

This is an Open Access document downloaded from ORCA, Cardiff University's institutional repository: <https://orca.cardiff.ac.uk/id/eprint/103190/>

This is the author's version of a work that was submitted to / accepted for publication.

Citation for final published version:

Mendes, Álvaro, Paneque, Milena, Sousa, Liliana, Clarke, Angus John and Sequeiros, Jorge 2016. How communication of genetic information within the family is addressed in genetic counselling: a systematic review of research evidence. *European Journal of Human Genetics* 24 (3) , pp. 315-325. 10.1038/ejhg.2015.174

Publishers page: <http://dx.doi.org/10.1038/ejhg.2015.174>

Please note:

Changes made as a result of publishing processes such as copy-editing, formatting and page numbers may not be reflected in this version. For the definitive version of this publication, please refer to the published source. You are advised to consult the publisher's version if you wish to cite this paper.

This version is being made available in accordance with publisher policies. See <http://orca.cf.ac.uk/policies.html> for usage policies. Copyright and moral rights for publications made available in ORCA are retained by the copyright holders.



Facilitating the communication of genetic risk information within families: a family systems perspective

ABSTRACT

As genomics expands, health professionals are increasingly asked for advice about the communication of genetic risk information within families. When an inherited genetic condition is diagnosed in an individual it has implications for other family members. The intrafamilial sharing of risk information can be crucial both in terms of health management and life planning issues. It also allows individuals the opportunity to learn about their health risks and treatment options in order to reduce morbidity and mortality in themselves and their family members. However, the sharing of this information is not straightforward and clients of genetic services do not always convey risk information to their at-risk relatives. A family systems approach can provide a suitable context to facilitate communication about an inherited condition to and within families. This article offers a brief overview on the communication of genetic risk information within the family, and on how a family systems perspective may contribute for comprehensive care within multidisciplinary in genetic healthcare to help families' navigate through this process.

INTRODUCTION

As genomic science expands those attending genetic healthcare are also confronted with significant psychosocial challenges. In genetic healthcare, individuals may know their predisposition to a wide range of inherited genetic illnesses, from rare incurable diseases (as Huntington disease and other neurological diseases) to common

preventable diseases (as some hereditary cancers or diabetes). Genetic inherited conditions differ from most other diseases because individual genetic tests often generate information relevant to family members. Although genetic illnesses affect an individual, they carry both health-related and psychosocial implications for the family system as a whole. When a condition is thought of as genetic, it is no longer a strictly individual matter; it is also a family matter, as it involves family history, current life decisions, and potential family futures. Also, the caring system is familial and the way in which (knowledge of) the condition is passed on is interactive and in the context of relationships. Hence, it is central to work in ways that can promote families' adjustment to genetic information and in supportive interventions to the development of an overall caring context (Street, Gray, & Soldan, 2000; Miller, McDaniel, Rolland, & Feetham, 2006).

Communication of genetic risk information within the family is a growing challenge for healthcare systems (Mendes, Paneque, Sousa, Clarke, & Sequeiros, 2015; Dheensa, Fenwick, Shkedi-Rafid, Crawford, & Lucassen, 2015; Bailey, Lewis, Roche, & Powell, 2014). Genetic information is usually understood as encompassing different types of information, ranging from genetic test results, medical family history details, and information regarding the diagnosis of genetic conditions and the associated risks of occurrence and potential transmission to offspring. Disclosing risk to other family members is not straightforward (Gaff et al., 2007; Featherstone, Atkinson, Bharadwaj, & Clarke, 2006; Atkinson, Featherstone, & Gregory, 2013), and difficulties with communication may prevent relatives of becoming aware of their increased risk for developing a medical condition, and thus of the opportunity to make informed choices regarding risk management of the disease and life planning decisions (Duster, 1999; Gaff & Bylund, 2010; Parker & Lucassen, 2003). This raises ethical issues for genetic

health professionals and services, especially because their degree of responsibility (and proactivity) for ensuring relatives' awareness of their risks is unclear and has long been debated (Mendes et al., 2015; Dheensa et al., 2015; Hodgson & Gaff, 2013).

