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SHARED DECISION-MAKING IN GENETIC COUNSELING: A SCOPING REVIEW

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Abstract: Background: It is challenging to make informed decision in genetic counseling. Shared decision-making provides a chance in balancing the information and preferences between counselors and counselees. However, the status and prescriptions of shared decision-making have not been extensively studied in genetic counseling. Aim: To develop an up-to-date literature review of the shared decision-making in genetic counseling, identify knowledge gaps, and provide inspiration and suggestions for the development and practice of genetic counseling. Methods: "Genetic Counseling" and "Shared decision-making" were used to search in PubMed, Web of Science, Embase, Wanfang, CNKI and CBM databases. The search deadline was March 26, 2021. Results: A total of 22 articles were included, and four themes were identified: how people involved in genetic counseling, different stakeholders involved in SDM, multiple facilitators and barriers to SDM and the effectiveness of SDM in genetic counseling. Conclusion: Each participant needs to recognize their boundaries and make the best effort to involve in the shared decision-making. In the future, multinational studies should be considered for bringing shared decision-making to the global scale and well-designed studies are required to explore the long-term impact of shared decision-making in genetic counseling.

Keywords: genetic counseling, shared decision-making, influence factors, scoping review

La toma de decisiones compartida en el asesoramiento genético: una revisión del ámbito de aplicación

Resumen: Antecedentes: Es un reto tomar una decisión informada en el asesoramiento genético. La toma de decisiones compartida ofrece una oportunidad para equilibrar la información y las preferencias entre los asesores y los pacientes. Sin embargo, el estado y las prescripciones de la toma de decisiones compartida no se han estudiado ampliamente en el asesoramiento genético. Objetivo: Desarrollar una revisión bibliográfica actualizada de la toma de decisiones compartida en el asesoramiento genético, identificar las lagunas de conocimiento y proporcionar inspiración y sugerencias para el desarrollo y la práctica del asesoramiento genético. Métodos: "Genetic Counseling" y "Shared decision-making" se utilizaron para buscar en las bases de datos PubMed, Web of Science, Embase, Wanfang, CNKI y CBM. La fecha límite de búsqueda fue el 26 de marzo de 2021. Resultados: Se incluyó un total de 22 artículos y se identificó cuatro temas: cómo se involucran las personas en el asesoramiento genético, las diferentes partes interesadas involucradas en la GDS, los múltiples facilitadores y barreras para la GDS y la efectividad de la GDS en el asesoramiento genético. Conclusión: Cada participante necesita reconocer sus límites y hacer el mejor esfuerzo para involucrarse en la toma de decisiones compartida. En el futuro, se debe considerar la realización de estudios multinacionales para llevar la toma de decisiones compartida a la escala global y se requieren estudios bien diseñados para explorar el impacto a largo plazo de la toma de decisiones compartida en el asesoramiento genético.

Palabras clave: asesoramiento genético, toma de decisiones compartida, factores de influencia, revisión de alcance

Tomada de decisão compartilhada em aconselhamento genético: uma revisão de propósito

Antecedentes: Tomar uma decisão informada em aconselhamento genético é um desafio. A tomada de decisão compartilhada (SDM) fornece uma oportunidade para contrabalançar a informação e preferências entre conselheiros e aconselhados. Entretanto, o status e prescrições da tomada de decisão compartilhada não têm sido extensivamente estudados em aconselhamento genético. Objetivo: Desenvolver uma revisão de literatura atualizada sobre a tomada de decisão compartilhada em aconselhamento genético, identificar lacunas no conhecimento e fornecer inspiração e sugestões para o desenvolvimento e prática do aconselhamento genético. Métodos: "Genetic Counseling" e "Shared decision-making" foram usados para pesquisar nos bancos de dados PubMed, Web of Science, Embase, Wanfang, CNKI e CBM. A data limite para a pesquisa foi 26 de março de 2021. Resultados: Um total de 22 artigos foram incluídos e quatro temas foram identificados: como pessoas se envolveram em aconselhamento genético, diferentes interessados envolvidos em SDM, facilitadores e barreiras múltiplas à SDM e efetividade da SDM em aconselhamento genético. Conclusão: Cada participante necessita reconhecer seus limites e fazer os melhores esforços para se envolver em tomada de decisão compartilhada. No futuro, estudos multinacionais devem ser considerados para trazer a tomada de decisão compartilhada a uma escala global e estudos bem desenhados são requeridos para explorar o impacto a longo prazo da tomada de decisão compartilhada em aconselhamento genético.

