



Multi-Disciplinary Team in In Utero Pediatrics and Case Management

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18.1 Multi-Disciplinary Team (MDT) in Fetal Medicine and in Utero Pediatrics

Since the 1980s, the introduction of a new concept (i.e., fetus as a patient) along with the development of medical technologies in the screening, diagnosis and treatment of birth defects have contributed to the advent of fetal medicine and in utero pediatrics. Unlike the era of perinatal medicine, maternal-fetal medicine considers the mother and fetus as individual subjects to provide

personalized, comprehensive, one-stop health-care management throughout their lifetime, rather than focuses exclusively on reducing the maternal and perinatal mortality [1].

18.1.1 MDT

MDT is a group of healthcare professionals from two or more relevant disciplines, including but not limited to surgery, internal medicine, radiotherapy, imaging, pathology, intervention, professional nursing, and psychotherapy. The members of MDT will attend clinical seminars regularly to propose systematic diagnosis and treatment plans, allowing for accurate diagnosis and proper treatment while avoiding overdiagnosis, overtreatment, misdiagnosis and mistreatment [2].

At present, the MDT concept has been widely recognized by the medical community, and has become an important diagnosis and treatment model in many large healthcare institutions for the treatment of tumors, diabetes, and other diseases. The collaborative diagnosis and treatment model involving multi-disciplinary experts can provide patients with standardized, comprehensive and individualized diagnosis and treatment plans, thus saving the medical resources and improving the efficiency and patient satisfaction of these plans.

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18.1.2 MDT in Fetal Medicine and In Utero Pediatrics

The diagnosis and treatment of fetal diseases usually involve multiple disciplines, including imaging, clinical genetics, neonatology, pediatric subspecialty, rehabilitation as well as adult internal medicine and surgery, in addition to obstetrics. Accurate diagnosis and health assessment should be provided by an experienced fetal medicine specialist to the affected fetus with focus on the fetal and maternal conditions. The well organized MDT would followed based on specific diseases for the outcome of the fetus. For families who decide to continue pregnancy, standardized, personalized and continuous evaluation and treatment plans should be established to reduce the perinatal mortality and morbidity of the affected fetuses and improve their long-term outcomes, while taking into account the safety of the pregnant women.

Since structural abnormalities are the most common fetal diseases, prenatal consultation, diagnosis, treatment and prognosis of such abnormalities as well as the involvement of pediatric subspecialists are of great importance. The optimal timing for diagnosis and treatment should be moved from “neonatal period” to “fetal period”, which also contributes to the development of MDT diagnosis and treatment model in the in utero pediatric diseases.

MDTs of fetal medicine and in utero pediatric diseases should be considered as a whole, as they not only work in a cooperative and parallel manner, but also provide diagnosis and treatment in a sequential and successive pattern. Their integration and development would result in a secure and “closed loop” system for the diagnosis and treatment of maternal and fetal diseases [1].

18.1.3 Role and Function of In Utero Pediatrics in MDT

The specialists in the MDT of fetal medicine and in utero pediatrics are expected to undertake their own responsibilities while cooperate with each other.

Fetal abnormalities are initially diagnosed by the *experts in maternal-fetal medicine or fetal medicine*, who will provide comprehensive medi-

cal examinations involving imaging, genetics and etiology to the affected fetuses based on the reproductive history, family history and medical history of their parents, and make clinical diagnosis according to his/her medical judgment. These physicians are responsible for transferring the “bad news” directly to the families and providing reasonable advices, but they are not involved in the postnatal treatment and long-term follow-up of the infants. It is difficult to provide the precise information for the pregnant women and their families, such as whether the fetus should receive surgery or drug therapy after birth, the efficacy and cost of the treatment, as well as the short-term or long-term outcomes.