A family systems perspective has been advocated as part of a comprehensive clinical genetics service (Rolland, 1999; McDaniel, 2005). Family therapists are well equipped to work in a broad range of health care settings (Doherty, McDaniel, & Hepworth, 2014), including participating as part of the genetic healthcare multidisciplinary team (McDaniel, 2005). Whilst there has been a relative consensus to consider genetic healthcare from a family or wider social perspective (Gaff & Bylund, 2010; Peterson, 2005; McDaniel, 2005, Rolland & Williams, 2005; Street & Soldan, 1998; Eunupu, 1998; Werner-Lin, 2007), clinical practice focuses almost predominantly on the support of the individual affected or at-risk and not including the family.

As crucial developments and implications of the 'new genetics' are changing the boundaries between health and illness and the ways we relate to ourselves (Arribas-Aylon, 2015; Timmermans & Buchbinder, 2010), this article offers a brief overview on the communication of genetic risk information within families, and the role that family systems ideas and practices can have within multidisciplinary teams working in genetics healthcare to help individuals and families' navigate through this process.

THE CONTEXT OF GENETIC COUNSELLING

Typically genetic counselling has been referred to describe the provision of services to clients affected or asymptomatic but potentially at-risk for genetic conditions. It would involve the discussion of genetic issues and dilemmas that clients face and the conditions they may have to cope with. The term "genetic counselling" is employed in

many ways and in different contexts, but carries two core components: (1) the provision of adequate information about a genetic condition and its risks, (2) and exploring the emotional consequences of being affected or at-risk (Kessler, 1979; Evans, 2006). The main aim of genetic counselling is to enable the patient to make an informed and autonomous choice regarding genetic healthcare options (as the uptake of genetic tests, for example), and to adjust to that options in the context of his or her own life. Its provision largely relies on a psychotherapeutic model of interaction to enhance the incorporation of genetic risk information in individuals' lives, in their health management, and in life planning issues (Kessler, 1979; Evans, 2006).

Genetic counseling is often viewed as a frontier discipline between traditional biomedical healthcare and psychotherapy (Lewis, 2002). In the early 20th century genetic counselling was deeply rooted in eugenics to educate for limiting the procreation of the inferior, sick or defective; in the post-Second World War developments saw an explicit distancing from eugenics by merging concepts from psychotherapy, namely a Rogerian client-centered counselling approach (Arribas-Ayllon, Sarangi, & Clarke, 2011; Clarke, 1997). An emphasis on non-directiveness signaled a shift from a strict medical and disease prevention model to a more psychosocial-based model of interaction where supporting clients' autonomous decision-making would enhance the assimilation of genetic information (Clarke, 1991; Elwyin, Gray, & Clarke, 2000; Weil, 2003). Genetic counselling is thus seen as an hybrid activity; differently from both mainstream doctor-patient interaction and from counselling and therapeutic settings, the genetics health professional spends a considerable amount of time gathering specific information (e.g., history taking around family trees), educational elements (e.g., explaining the mechanisms of genetic inheritance and the consequences of the condition, or the risks derived from knowing or

not knowing one's genetic status), and more reflective elements where consultands are encouraged to consider moral and psychological issues regarding, for example, decisions to undergo predictive tests, or about disclosing one's test results to at-risk relatives (Arribas-Ayllon, Sarangi, & Clarke, 2011; McCarthy Veach, LeRoy, & Bartels, 2003).

