objective not clear, but appeared to be to assess activity of newly established GC clinic and ascertain patient satisfaction.	Descriptive case series and cross-sectional survey.	Descriptive data are reported on 321 patients who attended a GC clinic in one institution. Of these, 30/135 (22% RR) completed the survey.	Descriptive statistics.	Genetic counsellors saw 321 patients over 2 years, of these 80% did not require additional consultation with a doctor. This allowed doctors to see complex cases or patients requiring clinical examination. Majority of patients satisfied or very satisfied with service according to range of measures such as waiting time, respect for opinions and feelings, knowledge of GC and presentation of info.97% would recommend the clinic.	61% Survey small, only 22% response rate. Satisfaction surveys generally not good indicators.
Hines KA et al. Genetic counselors' perceived responsibilities regarding reproductive issues for patients at risk for Huntington disease.	'to investigate how genetic counsellors participate in reproductive decision making with individuals at risk of HD and how they manage the tension between non-directiveness and other ethical	Qualitative descriptive study.	Members of the National Society of Genetic Counselors who had counselled patients at risk of HD. Potential participants completed an online questionnaire (n=93) and of 31 who volunteered for	Inductive and cross-case method of qualitative analysis.	Counsellor responsibilities are: information provision, involvement in reproductive decision making. Psychosocial support, addressing ethical issues. Counsellors also felt their responsibilities were dissimilar to those of genetic counsellors who dealt with patients with other genetic conditions or issues.	85%

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(2010) (mainly US)	issues regarding reproductive decisions' (p133-134).		a phone interview, 15 were interviewed.			
Hodgson J et al. "Testing times, challenging choices": an Australian study of prenatal genetic counseling. (2010) (Australia)	'To explore current practice in prenatal genetic counseling sessions in Victoria, Australia' (p23)	Counselling sessions with the GC were taped and the transcripts analysed.	52 women at increased risk of fetal anomaly after screening were invited, 21 took part.	Conversation and discourse analysis	Content of the sessions included the following: screening test, diagnostic testing, explanation of test procedure, explanation of risk of miscarriage, explanation of possible results, talking about decisions to be made. The interactions between client and counsellor were designated as: risk communication, decision making dialogue and discourse on abortion.	80%
James C et al. The Genetic Counseling Workplace—An Australasian Perspective. A National Study of Workplace Issues for Genetic Counselors and Associate Genetic Counselors. (2003) (Australasia)	'To obtain a clearer picture of the day-to-day situation for counselors, documenting their roles and resources' (p440)	Cross-sectional survey. Questionnaire included sections on demographics, level of responsibility, education and promotion, resources and technology and professional development.	Cohort consisted of non-medical genetic health professionals working in genetic counselling units in Australia and New Zealand. 76/107 were returned (Response rate 71%)	Percentages and frequencies	In main units, 50% of clients seen by genetic counsellor alone, this rises to 70% in outreach and rural clinics. Agreement in roles generally regarded as those of GC, such as pedigree drawing, explanation of inheritance pattern, risk assessment and psychological impact of diagnosis. Some discrepancies regarding some key activities such as clinical examination or ordering tests.	66%