In utero pediatric subspecialists, who are primarily responsible for the postnatal diagnosis and treatment, can provide evidence-based medical advice to the families, making them the most appropriate healthcare professionals to participate in the multi-disciplinary consultation of fetal diseases. Although the “unborn patients” cannot receive physical examinations, MDT may contribute to the diagnosis and treatment in the following aspects:

1. According to the diagnostic criteria of postnatal diseases, to assist fetal medicine specialists for further interpretation of the results from prenatal imaging and genetic tests, thus increasing the accuracy of prenatal diagnosis.
2. Aid the fetal medicine specialists to accumulate their knowledge on prenatal prognostic indicators. For example, prenatal assessment of the condition of pulmonary artery in the tetralogy of Fallot, can help to provide more accurate judgement for prognosis, regarding the difficulties in postnatal treatment as well as the expected morbidity and mortality of the newborns.
3. Support fetal medicine specialists to evaluate the indications for intrauterine intervention (e.g., prenatal assessment for the severity of severe aortic/pulmonary stenosis or atresia, diaphragmatic hernia and meningomyelocele), balance the potential benefit and risk, and contribute to the management of intrauterine treatment depending on the type and ease of the treatment.

4. Help to create an integrated management plan covering antepartum, intrapartum and postpartum for the affected fetuses, and establish a green channel for in utero transfer, neonatal rescue/transfer as well as pediatric diagnosis and treatment according to the disease severity, so as to improve the survival rate and quality of life for the newborns.
5. Provide long-term follow-up and medical care to the children until their adulthood.

The involvement of in utero pediatric subspecialists in the MDT consultation may contribute to the consistency of prenatal and postnatal information and the communication with the family members, which may include:

1. Interpreting the significance of available results from imaging and genetic tests. The medical judgment of the fetal conditions based on the information derived from available test results will be communicated to the families. Specifically, pediatric subspecialists should provide advices on the severity of the disease, the indication, timing and plan of intrauterine or postnatal intervention, along with the complications and effectiveness of the intervention, provided that they have a clear understanding of the natural history and outcome of the prenatal disease.
2. Pediatric subspecialists play a critical role in the follow-up of long-term outcome of fetal diseases such as neurological development and vital organ functions after birth. Families should be provided with professional instructions to make them aware of the potential long-term outcome.
3. Provide personalized consultations in certain cases of fetal disease, such as multiple pregnancy, pregnancy complications or concomitant conditions that may increase the risk of iatrogenic preterm delivery, to ensure that the families are adequately informed about the risk and outcome of the fetal diseases, therefore making pregnancy-related decision based on thorough understanding of all available information. (The role of the pediatricians in the diagnosis and treatment of fetal diseases)

The number of prenatal MDT consultations with a pediatrician in attendance has shown a negative correlation with the anxiety level of patients [2]. According to the data from the Diagnosis and Treatment Center for In Utero Pediatric Diseases of Xinhua Hospital, compared with 2018, the mid-term induced abortions due to fetal factors has decreased by 57.43% in all induced abortions in 2021, which seems to be benefitting from the MDT consultation for in utero pediatrics established in 2019.

18.1.4 Model and Process of MDT in In Utero Pediatrics

The diagnosis and treatment of fetal abnormalities requires the participation of a multi-disciplinary team, for the purposes of: (1) providing patients with optimal diagnosis and treatment plan according to the evidence based medicine (EBM) based supporting evidences; (2) more importantly, breaking the inter-hospital barriers, promoting the inter-disciplinary cooperation, and providing “one-stop” services in a patient-centered manner, thus the patients can avoid the frequent visits to multiple medical departments. Currently, there are two primary ways for in utero pediatric subspecialists to play a role in the multi-disciplinary diagnosis and treatment of fetal abnormalities:

18.1.4.1 MDT Led by Fetal Medicine Specialists and Supported by In Utero Pediatric Subspecialists

The MDT model led by fetal medicine specialists and oriented by fetal diseases develops a seamless connection with the subspecialty teams of in utero pediatrics (Fig. 18.1). As the leader of the multi-disciplinary consultation, fetal medicine specialists are “generalists” who have received subspecialty training in maternal-fetal medicine, and are required to have a variety of professional skills, such as prenatal imaging diagnosis, interventional prenatal diagnosis and genetic consultation, intrauterine intervention, management of high-risk pregnancy and maternal pregnancy