Palavras chave: aconselhamento genético, tomada de decisão compartilhada, fatores de influência, revisão de propósito

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1. Introduction

The profession of genetic counseling can be traced back as far as 1906. Early genetic counseling including premarital and post marital genetic counseling, which can analyze and explain different genetic variations, and make counselees understand the risk for themselves and the offspring. So genetic counseling has a significant impact for preventing hereditary diseases and birth defects*(1)*. This approach fit well with the interest of the eugenics. Until 1960s, the term "genetic counseling" and "eugenics" were interchangeable*(2)*. In 2006, the National Society of Genetic Counselors (NSGC) defined genetic counseling as the process of helping people understand and adapt to the medical, psychological, and familial implications of genetic contributions to disease*(3)*.

Nowadays, genetic diseases do not have good treatment methods at the current level of medical care, and genetic diseases accompany people throughout their lives. So, each choice of counselees has its own advantages and disadvantages. It is important for counselees to make informed decision based on their values in genetic counseling*(4)*. Non-directiveness counseling was once a typical model in genetic counseling. However, it may be impossible or hard to achieve for many reasons, like health service organizations promoting screening tests. When it comes to oncology genetic counseling, counselors can subconsciously intervene in counselor's decisions. Thus, non-directiveness counseling may confuse counselors and counselees, and counselors may tend to directiveness counseling in this progress*(5)*. Because of the limitation of the non-directiveness counseling model, shared decision-making (SDM) model has appeared. Shared decision-making was defined by involving at least two participants, including counselee and counselor who share information and preferences to reach an agreement on the decision-making process*(6)*. SDM is widely used not only for protecting counselees' autonomy and value as non-directiveness*(7)*, but also for respecting counselees' needs along with the evidence-based guidance by counselors*(8)*.

To date, it is reported that SDM were applied by all sorts of clinical scenarios. SDM excepted been valuable and had good acceptance in elective surgery*(9,10)*, and it was commonly used in oncology which could improve patient's emotional health*(11)*. Similar findings were observed in the field of mental health*(12)*. What's more, SDM was recommended for all, even the "low-risk" patient*(13)*. and including the elderly and children*(14,15)*. In terms of effectiveness, SDM reflect good results. In individual level, SDM showed fewer decisional conflict and greater satisfaction with improving adherence and increase trust. It has also been proven to contribute to reducing health inequalities for vulnerable groups*(16)*. In organizational level, shared decision-making resulted in a lower professional burnout rate, better resource utilization and cost reduction in the long term. Last, in healthcare system level, it would lead to innovative treatment, reduce malpractice costs, and improve cost-effectiveness*(17)*.

Despite the studies are increasingly published on expanding the prescription of stakeholders and the facilitators and barriers for implementing SDM in genetic counseling. The reported cases were mostly limited in a single population, single genetic counseling aspect and single country. And the lacks of orientation on implementation confuse practitioners in counseling progress. Considering the growing demand of genetic counseling, the scoping review was conducted to synthesis different stakeholders' experience and prescriptions of SDM in genetic counseling, identify the knowledge gap, and provide implantation for future practice.

2. Method

2.1. Study design

The protocol of this study was developed by Arksey's scoping review framework*(18)*. The process of this methodology includes five stages: (1) identifying the research question; (2) identifying relevant studies; (3) study selection; (4) charting the data; (5) collating, summarizing and reporting the results.

2.2. Research questions

This scoping review aimed to develop an up-to-date literature review of the SDM in genetic counseling, identify knowledge gaps, and provide

inspiration and suggestions for the development and practice of genetic counseling. The review questions were:

(1) What is the evidence regarding the perceptions of various stakeholders of shared decision-making for genetic counseling?