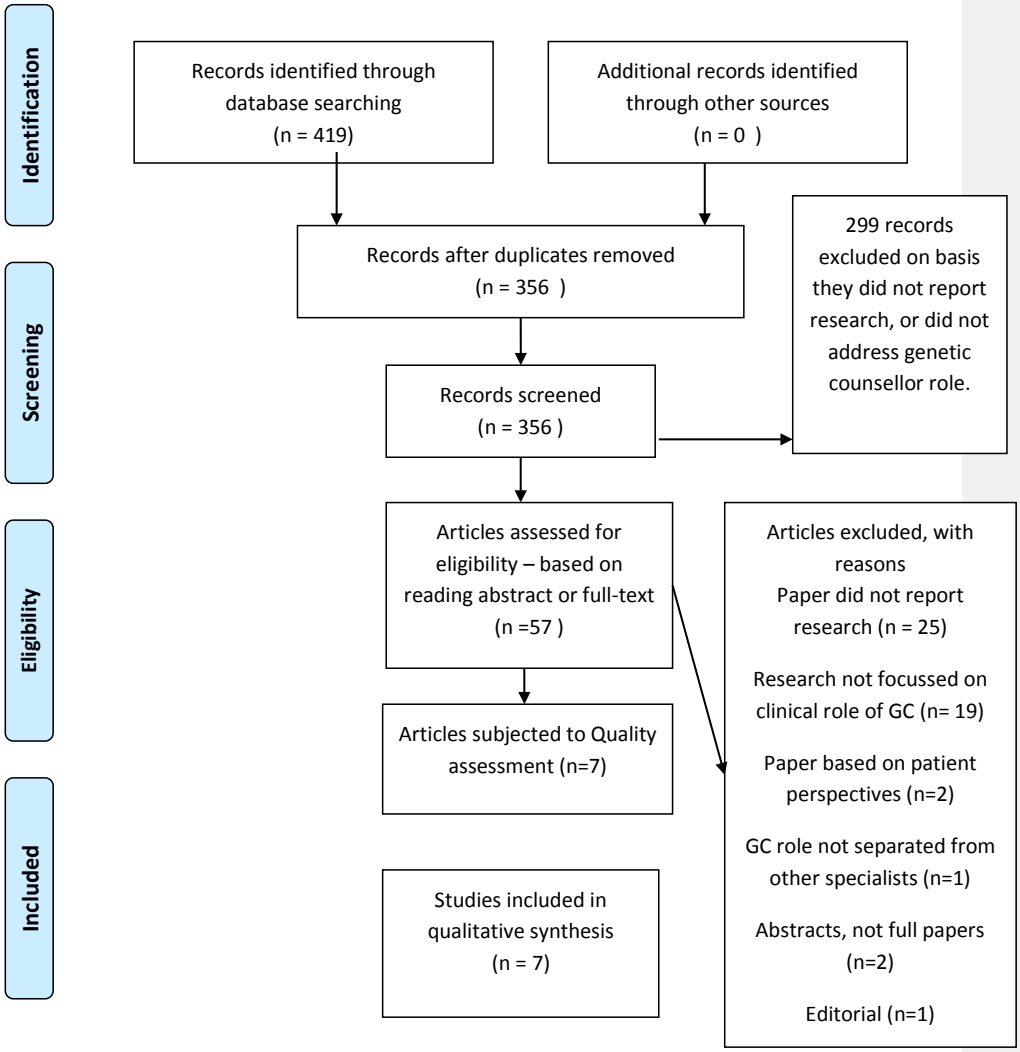
Kromberg JGR et al. A Genetic Counselling as a Developing Healthcare Profession: A Case Study In the Queensland Context. (2006) (Australia)	'To document nature and scope of genetic counselling services' (p33) over a two year period.	Descriptive case series through retrospective analysis of secondary data.	Database records of the Queensland Clinical Genetic Service were interrogated. These included information on counselling activity of ten professionals who were genetic counsellors or associate genetic counsellors.	Not indicated, but descriptive statistics only reported.	During the study period genetic counsellors saw patients with a total of 79 different disorders, They were counsellors or co-counsellors for 80% of patients seen by the service, 42% of sessions were conducted by the genetic counsellor alone. Most common issues were advanced maternal age (23%) and hereditary cancer (5%). Counsellors also involved in public and health professional education, research, audit, management of clinics, retrieval of medical information and searches for evidence.	69% No description of data analysis method.
Kromberg JGR et al. B Roles of Genetic Counselors in South Africa. (2013) (South Africa)	'to investigate the roles genetic counselors play in the provision of genetic services in South Africa' (page not available, online version)	Cross-sectional survey plus longitudinal retrospective study based register data and clinical records.	All genetic counsellors registered with the HPCSA (n=23). 16 completed questionnaires. Other data obtained from counsellor log books (n=13)and clinical records.	Descriptive statistics and frequencies. Thematic coding of open-ended questionnaire data.	All participants undertook counselling, but some combined this with research or teaching. Genetic counsellors saw 39% (medical geneticists 61%) of referred cases in the study period. Counsellors provided care for patients with 57 different diagnoses, most common AMA and for DS. Counsellors felt role would expand with pre and post test counselling required for greater number of tests for genetic disorders (particularly PST).	78%

Powell K et al. Expanding roles: a survey of public health genetic counsellors. (2010) (mainly US)	'To identify the work settings and public health activities in which genetic counselors participate' (p594)	Cross-sectional survey using a novel questionnaire.	All members of the Public Health Special Interest Group of the National Society of Genetic Counselors. 46 members were eligible, 32 surveys completed (RR 70%)	Descriptive statistics and measures of variability	53% had non-clinical position. 5 counselled adults patients, 4 paediatric patients, 2 prenatal. Conditions included cancer, developmental delay, chromosome disorders, advanced maternal age and prenatal screening results. Educate HP Educate public, chronic disease programmes (mostly counselling or education about cancer), newborn screening programmes, lobbying. Research Writing and administering grants Public genetics needs assessments.	89%. Small sample but 70% of available cohort.

Figure 1. Role of the genetic counsellor

1. To identify the needs of the individual or family and use an empathic client-centred approach to the provision of genetic counselling
2. To collect, select, interpret and analyse information (including family and medical history, pedigree, laboratory results and literature) relevant to the delivery of genetic counselling for individuals or families
3. To help people understand and adapt to the medical, psychological, social and familial implications of genetic contributions to disease
4. To assess the chance of disease occurrence or recurrence
5. To provide education about inheritance, testing, management, prevention, resources and research to relevant individuals or families
6. To promote informed choices and psychological adaptation to the condition or risk of the condition
7. To apply expert knowledge to facilitate the individual or family to access the appropriate healthcare resources, including a medical diagnosis and resources for management of the condition.[3](p172)

Figure 2. PRISMA flow diagram demonstrating selection of papers



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