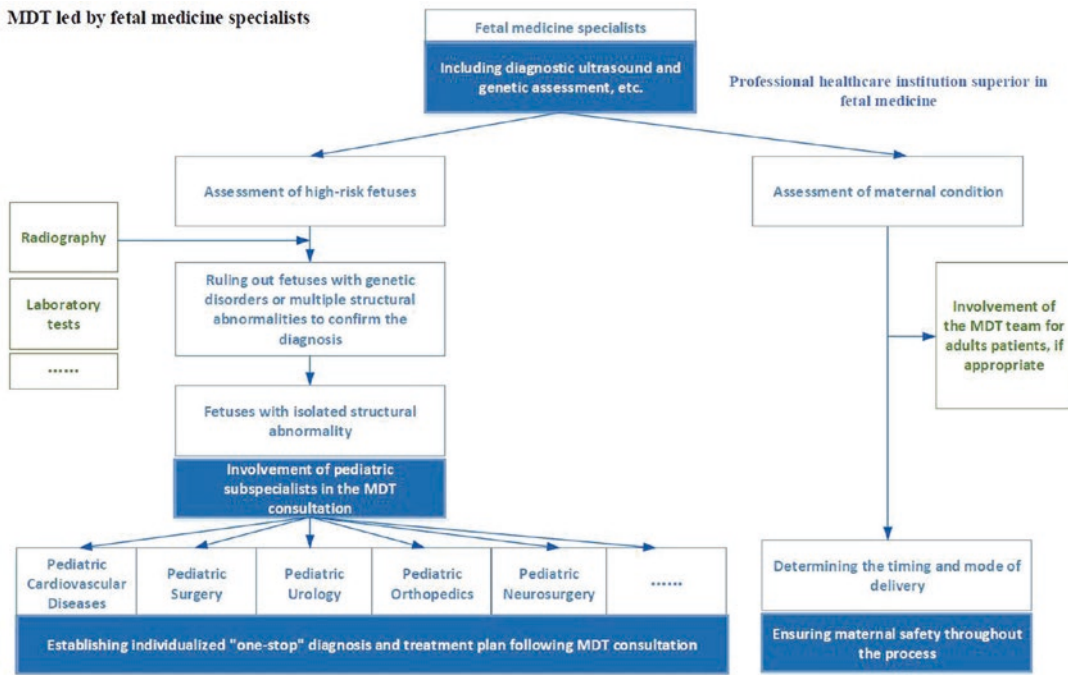


Fig. 18.1 MDT led by fetal medicine specialists (reproduced with permission from [1])

complications, as well as intrauterine monitoring and delivery of the affected fetuses.

In the multi-disciplinary consultation, the primary roles of fetal medicine specialists include: (a) to ensure the safety of the mother throughout the process. It should be noted that mother is considered as an important participant, decision-maker, recipient and even a patient (e.g., some pregnant women may have genetic diseases with milder phenotypes) in the intrauterine diagnosis and treatment of fetal diseases; therefore, it is necessary to evaluate fetal diseases in the context of the mother’s condition. As the guardian for the safety of pregnant women, fetal medicine specialists should keep in mind that protecting the safety and health of the mother is the first priority of all the practices in intrauterine diagnosis and treatment [3]. (b) to provide a comprehensive assessment for high-risk fetuses, such as ruling out other concurrent structural or genetic abnormalities of the fetus by prenatal imaging and genetic diagnosis. Subsequently, according to the type of fetal abnormalities, a disease-oriented multi-disciplinary consultation should be initi-

ated, with pediatric subspecialists in attendance to support of the prognostic assessment and the sequential treatment plan covering antepartum, intrapartum and postpartum periods. (c) to provide prenatal monitoring and perinatal management for the affected fetus. Fetal medicine specialists are expected to perform individualized prenatal monitoring and reasonable intra-uterine interventions, and to determine the timing, mode and place of delivery based on the severity of fetal abnormalities.