(2) What is the evidence regarding the facilitators and barriers for implementing shared decision-making in genetic counseling?

2.3. Searching strategies

A systematic search was conducted in six electronic databases (PubMed, Web of Science, EMBASE, CBM, CNKI, and Wanfang) from inception until March 26, 2021, using the following string of key terms: ((counseling OR clinic visits) AND (genetic OR hereditary disease OR genetic disease OR inherited disease)) AND ((((patient OR client OR counselee) AND (involvement OR participation OR engagement)) AND decision making) OR (shared decision-making OR decided together OR informed decision making))

2.4. Study selection

Figure 1 shows the flow diagram of the study selection process. The title and abstract of all articles were screened for eligibility by two researchers (PCY and NN). Disagreements were discussed by the third researcher (SM) until a consensus was reached. Articles were included that: (1) described the stakeholder in genetic counseling, included genetic counseling recipient and their families or caregivers, genetic counseling givers et al; (2) focused on SDM in genetic counseling; (3) the study design included cross-sectional study, randomized controlled trial, quasi-experimental study, cohort study, case-control study and qualitative research; (4) were written in English or Chinese. Articles were excluded if (1) studies focusing on the validity and reliability of scales; (2) studies focusing on developing and evaluating decision aid; (3) existing reviews and conference articles to avoid the risk of including the same studies more than once.

2.5 Charting data

Data of included articles were charted by two researchers independently (PCY and NN). A data extraction form was designed for this review based on Arksey's scoping review framework. The form captured detailed information which the content of authors, year of publication, study location, aim of study, study design, genetic counseling givers and recipients, study instrument, outcome measures and primary results.

3. Results

3.1. Search results

The search retrieved 2549 publications and 1829 after duplication. After title and abstract screening, 139 articles remained for full-text screening. 83 and 34 articles for not aimed at shared decision-making or genetic counseling and are conference or reviews publications were excluded. Eventually, 22 articles were included (Figure 1).

3.2. Article characteristics

Of the 22 articles, the publication year was between 2000 and 2021 and originated from 16 different countries, mostly from the USA (n=6). 12 qualitative and 10 quantitative articles were included in study and the study subject cover genetic counselors, midwives and pregnant women. Table 1 shows article characteristics, Supplements Table 1 and Table 2 show key characteristics in each article.

3.3. How people involved in genetic counseling

The study showed that genetic counselees had a strong desire to share but resulted in private decision progress for various reasons*(19-25)*. Influenced by diverse modes of communications, the consultation was often unsatisfactory. Counselors preferred to explain how the disease developed, but counselees were concerned about the outcomes or alternative options*(26)*. When talking about uncertainty, counselors tended to avoid in-depth discussions to diffuse their responsibility. However, instead of probability information, counselees wanted as much certain information as possible, including information about both good and bad outcomes*(19)*. As for the decision-making progress, counselors seldom tried to influence counselees' decisions overtly even if they felt uneasy about it*(24)*, which made counselees feel

