

# Please call the specialism: Using WeChat to support patient care in China

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## ABSTRACT

We examine how WeChat has been adopted to support nurse-patient communication in an IVF clinic in China. In this setting, the biggest challenge to delivering high-quality patient-centred care is the large number of patients. Nurses typically spend less than five minutes with each patient during clinical visits. To compensate for such minimal in-person consultation, nurse-facilitated patient groups were created on WeChat, to extend medical care and facilitate peer support. Through an ethnographic study, we examined how these groups fit into the clinic's communication ecosystem, and the challenges they raise for nurse-facilitators who receive thousands of messages daily. We propose a set of design suggestions aiming to make the work of the nurse-facilitator easier and more effective. In highlighting the opportunities and challenges of using chat to extend care beyond the clinic, we contribute to a burgeoning discussion of how chat can support patient care in the Global South.

## CCS Concepts

•**Human-centered computing** → **Field studies; Ethnographic studies; Empirical studies in HCI; Interface design prototyping;**

## Author Keywords

Ethnography; chat apps; nurse-patient communication; peer support; WeChat; healthcare

## INTRODUCTION

Chat apps such as WeChat, WhatsApp, Line and Telegram have become almost as prevalent as the smartphones they operate on. In China, the most popular chat app is WeChat. Its popularity is driven in part because it has been designed with an easily programmable API enabling third parties to create official accounts and mini programs to run on it. For example, a business on WeChat can post an offer to its customers and allow them to find the nearest branches, reserve a spot, place

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their orders, or enquire after their gift card balance, without having to install a separate app for each business/brand. As a result, WeChat has become highly popular, with over 1.1 billion monthly active users [51]. It has become the *platform* through which people chat, connect, receive services, make purchases, manage their finance and conduct their work, doing anything from booking a doctor's appointment to trading with business partners overseas.

Whilst initially designed for personal communication, chat apps have been widely adopted in workplaces across the world [24, 31, 33]. Healthcare is no exception, with chat apps increasingly used for both internal communication between healthcare professionals e.g. [4, 17, 23, 36] and patient-facing communication e.g. [16, 21, 26].

Improving care quality and outcomes is a primary goal of technical adoption in medical settings. The Institute of Medicine defines six dimensions to the quality of care: safety, effectiveness, timeliness, efficiency, equity and patient-centredness [9]. The delivery of patient-centred care, however, remains a major challenge (ibid). This is especially the case in time-pressed settings with high patient numbers, common in the Global South, but is increasingly also found in the stressed health services of the Global North. Good communication plays a central role in health outcomes, impacting medical adherence [2, 34], which can be psychologically, socially, and logistically challenging for patients [14, 46], especially when it requires lifestyle changes [6, 28, 47]. It is no wonder then that healthcare organisations might turn to new digital channels, as a way of better supporting their patients.

Such is the case in our research site an IVF Clinic in Gansu province, China. This clinic pioneered WeChat adoption as a way of patient engagement during IVF treatment. Due to the pressure of patient numbers, nurses get little face-to-face time with patients, as a result they are inundated with phone calls from patients who, for example, did not understand or cannot remember the medical instructions they received, or simply require some medical advice. To better support their patients the clinic set-up nurse-facilitated patient groups on WeChat.

We undertook an ethnographic study of the nurses work, including their use of WeChat, with the aim of understanding 1) how chat fits into the hospitals patient-facing communication ecosystem, 2) what role such groups play in the IVF program, and 3) the impact they have on the nurses work. We found that

these patient groups were widely used, with many messages per day and were considered by the nurses to be a valuable extension of the treatment program beyond the time constraints imposed during clinic hours; enabling nurses to support patients even during the long periods of treatment when patients had returned home; and crucially providing much needed peer support during an often stressful treatment journey. However, managing these WeChat groups was no mean feat for the nurses, who had to deal with thousands of messages daily. In this paper, we reveal the work the nurses must do to make these groups work, and propose design solutions to reduce the burden of this work. We contribute a deeper understanding of, and ideas for improving, chat as a tool to help nurses bridge the healthcare provider-patient communication gap.

## RELATED WORK

We describe how chat has been widely adopted in healthcare settings, to support clinicians internal communication and their interactions with patients and the public, plus the value of technologically mediated peer support.