The above-mentioned model requires the healthcare institution involved in the MDT to have a well-established maternal-fetal medicine or fetal medicine center as well as experienced staff in these areas; currently, this model has been adopted by the fetal medicine department of the First Maternity and Infant Hospital Affiliated to Tongji University. However, since the concept of fetal medicine has been introduced recently into China, only few healthcare institutions have set with well-established fetal medicine subspecialties. Moreover, given the absence of discipline construction standards and training systems,

most healthcare institutions are not qualified to organize such consultation to provide “one-stop” management for the fetuses and their mothers [1].

18.1.4.2 MDT Led by In Utero Pediatric Subspecialists and Supported by Fetal Medicine Specialists

With the widespread use of prenatal ultrasound screening, more structural abnormalities can be identified in prenatal period. Therefore, in utero pediatric subspecialists have become the attending physicians of the affected fetuses. In this case, the MDT consultation should be led by in utero pediatric subspecialists with experts in prenatal imaging, genetics and perinatal management in attendance, so as to perform comprehensive assessments for the fetuses and provide solutions regarding the delivery of the pregnant women (Fig. 18.2).

The advantage of this model is that the in utero pediatric subspecialists, as the attending physician of the fetus after birth, can participate

in the whole process of prenatal and postnatal management. However, this model has the drawback, that is the pediatric subspecialists only focus primarily on the diseases in their own specialties, which might neglect the maternal conditions while the fetus is being managed. Thus, the assistance and involvement of fetal medicine specialists are necessary to ensure the adequate assessment of maternal safety at the same time.

18.1.5 Form of MDT in In Utero Pediatrics

MDT consultations can be implemented in flexible and diverse forms, including offline “face-to-face” communications or online video consultations via the Internet. However, most MDT consultations are carried out by a professional core team with fixed members on a regular basis. The purpose of MDT consultation, regardless of the formats, is to make the family fully informed of the diagnosis and treatment plan along with the outcome of the fetal disease in

MDT led by intrauterine pediatric subspecialists

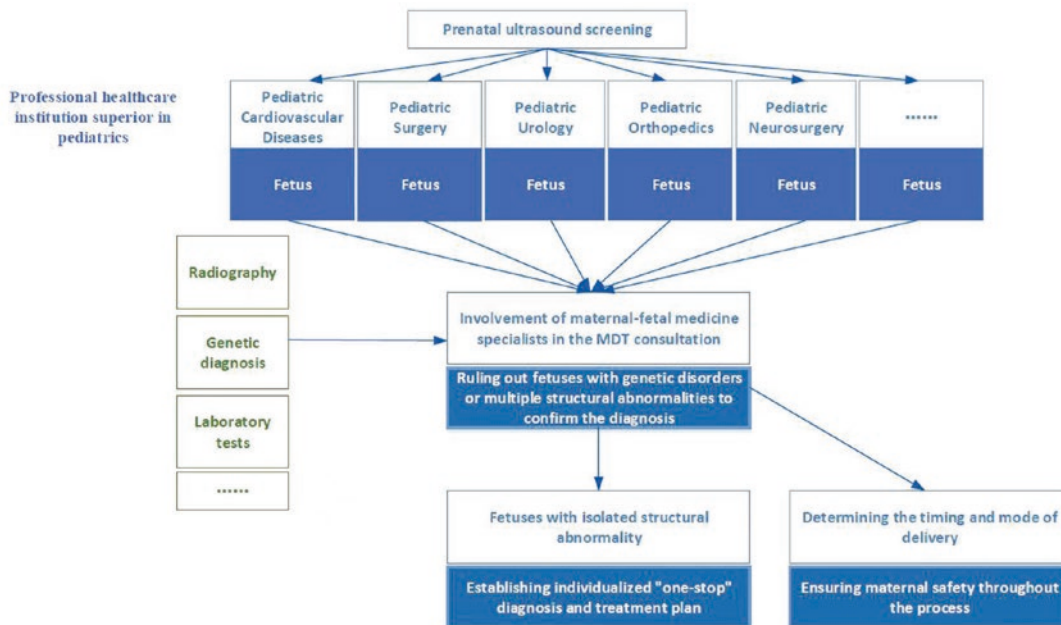


Fig. 18.2 MDT led by in utero pediatric subspecialists (reproduced with permission from [1])