Delivery of genetic counselling varies considerably across and within countries. Typically, clinical practice is carried out by a variety of professionals, ranging from specialist nurses, genetic counsellors, and medical geneticists. Broadly, the communicative process of genetic counselling entails first listening to the clients to address their concerns and assess their baseline understanding and knowledge of the disease, previous experience and background. If genetic testing is feasible, there may be a discussion on the pros and cons of testing and about practical decisions to be made; for example, concerning reproductive options of surveillance (such as colonoscopies) or risk reduction measures (as prophylactic surgeries). According to the characteristics of the disease, genetic counselling protocols usually comprise 2 or 3 sessions over a period of time leading up to genetic testing; this allows clients the necessary time to reflect on their decision to test or not to test and to disclose or not to disclose their test results to their relatives. In this pre-test period, a psychosocial evaluation is generally performed, where professionals usually handle explanations about risk and of clinical and scientific evidence and invite consultands to reflect about hypothetical scenarios, namely about their intentions to share test results to potentially at-risk relatives and other family members and the potential obstacles to do it. Post-test follow-up usually addresses psychosocial coping and may include an update on the disclosure of risk information within the family. (Arribas-Ayllon, Sarangi, & Clarke, 2011; McCarthy Veach, LeRoy, & Bartels, 2003).

GENETIC RISK AND FAMILY SYSTEMS PERSPECTIVE

Genetically linked conditions are an intense bio-psychological experience for multiple family members and a demanding crisis for the family system. A family systems perspective offers a potentially useful framework for understanding family issues in the scope of genetic illnesses (McDaniel, 2005; Peters, Djurdjinovic, & Baker, 1999; Rolland & Williams, 2005; Street, Gray, & Soldan, 2000). Research states that the family influences and is influenced by the response, the use, and the meaning ascribed to genetic risk (Richards, 1996; Miller et al., 2006; Van Oostrom et al., 2007). Genetic inherited conditions commonly reveal multigenerational patterns of illness manifestation, and can shape families' processes and patterns of communication, norms and expectations about the individual and the family life cycle. The interactions between transitions occurring in individual and in the family life cycle and health-related information assume particular clinical significance (Brouwer-Dudokde et al., 2002; Street et al., 2000). Also, families exposed to inherited risk tend to define their identity based almost exclusively on that experience; this reorganisation around the ambiguous territory of risk and the need to develop coping efforts under emotionally charged contexts can lead to rigidification of family functioning and development and erode the sense of family identity (Patterson, Garwick, 1994; Sobel & Cowan, 2000).

Families dealing with genetic illnesses are typically confronted with several practical and emotional challenges, often carrying significant uncertainty (concerning disease inheritance, timing of onset and symptoms severity, preventative and prophylactic procedures and timings, personal and family planning) and psychological distress, since procedures are permeated by anxiety and the highly complex nature of genetic information (Evers-Kiebooms et al., 2000). Patterns of family communication and behavior can be challenged and modified as family members handle genetic risk

information. Genetic conditions bring to the forefront the multiple roles in which family members can be impacted by a diagnosis or a family history of a genetic condition. Family members may become worried for an affected relative, or distressed for the potential implications for their own health and for other family members. Even those family members who are unaffected and not at-risk may experience higher levels of anxiety, and survivor guilt, after receiving a non-carrier result (Biesecker & Marteau, 1999). The more vulnerable points in family interactions are tested under the stress-laden information of a genetic diagnosis, or the uncertainty of genetic testing; and can occur. This can prompt new alignments either due to more close, distanced or disengaged patterns of interaction (McDaniel, 2005; Galvin & Young, 2010).

Communication in families about a diagnosis of an inherited genetic condition and its implications is not a single event or act, but rather an ongoing and dynamic process that occurs over time. Families can respond and communicate very differently when dealing with genetic illnesses: there may be open discussions, selective attempts to avoid talking about health-related issues, or secrecy. Such dynamics can evolve as family members go through their life cycle and families exchange resources such as information and support. For example, parents may decide not to inform their children about the genetic condition as they feel unconfident deciding when and how to talk; they may change their decision as children reach adulthood and information can have implications for relevant life decisions, as partnering. Delayed or non-disclosure of risk information in families may affect family cohesion and can result in conflicts and poor emotional and psychosocial well-being in families.