### Chat and healthcare

The growing popularity of chat at work is not incidental, as [8], suggested two decades ago while studying PC-based messaging tools: messaging's simple lightweight nature makes it a great adjunct to formal communication tools. Chat apps, on the back of the growing popularity and affordability of smart phones, and increasing access to data, have become pervasive. Phone based chat apps are mobile, to-hand and able to support multi-modal communication, including text, image, video and audio, making them popular both within [24, 31, 33] and outside of the work context [39, 43]. One survey found that 98.9 of UK hospital clinicians now have smartphones, with about a third using WhatsApp or a similar messaging tool [35] despite the clear ban of WhatsApp by NHS for its failure to meet the required standards for privacy and confidentiality, particularly around the sharing of patient information [37].

Compared to WhatsApp, WeChat supports third-party official accounts and mini programs, which enable users to do much more than exchange messages. Such features are commonly used for public engagement by banks, hospitals, stores and so on. As a consequence, in China more and more hospitals have WeChat official accounts, which they use to engage the public with health-related material; or even enable patients to access their tests results, make payments and pay bills.

### Chat use by clinicians

Research has begun to examine how chat, typically WhatsApp, is used to support internal communications amongst clinicians. This research tends to use surveys, to provide an overview of chat use in hospitals. For example, Nardo et al. [36] examined how surgical management in Italy could be optimised using WhatsApp. They concluded that chat apps, when deployed as user-friendly adjuncts to communication, can help to bridge both the temporal and physical distances of busy distributed healthcare settings. Ganasegeran et al.'s [17] studied the perceived benefits of WhatsApp amongst clinicians in Malaysia. They found that the majority of respondents perceived WhatsApp as beneficial for clinical practice. In a meta-study, [32]

confirms the usefulness and wide adoption of WhatsApp by clinicians and primary care teams for various clinical practices, pointing out that although chat can be useful, the medico-legal-ethical issues (e.g., patient data security) should not be ignored. One study of WeChat use in Chinese hospitals found it to be a useful tool for in-service training for nurses [53].

### Interacting with patients and the public

Some early research explores the use of chat to support interactions between healthcare providers and the public. For instance, a review of WhatsApp usage in healthcare settings [18] concluded that chat is promising, for communicating, not just between clinicians, but also for providing healthcare information to the public. Another study found information about malaria posted to the Chinese diaspora in Niger on WeChat raised awareness about malaria prevention [30].

Other research has begun to look at how chat (and other messaging) can be used to support patient-provider interactions. One system designed to send out automated text messaging to support adolescents with diabetes, ended up being used by patients to submit clinical data and queries and to the healthcare provider [16]. Patients also used the service to ask questions, submit information about their self-management, and order supplies. Messaging is used in asthma management too [26, 27]. ADAPT is a smartphone app, connecting patients to a desktop application for community pharmacists. The app includes a questionnaire to rate asthma symptoms and monitor these over time; short movie clips with medication and disease information; a medication reminder; a chat function with peers and another with the pharmacist. The pharmacist can then send information and feedback to patients based on the data gathered through the app. The use of the app was found to improve medical adherence for adolescents with poor adherence rates at the start of the study [26]. Another study examined WeChat use for continuation of care after discharge for patients with ankylosing spondylitis [21]. The authors conducted a controlled comparison of patients given access to support through WeChat and a control group. On WeChat they posted relevant health articles on an official account, and created a chat group for the patients, with 1 doctor and 2 nurses, one of whom was active every day for 30 minutes to answer patient questions and participate in their discussions. The participants using WeChat did statistically better on medical adherence and relapse compared to the control group.

Through a quantitative study, Zhou et al. found that the introduction of a patient messaging portal on an Electronic Medical Record (EMR) system connecting the patients directly to their healthcare providers significantly reduced both the number of patient visits and phone calls to the providers compared to patients in the control group who did not use such messaging [55]. Additionally, Sun et al. conducted a qualitative analysis of the content of the EMR patient portal messages and found a wide variety of information being exchanged between patients and their providers from medication enquires to expressing emotional needs [48]. They recognised that managing such messages might pose a burden on the providers workload and they highlighted various summarising practices which they hypothesised arose as a means to reduce this burden.