prenatal and postnatal periods through effective communication, and facilitate the pregnancy-related decision and perinatal management. The frequency of MDT consultation should also be determined on a case-by-case basis, and multiple consultations may be feasible if changes have been noted in fetal disease.

The clinicians involved in MDT consultation include neonatologists, radiologists, geneticists and assistant physicians, in addition to in utero pediatric subspecialists. The assistant physician in MDT consultation is responsible for collecting the medical history, preparing the consultation records, and compiling and archiving the files from individual specialties. The geneticists and radiologists with relevant expertise can facilitate the accurate diagnosis of complex fetal diseases and provide guidance on disease management [4]. The neonatologist and the nursing team also play a crucial role in the successful delivery of the fetus, the medical management during the neonatal period, and the referrals to the corresponding pediatric subspecialties.

18.2 Case Management Model in the Diagnosis and Treatment of In Utero Pediatric Diseases

The diagnosis and treatment of a fetal patient is quite challenging, since the maternal safety should also be taken into consideration rather than focusing only on the fetal disease itself. This involves not only the treatment of relevant diseases, but also the long-term pregnancy management as well as the growth and development through infancy, which requires the assistance from a comprehensive medical service support system. The introduction of case management achieves full management of diagnosis and treatment for the pregnant women and their fetuses, as well as providing psychological supports to the family members of the patient. Case management allows for the family to receive continuous, comprehensive, efficient, high-quality and considerate services. It plays a special and important role in the standardized management of intrauterine

pediatric diseases and the improvement of medical management services. The case manager in in utero pediatrics is also known as the disease manager of the family.

18.2.1 Case Management

The concept of case management (CM) was proposed in the mid-nineteenth century. At that time, case manager was referred to as the plan coordinator who provided medical care to the vulnerable groups such as the poor, the sick or the elderly. Since 1980, the US government has undertaken a reform of the national health system to control the sharp increase of medical costs and improve the medical resource utilization. In this context, case management and clinical pathway were implemented in public health system, aiming to reduce the length of hospital stay and the medical costs while maintaining the quality of medical service. In 1985, hospitals in Taiwan introduced the case management process to the medical care of diabetic patients, and demonstrated promising results. At present, case management is receiving increasing awareness in China, which has been applied to the diagnosis and treatment of tumors as well as the management of chronic diseases. It has shown favorable results.

Case management takes a case-centered approach to provide integrated and comprehensive medical services, which focuses on the cooperation among multiple medical teams. It has apparent advantages in improving the management efficiency and reducing the waste of medical resources [5].

As multiple disciplines are involved in the diagnosis and treatment of individual case, case managers should coordinate and integrate the opinions of the healthcare professionals from different specialties to ensure that the patients receive integrated and continuous medical services at appropriate time and place, allowing for a balance between cost-effectiveness and quality. Case management plays an important role in the standardization of hospital management, improvement of medical service process, integration of community resources, patient and disease

management, and continuity of the medical care, thus achieving a triple-win situation for patients, medical team and nursing team. Case management model is mainly developed for patients with specific diseases. The role of therapeutic alliance (TA) is similar to a “disease manager” for patients; as for the physicians, TA acts as a “secretary to patients with specific diseases”.

18.2.2 Case Management Team in In Utero Pediatrics

The case management team in in utero pediatrics consists of the following members: MDT physicians, case managers, specialists, nurses, rehabilitation therapists, and social workers. These members take a holistic approach to provide seamless, comprehensive, integrated healthcare management services to the mothers, fetuses and their families. Among them, the case manager will participate in and manage the diagnosis, treatment and follow-up of the patient throughout the process.