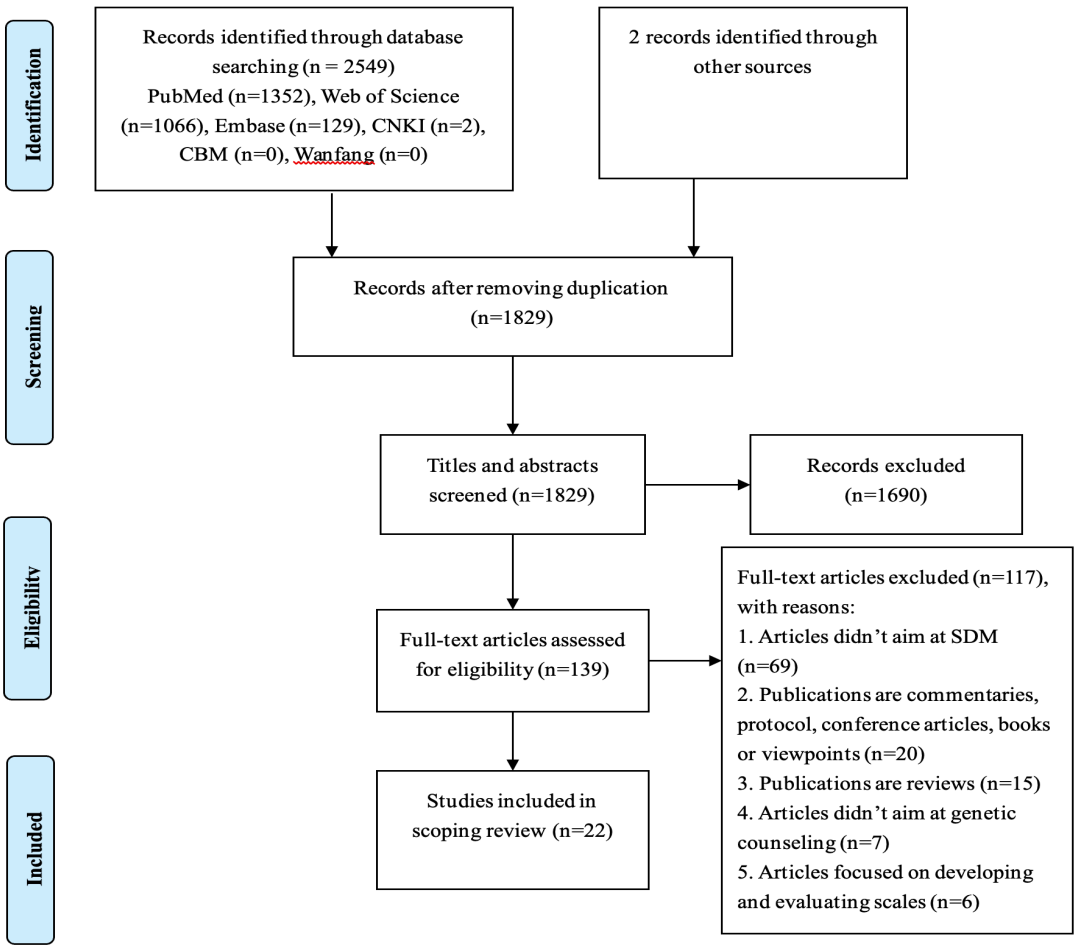


Figure1. Flow diagram of article selection process

frustrated*(25)*. On the contrary, some counselees complained that if they refused the counselor's advice, they were considered irresponsible or irrational*(25)*. Counselors had also made efforts towards SDM by directing patients to consult different specialties to gain more comprehensive knowledge. However, patients have received contradictory information, which has been extremely confusing for them*(26)*.

3.4. Different stakeholders involved in SDM

3.4.1. Involved decision as a couple

In pediatric genetic counseling, healthcare providers thought parents should make independent decisions for their child because only parents knew exactly how their child suffering at home and parents took the responsibility as guardians for the future of child*(27-29)*. Moreover, if had an affected child, parents might feel guilty and self-blamed*(30)*. So they made decisions collaboratively and share the risks to give each other more support*(23)*. The situation was comparable for prenatal genetic counseling. While in prenatal testing, males tend to hand over power to females because it happened to females but not males*(29,31)*. As to encountering disagreement, the most common response was: talking it over until we come to a compromise or agreement*(31)*.

Article characteristics	Types and numbers						
Location	USA (n=6)	China (n=2)	Switzerland (n=2)	Iran (n=2)	UK (n=2)	Italy (n=2)	Netherlands (n=2)
	Australia (n=1)	Denmark (n=1)	Canada (n=1)	Ghana, Cameroon and Tanzania (n=1)	Israel (n=1)	France (n=1)	Pakistan (n=1)
Study design	Cross-sectional study (n=6)	Randomized controlled trial (n=1)	Cohort study (n=1)	Quasi-experimental study (n=2)	Qualitative research (n=12)		
Genetic counseling givers	Genetic counselors (include master's degree in nursing and genetic counseling intern) (n=5)	Gynecologists (n=3)	Midwives (n=2)	Breast surgeons (n=1)	Oncologists (n=1)		
Genetic counseling recipients	Pregnant and birth-giving women (n=9)	Genetic risk Carrier (n=6)	Families or caregivers (n=4)	Patients (n=3)	Religious leaders and community leaders (n=1)		