Patient-provider chat seems to be a promising channel for improving patient adherence, although interestingly none of these studies discuss the *practicalities* of such initiatives in terms of provider workloads. Whilst Sun et al.[48] recognise the burden on providers, they did not directly investigate it and they called for more research on this.

### Chat for peer support

Other research examines how peer support mediated through technology such as internet forums, Facebook and chat apps can improve medical adherence [1, 7, 54]. Zhou et al. [54] found that though initially set up as an online educational platform for diabetes patients in China, it was the ‘*community support*’ that eventually attracted not only the patients but their families to exchange support with one another. Cheung et al. [7] compare the effectiveness of group discussion and reminders via social groups created on WhatsApp and Facebook to prevent relapse in smokers who had recently quit. Participants in both groups reported fewer relapses than in the control group at the two- and six-month follow-ups. The WhatsApp groups had more posts overall than the Facebook groups, but there was no significant difference between their impact. Peer support may also be combined with interaction with healthcare providers. For example, the ADAPT system [27] mentioned above also includes a peer support chat channel. However, this was not discussed in the evaluation [26] so we have little idea how and how much it was used.

As [1] found, when setting up an online community for an IVF clinic the opportunity for peer support in addition to the ability to connect with providers was considered one of the most important advantages. The forum was designed with two separate channels: a peer support channel and an expert channel where the patients interacted with the healthcare provider. Patients were appreciative that they could engage with both the healthcare provider and their peers from the same clinic at the same time. Furthermore, patients valued the opportunity to pose questions and find answers within the community, because doing so improved the accessibility of care outside working hours though both patients and clinicians emphasised should not replace the face to face communication. Lastly, healthcare providers also benefit from having access to these posts and questions, getting more insight into patients’ needs and wishes. Interestingly, though the patients felt positive that the forum disrupted the doctor-patient hierarchy, the clinicians expressed their discomfort.

As well as academic research we are becoming aware of real-world interventions which use popular chat apps to extend healthcare beyond clinical settings. For example, in India, connecting patients to healthcare providers to extend healthcare provision to rural women during pregnancy [20]; or connecting HIV positive youth to providers and peers in Kenya [40]. This research demonstrates that the opportunities for interventions that connect providers to patients, and patients to peers and chat is clearly a promising tool for this.

It is early days for such interventions however and there is a lack of work examining in detail what goes on in these chat groups, how support is provided, crucially, what is it like for the healthcare providers who run these groups. As Thomas et

al. [49] say “as WhatsApp gains in popularity, the question of **how clinicians use** it – and, if they shouldn’t, what they should use instead – becomes more urgent” (our emphasis). Any disadvantages of introducing such chat into the clinical setting have also yet to be, beyond (important) concerns around data privacy [4, 23]. All of which is important, if such chat groups are to become an established part of healthcare. In this paper we provide a first step at addressing these gaps.

### METHODOLOGY AND SETTINGS

We conducted an ethnographic study of an IVF clinic in Gansu, China. To understand work in the IVF clinic, the first author conducted 10 days of ethnographic observations, supplemented by six semi-structured interviews in addition to the ad-hoc interviews during the observation. Finally, screenshots representing the nurses work in the WeChat groups selected over a 21 day period (consisting of approximately 1500 messages) were collected. One-to-one messages between nurses and patients were not collected. This data set is consistent with ethnomethodological ethnographies in HCI [11, 13, 41].

The six semi-structured interviews were conducted with the head doctor running the clinic, the head nurse, two specialism nurses, a student nurse and one patient. The aim was to get a holistic understanding of how WeChat has been integrated into the clinic’s work, thus the observations and interviews encompassed the entire communication ecosystem including WeChat, desk phones, mobile phones and face-to-face communication.

Data collected consisted of field notes, audio recordings, photos of the settings and relevant artefacts, such as chat messages, paper files, notebooks, digital systems and scratch paper. The anonymisation of photos happened before taking where possible, e.g. physically covering up any personally identifiable information (PII) (e.g. names, phone or ID numbers) or once collected where not. Fieldnotes were written up, audio files anonymised, transcribed and translated. Following the observation and interviews, in order to further understand the nurses work of facilitating the WeChat groups, the specialism nurse sent selected screenshots from messages sent to one WeChat group over a 21 day period (roughly 1500 messages). The nurse ensured that no sensitive medical or personal information about the patients were shared. Where necessary, additional anonymisation was carried out on these screen shots and the originals deleted.