1. Case manager/case management leader: the case manager of in utero pediatrics is the core personnel in the case management team who is responsible for developing specific plans for case management and healthcare services, aiming to provide optimal care to mothers and fetuses/newborns through integration, coordination and optimization of the process. A case manager must have extensive experience as a senior professional nurse in obstetrics or pediatrics, or have served as head nurse in these departments.
2. Multi-disciplinary support team: as a fragment-integrated care model, case management does not rely exclusively on the case manager; on the contrary, multi-disciplinary and cross-institutional collaboration led by the case manager has become the mainstream trend, which involves hospitals at all levels, communities and other institutions. The case management team can be comprised of the case managers, specialists, nurses, healthcare technicians, pharmacists, dietitians, psychologists, rehabilitation therapists, community nurses and social workers. Each member in the team will take his/her own responsibility according to the overall arrangement by the case manager. The case manager who acts as the organizer, director and communicator of the team is expected to conduct effective coordination, allowing for the complete and ongoing implementation of the case management [6]. For fetuses with poor outcomes, symptomatic treatments should be administered; while the familial physical, psychological and social problems should be addressed carefully. The medical care and guidance for the future pregnancy would be provided, which is an important part of maternal-fetal comprehensive care.
3. Responsibilities of the case manager: to coordinate the communication between the family and the hospital around the treatment and nursing services, make an appointment with the physicians, arrange for hospital admission, contact the patient for follow-up, and provide additional medical services associated with the diagnosis and treatment. More specifically, the responsibilities include: (a) to coordinate relevant medical resources for MDT consultation as per the diagnosis and treatment plans; (b) to communicate with the nursing teams of the outpatient and ward departments to arrange for a hospital visit on behalf of the patient; (c) to answer the questions raised by the patient during diagnosis and treatment and provide reasonable solutions; (d) to follow the patient after discharge, maintain a record for the growth and development of the child, and prompt the family to practice health-related self-management until the end of diagnosis and treatment.
4. Case management team of in utero pediatrics: at least one head nurse or a nurse with experience as head nurse should be staffed, who would provide overall tracking of patient management, such as coordinating and arranging laboratory tests, participating in the disease assessments, addressing the needs of the patient, organizing multi-disciplinary consultation, as well as monitoring and managing

the implementation of the treatment plan in accordance with the clinical pathway of the disease. The case manager is also responsible for the medical services after discharge, including patient follow-up and supervision of the return visits. There should also be a customer service team in place to provide information regarding the facilities around the hospital, including the catering, accommodation and transportation, and is responsible for the communication and interview with patients and their families according to the workflow. Understanding the needs of medical team, nursing team and patients in a timely manner, enables the case management team to establish a communication platform and a maintenance mechanism for providing “one-stop” services to patients and their families.

18.2.3 Process of Case Management in In Utero Pediatrics

The case management team focuses on the needs throughout the maternal-fetal or maternal-infant diagnosis and treatment, and provides appropriate, timely and adequate support for communication. The communication channels would be established for follow-up. Via Internet and telephone, the team can contact the patients both in normal and emergency conditions, and then address the needs of the patients and their families in a timely manner (Fig. 18.3).

The implementation of case management in in utero pediatrics mainly involves three steps, namely “case registration, case management and case closure”, while each step involves five key aspects, including “assessment, plan, implementation, evaluation and feedback”.