Table 1 Article characteristics

3.4.2. Families involved in SDM

The participation in decision-making was dynamic in families. When counselees were thought to be vulnerable or immature, their families could intervene in the decision-making progress*(27,32)*. Since the disease originated from family, counselees were willing to discuss it with family members*(27)*. On the contrary, other counselees considered that families might not understand the complexity of the situation especially the families "in-law"*(29,32)*, and too many different views from families would lead to difficulties in decision-making progress*(23)*.

3.4.3. Healthcare providers involved in SDM

Involvements in SDM presented vary among healthcare providers. Counselors believed that they had a higher degree of SDM, though the observer's ratings were in the middle level*(33)*. Likewise, clinical geneticists scored significantly lower than residents or genetic counselors on the degree of SDM*(34)*. Almost all counselees committed that healthcare providers played an important role in genetic counseling. In genetic counseling, healthcare providers include genetic counselors, nurses, gynecologists, midwives, oncologists and so on. Healthcare providers were considered as involved in decision-making because they were knowledgeable about the disease*(27)*. On the other hand, healthcare providers couldn't constitute an arbiter but represent an information giver and a preference constructor*(23,28)*. Getting involved in SDM could make a trustworthy relationship between counselors and counselees*(25,28)*.

3.4.4. Religious leaders involved in SDM

Counseling religious leaders were seen as a pathway in religiously developed regions. Counselees felt that religious beliefs would have some guidance on decision making, but would not be the reason for them to refuse screening or testing(29). In some religious denominations, people would even think of consulting their pastor for this decision. They also stated that consulted clergy as a sign of respect and that whether they consulted

them were also related to the status of the counselees in their community or tribe(27).

3.5. Multiple facilitators and barriers to SDM

3.5.1. Counselees' characteristics and SDM

There are 39%-95%*(23-25,27)* of counselees who prefer SDM. There are a few predictors for this preference. The first one is the education level: a lower education level has a strong relationship with the low autonomy decision making*(20,24)*. On the contrary, K. Tiller*(23)* reported that the preference was not found to be associated with education level, which may uniquely for their participants. And the second one is ethnicity: white men preferred autonomy decision-making, instead, black men preferred provider-driven decision-making, while Asians showed more interest in SDM*(24)*. Meanwhile, informed decision-making ability is another important predictor. When counselees were thought to be vulnerable or immature, family and community would engage in and assist them to make an informed decision*(21,29)*. However, age cannot predict any preference*(20,23)*.

3.5.2. Healthcare providers' characteristics and SDM

Affected by different counseling models, healthcare providers' preferences of SDM were not quite the same. As the typical counseling model, non-directiveness counseling was deeply rooted in genetic counselors' minds. Healthcare providers thought they must withdraw the decision making progress to protect counselees' autonomy*(31)*. With the development of the counseling model, SDM was accepted by clients gradually. About 47% of healthcare providers were in favor of SDM*(21)*. Counselors with a more positive attitude towards SDM showed a higher degree of SDM in genetic counseling. Some healthcare providers criticize the over-regulation in the doctor-patient relationships and they considered that involving the decision was part of a trustworthy relationship between patients and healthcare providers*(31)*. However, there was not any association between years of working experience, training in communication skills, or perceived social norm and shared decision-making degree*(22)*.