A family resilience approach (Walsh, 1996) enables families to manage such demands by strengthening relational ties and coping styles, not only through problem-solving or decision-making, but also through problem prevention and preparing family members to

meet future challenges. This systemic focus also involves support networks and larger systems to promote community connections that families may have lost. Resilience is also promoted by contextualizing and normalizing the crisis, and by offering pragmatic guidelines for adaptation, as for the facilitation of family communication. It is generally accepted that family-oriented psychosocial interventions in genetic healthcare are a key tenet to address the immediate and long-term needs for those genetically at risk (McDaniel et al., 2006).

A conceptual framework addressing the set of psychosocial issues faced by families with genetic conditions was provided by Street & Soldan (1998), based on Rolland's previous work on Family Systems Illness Model (Rolland, 1994). These authors have proposed an expansion of the time phases (course) of the illness, because of its insufficiency to account the time before the illness onset: the pre-illness phase; this is especially relevant since in many cases mutation carriers live pre-symptomatically for a considerable amount of time, before visible symptoms of the disease become noticeable. Subsequently, Rolland & Williams (2005) developed a psychosocial typology of genetic disorders where they include the timeline of genetic illnesses, distinguishing its non-symptomatic and post-clinical onset phases, each with sub-phases and related psychosocial demands. The typology is based on four biological variables: the likelihood of developing the genetic condition; its clinical severity; timing of clinical onset; and the availability of treatment or preventive measures. This typology has also conceptualized the interface between the time phases of genetic conditions through the individual and family life cycle, suggesting a way for health practitioners to consider it longitudinally as an ongoing process with transition points and changing demands. The influence of anticipatory loss is also acknowledged; living with uncertainty due to possible, probable or inevitable future loss is challenging for individuals and their

families. Uncertainty contained in genetic information is clearly out of synch with those normative expectations which are associated with personal life cycle stages. This typology attempts to develop a framework to organize the inherent complexity of genetics into a common meta-language for professionals. For example, a condition that can be present in newborns or in childhood, progressive and life-shortening, untreatable, and with high risk of recurrence in descendants is likely to impact very differently on a family than one preventable, adult-onset condition that confers only moderate risk to relatives. Overall, the interaction of these factors is likely to influence aspects of family communication that may be relevant for the provision of genetic healthcare.

FAMILY COMMUNICATION OF GENETIC RISK

Clients of genetics services are the main gatekeepers of genetic information to other family members (Gaff & Bylund, 2010). Empirical research has shown most patients undergo genetic tests not only for their own benefit but also for the sake of their relatives (Weiner, 2011). Patients perceive themselves as responsible to disclose risk information to relatives and they actually intend to tell their at-risk relatives about genetic test results and other relevant risk information. However, the sharing of this information can be problematic and the client does not always convey risk information to their at-risk relatives. Literature has shown that common difficulties with communication include: doubts about whom, what and when to tell, and whether relatives ‘need to know’; conflicting senses of personal responsibility towards kin around ‘doing the right thing’; the wish to protect relatives from anxiety and alarm; guilt and fear of blame; geographical distance, poor family relationships, rifts and family re-configurations; and a perceived imperfect understanding of the information provided in genetic counselling (Gaff et al., 2007; Seymour, Addington-Hall, Lucassen,

