A concept of empathy from clients' perspectives in genetic counseling

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Genetic counseling is the process of helping people understand and adapt to the medical, psychological and familial implications of genetic contributions to disease. This process integrates the following: interpretation of family and medical histories to assess the chance of disease occurrence or recurrence. A genetic counseling process is based on a trust and collaborative relationship between a client and a genetic counselor, and "empathy" is a vital role to build the relationship. A concept of empathy and its role have been discussed in many fields. In the context of clinical psychology or medical care, empathy has been said as a reciprocal phenomenon consisted of a sender and a receiver. Success of empathic communication in genetic counseling depends not only on sender's practice, but also on receiver's perception. Several studies reported the perspective of empathy from genetic counseling practitioners. I also conducted an empirical study and revealed a concept of empathy of certified genetic counselors in Japan (Tomozawa et al, 2022). However, few studies have focused on perspectives of clients as receivers of empathy. To clarify this knowledge gap, I carried out two empirical studies to evaluate client perspectives on empathy in the context of genetic counseling.

In the first study in a non-clinical cohort, semi-structured interviews using interpersonal process recall (IPR), and an online survey were conducted with clients and genetic counselors of simulated genetic counseling consultations. A total of 10 simulated consultations were performed by 15 participants (10 participants in client roles and five in counselor roles) using the client scenarios chosen by the client. In the IPR interviews, the interviewer attempted to have the participants identify and focus on specific moments regarding empathy during the video-recorded interaction to elicit the interviewees' thoughts and feelings. Online surveys were also conducted for the clients after the IPR interviews. A qualitative method was used to analysis the interview data and free descriptions from the survey. The results showed that the genetic counselors tried to understand a client's background with referring to one's clinical experiences and managed the session with sensing the client's feeling/thoughts. These practices of the genetic counselors were perceived by the clients. The clients felt senses of secure and trust, which was represented by a category "mind relaxing due to counselor's questions and responses." The clients also experienced a self-understanding, which was represented by a category "gaining awareness and thinking due to the counselor's approach." Some experience of perceived empathy promoted a decision-making process based on self-understanding and self-efficacy at the end of the genetic counseling session. The results of the online survey also showed that the clients perceived empathy from the counselors. Thus, the first study revealed that clients perceived empathy from practitioners. Comparing previous studies in another research fields, how and what informed in genetic counseling might be a unique factor as affecting a sense of empathized.

In the second study, the author conducted semi-structured interviews to reveal experiences of perceived empathy in a clinical cohort. A total of 13 participants were recruited from organizations of patients with cancer, among whom 11 were patients with hereditary breast and ovarian cancer (HBOC) and two were relatives of patients with HBOC. The interview data were analyzed using a qualitative method. Data analysis was organized into five categories related to experiences with empathy: (i) *prior context to perceive empathy* (ii) *consideration and understanding*, (iii) *impression*, and (iv) *impacted area of perceived empathy*; and (v) *no empathy*. Of these categories, the perceived empathy: *consideration and understanding*, and *impression* were core categories, and similar to the concepts revealed in the first study. Other categories showed that clients had different experiences prior to the perceived empathy, that clients had feelings related to insufficiency, and that the perceived empathy might influence clients experience in the long term. The clinical cohort showed diversity of clients' perspectives. Findings of the second study were as follows: core concepts of perceived empathy are similar between non-clinical and clinical cohort; different clients have different experiences prior to perceived empathy, and some clients had negative feelings related to empathy. Future research directions were also suggested, for instance, identifying factors related to perceived empathy, or further research in different population.

These two studies added the clients' perspectives to concepts of empathy in genetic counseling that had been mainly described as the context of practitioners. My previous study (2022) showed that genetic counselors' practice of empathic understanding included changing strategies, adjusting clients, and trying to find out clients' thoughts with multidimensional process. Moreover, genetic counselors met challenges of empathy and felt uncertainty. Present two studies newly revealed that clients received empathy from practitioners, which means, empathy practice was not practitioners' "self-satisfaction". The clients' experiences of perceived empathy could be the basis of self-understanding and decision-making process. However, clients had experienced empathy not only positively but also negatively. These findings also suggest that the practice of empathy which supports effective genetic counseling process is not a standardized skill but a flexible one including manners to suit each client. A reciprocity between a client and a practitioner is at the core in genetic counseling process, and a genetic counselor should practice clinical skills with a perspective of clients. These studies illustrated that genetic counselors should find out the best way to practice empathy in each case with going back and forth between a "micro" view to understand clients deeply and a "macro" view to catch their needs affected by their social and cultural background.