3.5.3. Factors related to counseling progress

In the case of cross-national, linguistic and cultural consultations, the use of qualified medical interpreters*(35)*, with similar cultural backgrounds can facilitate the implementation of SDM*(30)*. In terms of information provision, progressively more decision-relevant information that is more complete and consistent with counselees' preferences can also facilitate SDM*(26,35)*. Concerning decision goals, researchers have suggested short-term decision goals*(35)*, the alignment of consultation goals and values between the decision participants*(36)* are also among the factors that influence the implementation of shared decision making. In addition, R. Kenen*(24)* found that the use of multidisciplinary consultation could also enhance participation in SDM. However, the degree of SDM was not linked to the approach of health education (video, comic, brochure)*(22)*.

3.6. Effectiveness of SDM in genetic counseling

Using SDM in genetic counseling would enhance participants' satisfaction. The greater degree of involvement, the satisfaction would get larger, even in the case of poor results*(37)*. And there was an interaction between the doctor-patient relationships and SDM, which could contribute to a trustworthy relationship between doctor and patient and vice versa*(20,38)*. Another interaction was informative and SDM, before the consultation the more information you knew, the easier it was to meet SDM. Likewise, the doctor would also provide more information to the patient in a SDM communication model*(32,34)*. The use of SDM also had an impact on the counselee's psychology. Counselees in shared decision-making group had higher anxiety scores than the control group which might be due to the SDM group receiving more information and resulting in information overload*(33,39)*. In the longitudinal view, counselees with SDM averaged a 50% reduction in anxiety*(33)*. Moreover, the use of SDM in genetic counseling could also reduce decisional conflicts and the risk of decision regret*(33,40)*.

4. Discussion

This scoping review provides an overview of the existing literature on the current status,

stakeholder's prescription and the facilitation and barriers of SDM in genetic counseling. In this review, 22 articles were included, which were mainly focused after 2018, with predominance in countries such as Europe and the Americas and several research aspects, including prenatal genetic counseling, pediatric genetic counseling and oncology genetic counseling. Overall, implementation of SDM in genetic counseling showed positive effects, and most counselees were in favor of SDM, while some factors prevented them from being deeply involved in which suggests the necessity to respect counselees' preferences and promote them deeply involved in. On the other hand, affected by the non-directiveness guideline, counselors' views on SDM are mixed. It may require more appropriate training for counselors. As the largest group of healthcare providers, nurses have the potential for a significant impact on facilitating the practice of SDM in genetic counseling.

4.1. The boundary of shared is negotiable

4.1.1. The boundary between counselor and counselee

Four steps in SDM: (1) at least two participants: counselor and counselee; (2) both parties share information; (3) build consensus about preferred treatment; and (4) reach an agreement on treatment to implement*(6)*. This review revealed that today's genetic counseling remains in the first step even: because of the low education level, the differences of culture and linguistic, both parties do not share well. What's more, counselors are prudent in the consideration of autonomy, while counselees need more help in some cases. Thus healthcare providers are required to take more effort to elicit counselee's preference to explore the boundary between private and collaboration. In addition, the boundary is not fixed, as the discussion progressed, the boundary may swing from healthcare providers' side to the private side. Healthcare providers need to grasp the line between shared and private accurately to promote good doctor-patient relationships.

4.1.2. The boundary between family and counselee

Families involved in SDM are welcomed in vulnerable groups, like children, old people and the mental disordered*(41-43)*. However, the involvement of families in genetic counseling is variable. Considering personal privacy, many people thought the decisions were limited to couples. Too many different views from families may confuse counselees and result in decisional difficulties. Notably, family history plays an important part in genetic diseases*(44)*. and genetic counseling is also family-based. Detailed and clear family history can provide much help in the diagnosis and treatment of genetic diseases. Healthcare providers welcome the involvement of families*(45)*. In this review, we found that the families' involvement was not routinely implemented, which suggests healthcare providers have to highlight the importance of families' involvement and encourage the involvement of families while protecting their privacy.

4.2. Culture and SDM

Five studies mentioned the influence of culture on SDM*(27,29,30,32,35)*. A shared cultural background has the same language and the same common saying, which can reduce misunderstandings and improve the effect of communication during consultations. Culture can have an impact on the decision-making progress: in China strong clan culture and family ties made the paternalistic decision-making model deeply entrenched. During the decision-making progress, they depend on the views from seniors like parents, community leaders and neglect the views in their mind. In this condition, healthcare providers are required to develop a deep understanding and respect for counselees from cultural background above, and elicit the counselees' self-preference when necessary.