Foster, 2010; Wiseman, Dancyger, Michie, 2010). Besides these individual aspects and patterns of family dynamics, disease characteristics and cultural factors may also withhold or delay disclosure of genetic information to at-risk relatives (Forrest et al., 2003; Wilson et al., 2004; Hallowell, 2005). Patients may be unsure of the professionals' responsibility and some can actually think that professionals should inform relatives rather than themselves (Mesters, Ausems, Eichhorn, & Vasen, 2005). There are also cases where information is actively withheld, cases where a 'passive' failure to disclose information occurs, and cases where even when attempts to communicate are made, they may not be open enough to allow the flow of information between family members (Gaff, Collins, Symes, & Halliday, 2005). Also, patterns of mutual surveillance for signs of disease and moral scrutiny, as well as beliefs about inheritance and disease are critical in the shaping of intrafamilial communication (Atkinson et al., 2006). Overall, nondisclosure can seriously hinder family's relationships and undermine its support structures (Sobel & Cowan, 2000; 2003). Furthermore, research has also shown that even though clients feel committed in transmitting genetic information to relatives, they also feel burdened by the lack of professional guidance to carry on this task (Hodgson et al., 2014; Gaff & Hodgson, 2013; Mendes & Sousa, 2012).

Communication is most likely to occur among first-degree relatives or spouses and when relationships are defined as cohesive and without conflict. The transmission of risk information in families was found to be mainly a female 'gendered' activity, and children and young people under 18 years old are less likely to be told (Seymour et al., 2010; Wiseman et al., 2010). One of the biggest challenges for families living with inherited genetic conditions is the decision for parents to talk to their children about the genetic condition, in ways that can be age and developmentally appropriate and without

causing them anxiety or limit their self-concept and self-esteem (Metcalf, Coad, Plumridge, Gill, & Farndon, 2008).

Genetic information is not neutral-objective; knowledge of genetic information may change the individuals' notion of identity and agency, and affects the one who receives it and has different implications for different individuals (Boddington & Gregory, 2006). Literature shows that family communication about genetics is a deliberative process in which several aspects are assessed, namely: knowing one's personal risk before deciding who and what to tell; consideration of the effects of the disclosure, where the degree of vulnerability and receptivity of the relative are assessed in terms of weighing the wish to provide them with useful health-related information and protect them from potential unwelcome news; decisions about what to be disclosed; and the right time to disclose such information, where the mean and context of the communication and the life stage of the relative are taken into consideration (Gaff et al., 2007). Several communication strategies were identified, varying within and between families, and ranging from complete openness, limited and selective disclosure, and total secrecy. In some cases direct disclosure occurs, while the use of intermediaries to inform other relatives has been reported to be used mostly by men. Furthermore, (). The sharing of genetic risk information to other family members is aligned with the rhythms of the families' communication patterns and with their temporal and biographical timeframes, and therefore intrafamilial communication may be whether facilitated or undermined by external pressures or prompts (Atkinson, Featherstone, & Gregory, 2013; Lafrenière, Bouchard, Godard, Simard, & Dorval, 2013; Geelen, Van Hoyweghen, & Horstman, 2011; Gaff et al., 2007).

COMMUNICATION OF GENETIC RISK INFORMATION WITHIN THE FAMILY: ETHICAL AND PRACTICAL ISSUES

Professional guidelines recommend that professionals should not contact family members directly, but they also state that professionals should actively encourage consultands to transmit relevant risk information to relatives and support them throughout the communication process; however, there is lack of clarity regarding how this should be done (Forrest, Delatycki, Skene, & Aitken, 2007).

Genetic health practitioners typically rely on the client to inform relatives about their potential at-risk status. Subsequently, they also rely on other family members who come forward for testing, which to some extent makes those members responsible for sharing information with additional family members. For clinicians, adherence to the principle means that both the clients' wish of (not) to disclose information to relatives or their wish of (not) knowing must be respected (Hodgson & Gaff, 2013). However, when consultands fail to disclose important information to relatives, professionals are confronted with potential ethical tensions between addressing the needs of the individual and those of their family in relation to the genetic risk information (Dheensa et al., 2015).