1. Case Registration Process:

- (a) Explaining the management plan: explain the purpose of the plan to the family before registration along with the routine outpatient procedures that require their cooperation;

- (b) Establishing case management file: enter the information and establish contacts with the family;
 - (c) Making an initial assessment: assess the education level, economic condition, family support system, awareness of the diseases, previous healthcare compliance, diet and exercise habits, and nutritional status of the family;
 - (d) Developing plan: develop health management plan following discussion with the family, especially the pregnant women, such as self-monitoring of blood glucose, diet prescription, and exercise prescription;
 - (e) Making an appointment for an outpatient visit or hospitalization: explain the precautions for the next examination and provide support for appointment service.
- #### 2. Operation Process of Case Management for Subsequent Visits
- (a) Remind the patients of the time for outpatient or inpatient treatment;
 - (b) Re-assessment: assess the physical and mental state of the mother, fetus and the family;
 - (c) Physician-nurse communication: coordinate and communicate with physicians and nurses promptly for the problems in individual cases to share the information;
 - (d) Providing consultation and question answering services on an ongoing basis: provide health education in a timely manner regarding the problems involved in individual cases and give further explanation for their consultations;
 - (e) Records Registration.
- #### 3. Operation Procedures for Case Management:
- (a) Establishing a relationship: establish a trusting relationship with the patient;
 - (b) Assessment: assess the disease awareness (e.g., current medical history, prior medical history, high risk factors) of the patient, economic condition (medical insurance, family support system, finance) of the family, psychological needs, resource problems and other personal needs from the views of patients,

Service Model and Process of Case Management in Intrauterine Pediatrics of Xinhua Hospital