4.3. SDM supported by decision aids

Similar to previous studies, information is the most common barrier in shared decision-making*(46)*. Insufficient information may come from lack of information provision, low education level and poor communication between healthcare providers and counselees. Decision aids are a sort of knowledge syntheses tool which translate evidence into patient-friendly to inform patients on their options, help them clarify the value they place on benefits versus harms, and guide them in the process of decision-making*(47)*. Formats for

these tools include paper-based booklets, video/DVDs, decision boards and Internet-based materials. Using decision aids to help counselees gain more evidence-based knowledge and clarify their value before the consultation, which can enhance the involvement in SDM. Researchers show that the frequency of values-incongruent choices and decisional conflict were significantly dropped and satisfaction was increased by decision aids*(48,49)*. Those imply that researchers develop more target decision aids for genetic disease and relative tests.

4.4. Healthcare providers promote SDM in genetic counseling

The complexities of decisions in genetic counseling need healthcare providers make efforts to provide more opportunities for counselees' discussion. Our review demonstrates that nurses seldom involved in SDM. However, a recent study revealed that nurses who have more direct long-term contact with patients and tend to be more positive about the need for SDM*(50,51)*. Bottorff also presented the importance of nurses in the genetic era in early 2005*(52)*. First, nurses comprise the largest proportion of the health workforce, and nurses were more likely to provide genetic counseling in the remote area. Second, nurses have more opportunity to educate the public on genetic health care issues. Moreover, nurse-involved genetic counseling better reflects the philosophy of person-centered care, and nurses also show higher satisfaction with the genetic counseling they provide*(53)*. Furthermore, during the current COVID-19 pandemic, social distancing and health service reallocation interfere with a preference for an in-person visit*(54)*. Those above present potential for nurse showing the leadership of SDM in genetic counseling.

4.5. Implementation and future exploration of SDM in genetic counseling

This review points out that the SDM shows positive effects among genetic counseling. Use of SDM in genetic counseling could be strongly promoted in the future. However, the role of cultural background and information in SDM should be noted, and it is necessary to generalize the training of SDM for all healthcare providers. Whereas, the evidence that implements SDM in genetic counseling is limited. And the current studies mainly adopt the cross-sectional study and qualitative research which can only explain the correlation between factors and describe the current situation. In the future, multinational studies should be considered for bringing SDM to the global scale and researchers may focus on randomized controlled trial and cohort studies to confirm the effectiveness. Therefore, well-designed studies are required to explore the impact of shared decision-making in genetic counseling in the long term.

4.6. Limitations

The studies were mainly described genetic counseling in prenatal, pediatric and oncology and there were no study included genetic counseling in neurology, ophthalmology and psychiatry. And the publications retrieved in the grey literature search were presumably not perfectly complete, some publications were not accessible for our research team, and publications could have been missed due to the great diversity of possible sources. Therefore it is difficult to generalize the use of SDM in all genetic counseling in this study. Also, we only included articles written in Chinese and English. Missing articles in other languages may bias the impact of culture on SDM. Finally, in line with the scoping review checklist*(55)*, no quality assessment was Journal Pre-proof performed on the included studies. This may challenge the interpretation of results, particularly when discussing and drawing conclusions on the effectiveness of SDM in genetic counseling.

5. Conclusion

This review provides a comprehensive synthesis of the literature focusing on the current statues and perceptions of various stakeholders of SDM in genetic counseling. It was found that various stakeholders were involved in SDM in different levels. And stakeholders had positive views on the use of SDM in genetic counseling. Moreover, it is essential to be in the same cultural background and have adequate information between counselors and counselees. Furthermore, decision aid and nurses may play a significant role in the future of genetic counseling. Finally, further exploration can focus on multinational and longitudinal study design to provide more evidence on SDM in genetic counseling.

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Conflict of interest

The authors have no conflict of interest to disclose.

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