Professionals are ethically poised between the need to balance patient's right to confidentiality and the potential for harm, or at least for preventing the opportunity for benefit, to uninformed relatives. This will be dependent on the implications of the condition and of the nature of information involved. Depending on the genetic condition, genetic information can be so important for family members than for the patient itself, as they also have risks arising from their genetic inheritance and health management and life planning options that could be put in practice. There are genetic

conditions for which the value of disseminating genetic information in the family would not be so pressing. However, there are genetic conditions with a strong potential impact on family members, especially those that are treatable if detected early and potentially fatal if detected late (such as hereditary cancers); and those conditions that are not preventable nor treatable but for which advance knowledge allows individuals to make life and reproductive choices they otherwise would not have made (such as several neurodegenerative diseases, Huntington's disease, for example) (Middleton, 2012). With genetic diseases increasingly having potential treatments or preventive measures, a more proactive role of health services is being advocated (Otlowsky, 2013).

Traditional biomedicine models assert the consultand as the 'owners' of medical information; this model is challenged when, for instance, there is potential of harm to uninformed relatives (Leonard & Newson, 2010). Some authors have challenged the supremacy of individual autonomy and confidentiality in genetic medicine and introduced versions of genetic information as a 'joint account' model, in which patients' clinical information is thought as confidential but genetic information is taken as familial, so that family members would have equal rights of access to that information without representing a breach of confidentiality (Leonard, Newson, 2010; Parker & Lucassen, 2004). These dilemmas of breaching confidentiality or allowing potential harm for uninformed relatives have been sidestepped by alternative approaches to genetic information ownership. The 'genetic unity' approach states that before testing takes place, consultands are told that genetic information is inescapably familial and as such it must be communicated to family members, either by the consultand him/herself or by the genetic service as necessary. The 'family comity' approach argues that professionals should take an active role in promoting the sharing of genetic information within the family; this model seeks to balance notions of individual autonomy and more

relational and communitarian ethical theories, where the concept of ‘genetic solidarity and altruism’ come to the fore (Davey, Newson, & O’Leary, 2006; Doukas, 2001).

Genetic information pushes the boundaries of individual autonomy from pure independence to a more nuanced ‘autonomy-in-relation’, which emphasizes that people can enhance autonomy through engagement with others and social embeddedness and so developing their capacity to make autonomous and informed decisions (Gilbar, 2007; Seaburn, McDaniel, Kim, & Bassen, 2004). In any case this debate is permeated by ethical issues: while it has been argued that genetic information cannot by its very nature be private, of course a case can also be made for genetic information be regarded as the most private information of all, and which will, inevitably, belong more strongly to the person at hand than to his or her relatives (Clarke, 2007).

So, genetic healthcare services are currently confronted with the challenge of how to adequately support clients who wish to share genetic information with other family members but face difficulties in doing so. We recently undertook a systematic review of the literature showing that the dissemination of information within families is actively encouraged by professionals (Mendes, Paneque, Sousa, Clarke, & Sequeiros, 2015). When the patient is initially reluctant to share relevant information with their relatives, only very rarely do health professionals override their patients’ confidentiality. There are various ways of addressing the issue of family communication about genetics in practice, ranging from more process-focused approaches (such as direct contact) to others that privilege the provision of specific guidance, such as psychoeducation and written information aids. These interventions were generally effective “cues for action” both in terms of intrafamilial disclosure of genetic information and of genetic testing uptake among at-risk relatives. Most the interventions used to support patients to communicate genetic information to their relatives focused on information content and

were delivered as a single transaction with consultands. Additionally, research also suggests that patients feel poorly supported by genetic services, while supportive or counselling elements of risk communication have shown more benefits than informational or educational elements (Edwards et al., 2008). However, this standard of care is compromised when limited multidisciplinary involvement or specialised training are crucial constraints in genetic healthcare in some countries (Mendes, Paneque, Sousa, 2012).