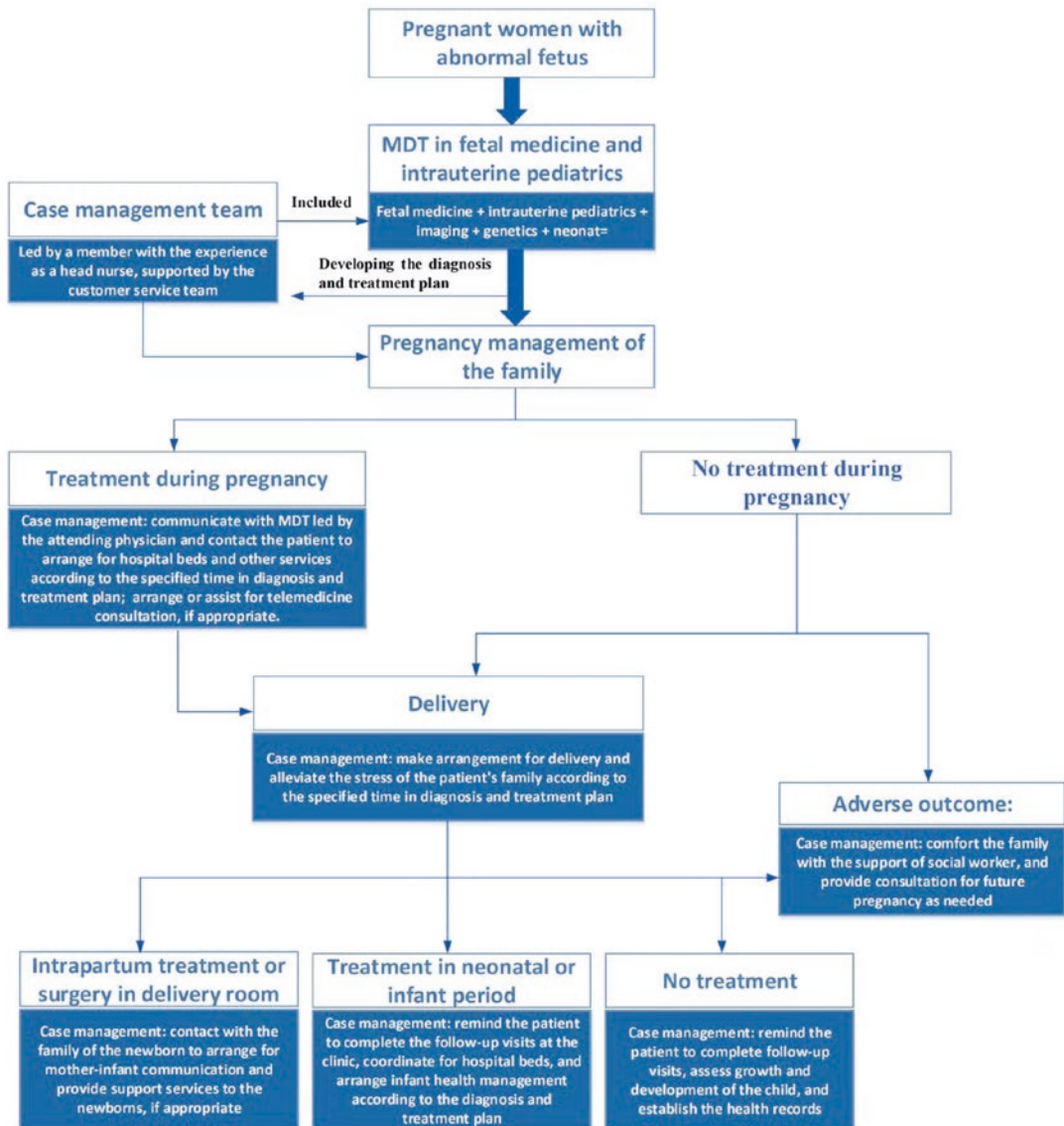


Fig. 18.3 Service Model and Process of Case Management in Intrauterine Pediatrics of Xinhua Hospital

family members and healthcare providers.

- (c) **Planning:** the patient and his/her primary caregiver should also contribute to the development of an individualized plan. Case manager will make decisions on the accessibility, feasibility, appropriateness

and priority of the patient's needs, with full respect for the patient's own wishes.

- (d) **Resources access:** integrate the resources within the hospital, including the social workers, as well as the information about the hospital and its surrounding facilities for the patients' conveniences.

- (e) Integration and supervision: according to the monitoring indicators and integrated data, the team can supervise and monitor the plan progress toward completion. The case manager should analyze and evaluate each patient, identify the special circumstances that occur during the implementation of the plan and the reasons for failure to fulfill the task as planned, followed by reanalysis, revisions and re-evaluations.
- (f) Case closure and feedback: terminate the relationship with the patient, make summary and evaluation, provide feedback on the medical management mechanism, and optimize the process; provide collaborative supports for long-term care of patients and primary caregivers, and establish long-term operation mechanism.

18.3 Other Supports for MDT in In Utero Pediatrics and Case Management

1. At present, there is no industrial standard for the charging and quality control of MDT consultation in China. Therefore, a unified standard should be established to ensure the sound and sustainable development of the MDT consultation model. Given the impact of COVID-19 pandemic in recent years, it is quite challenging to conduct inter-hospital consultation and cross-region referral. Fortunately, the introduction of “5G+ artificial intelligence” cloud service platform for the diagnosis and treatment of in utero pediatric diseases, which has the potential to achieve the ultimate goal of MDT consultation. Moreover, the techniques might bring maximum benefit to the mother and fetus with the optimal medical resources at the minimum costs, so as to avoid the waste of medical resources and reduce patients’ traveling and anxiety arousing by the repeated hospital visits.
2. Establish a Customer Relationship Management (CRM) system to support the case manager’s work. The user-friendly CRM

system allows to manage cases in batch, which brings convenience for the long-term follow-up. Meanwhile, the CRM system facilitates the establishment of individual health records for the long-term health management, involving the postnatal growth and development, and thus can contribute to conduct the clinical studies.

3. The development of fetal disease specialty has received increasing awareness in recent years. To establish a medical service model based on the needs of the fetuses and their families, can promote the continuous development of this discipline, and also helps the further interdisciplinary integration. Breaking down the boundaries between disciplines and hospitals is a must for the development of fetal medicine and in utero pediatrics, while more EBM based experience should be accumulated. Meanwhile, the core concept of “fetus as a patient” should be practiced in clinical work, and direct to a “one-stop” closed-loop for fetal diagnosis and treatment, which would develop a high-quality diagnosis and treatment system for the fetal diseases in China. These efforts would bring “new hopes” for the fetus and its family, and finally improve the postnatal life after birth.

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