IMPLICATIONS FOR HEALTH CARE

The experience of a genetic disorder is an intense biopsychosocial and familial process (Kessler & Blosch, 1989; Sobel & Cowan, 2003). If there are families who navigate smoothly with their difficulties and can cope with stress, others require specialist attention to deal with various issues attached to their at-risk status for a genetically-linked condition. As genetics is also concerned with the impact of genetic technology on families, the input of a family system perspective can be particularly well suited when reflecting on the value of genetic information for individuals and families, or fostering the capacity or willingness to communicate in families.

Communication in families about genetic risk and its implications holds different patterns of understanding around the transmission of information between individuals. Genetic information, as other difficult health issues, can have different meanings and rules attached according to cultural background and can also impact very differently in individuals and their family members. Considerations about 'who is the family' need to be taken into account: often the biological family would be the primary concern when it comes to disclosure of genetic risk, but family members who are not related by blood ties can benefit from genetic knowledge too. Also, access to genetic information may

represent a significant change for every member of the family and reverberates throughout individuals' and families' life cycles and over generations (Brouwer-Dudokde, Savenije, Zoetewij, Maat-Kiewit, & Tibben, 2002; Gregory, Dimond, Atkinson, Clarke, & Collins, 2007; Boddington & Gregory, 2006). Consideration of roles and communication patterns in the family is key for addressing openness to talk about genetics within the family and the alignment of the boundaries between intrafamilial subsystems. Research has identified the different roles assumed in families while communicating health information in general and genetic information particularly (gatherers, disseminators and blockers) (Ashida et al., 2011; Koehly et al., 2009); this may be anticipated when working with families along with the possible problems individuals' may experience while adopting such roles.

As communication is transactional and mutual, it needs to be seen beyond a 'sender-receiver' logic that merely focuses the 'act' of communication and primarily assesses 'what' is communicated (and how it is recalled, like in a exam) and with 'whom' clients have communicated (Gaff & Bylund, 2010; Mendes et al., 2015). When thinking and working on the communication of genetic information within families, one must work beyond the mere provision of informative-based resources to be passed to family members. The goal should not be to simply highlight the merits of communication, or that being informed is better than being uninformed. One might want to acknowledge untold rules and motivations, often transmitted vertically across generations and being part of familial scripts that inform current patterns, facilitators, and barriers to communication. Declining to inform a relative may be perceived as positive (for example, acting in order to produce benefit or prevent harm) or neutral (perceiving that nothing is needed) (Gaff et al, 2005). So, for some families, effective communication can well be seen as 'failure' to communicate. There is a need to acknowledge the

balance between rights, responsibilities and autonomy of individuals dealing with their own genetic information and the way this is intertwined with those of couples and families. This poses a core ethical dilemma between individual autonomy and collective family responsibility that needs to be confronted within each family according their own moral and value system. The use of reflecting frames (Tomm, 1987a; 1987b; Sarangi et al., 2004) and the adoption of a not-knowing position (Anderson, 2005) may be an appropriate mean to facilitate meaning-making and reach pondered decisions that take into account the intertwining interactional context between personal and interpersonal goals.

CONCLUSION

As genetic healthcare services are required to engage with their clients in reflective considerations of transmitting risk information within families, family systems ideas and practices can provide a suitable context to facilitate better communication about an inherited condition for and within families. Clinically, the tradition of individualized health care is challenged by familial illnesses (McDaniel & LeRoux, 2007). One can state that the psychological and interpersonal aspects of genetic illnesses are a natural venue for family therapists to participate as part of healthcare teams (McDaniel, 2005); however, to ‘do family therapy’ in clinical genetics services would be perhaps a dubious enterprise. But still, knowledge of how families function and communicate and some techniques originated in systemic family therapy are suitable of being adapted to enhance the work of multidisciplinary teams. A family systems approach can aid genetic healthcare teams in exploring the family dynamics and patterns of communication, namely by fostering sensitive ways to appreciate the relevance and

value of genetic information, exploring how communication would occur and its potential impacts on the individuals and in the family as a whole.