Our analysis took a broadly ethnomethodological perspective. Ethnomethodologically-informed ethnographies explicate the knowledgeable, artful ways in which participants organise their practice and reveal the ways in which technologies and other artefacts are used as part of the accomplishment of that practice [3, 44]. As well as analysing field notes, the collected chat messages were examined in detail to get a holistic picture of nurses’ patient-facing communication work. Through this close looking at the seemingly ordinary details in the field notes, transcripts and messages our analysis seeks to unveil not just what the world looks like but how it comes to look as it does. The data was analysed by the first author individually and by the first author and the third author (who also made a brief field visit to get a sense of the context) in ad hoc sessions

explicating a particular topic, as is typical of the ethnomethodological approach. These analytic sessions allowed interesting topics to be identified and endogenous themes to emerge from the data. Ethnomethodological ethnographies are valuable in informing design [11, 22, 41], and we used the resulting understanding of the nurses work to inspire a set of design ideas which aim to address some of the challenges nurses face and therefore better support their work in these groups.

### **About WeChat**

Before we describe the IVF clinic, we outline some core features of WeChat. WeChat groups can have up to 500 members. As well as the usual messaging functions (text, voice, photos and locations), plus audio and video calls, WeChat supports some additional functionalities. Users can also post updates to their networks using Moments (similar to Facebook's Wall and Instagram). As mentioned, the official accounts and mini programs increase the utility of WeChat and it has been weaved into the fabric of people's daily life in China. Instead of installing stand-alone apps to access services and businesses, people use WeChat to hail a ride, order from restaurants and arrange hospital appointments. WeChat is thus becoming the central portal bridging the digital and physical world for people in China. However, WeChat only allows one personal account per mobile device, making it inconvenient for users to simultaneously use different accounts or manage diverse social networks from both professional and personal circles [43, 50] Meanwhile, Nouwens et al. argue communication apps should support cross app communication, conversations and functionalities to allow users the flexibility in managing their various communications needs while recognising the difficulties in migrating people from one app to another [38].

### **About the IVF clinic**

The IVF clinic is part of a university teaching hospital with a strong research arm. It ranks in the top three IVF clinics in China and attracts a large number of patients from across the country. As a result, the IVF clinic has an extremely low nurse/patient ratio (1:85). On an average day, two nurses in one specialism handle roughly 170 patients with formal appointments, not including those who drop by for ad-hoc appointments. Thus, being able to attend to all the patients and provide adequate medical care becomes a volume game. Compounding this, the IVF clinic is located in the North West of China which is culturally and ethnically diverse yet economically less developed. The resulting diversity of patients brings its own challenges, a higher proportion of patients have limited written literacy. Some of them leaving their villages for the first time to come to the clinic and many speaking the Chinese dialects of their local region and understanding little Mandarin, which is spoken by the nurses and clinicians.

### **Inside of a specialism**

There are seven parallel treatment groups in the IVF clinic, known as specialisms. Each has a slightly different speciality in IVF treatment: specialisms 1 to 5 share more similarities than differences, focusing on female infertility; specialism 6 receives the most 'difficult and complicated' cases being linked to the clinic's research arm; specialism 7 focuses on male infertility. Despite the medical differences, all specialisms share

the same organisational structure. There are six working staff including two doctors (one charge doctor who is responsible for their specialism and one associate doctor), two nurses, one medical student as an intern doctor and one student nurse. Of all the people working in one specialism, only the two nurses and the charge doctor have direct contact with the patients while the rest provide support services. Most charge doctors choose to only handle in-person communication during the patient consultations and rarely give patients their personal phone numbers or WeChat contact. The two nurses in each specialism are the central point of contact, handling the communication with patients (in-person, phone calls and WeChat), communication within the specialism, communication between specialisms and with the labs and operation theatres in the main hospitals too.

## **FINDINGS**

### **Unique patient journey**

One notable feature of IVF treatment is the complexity and intricacy of medical work, communication and adherence, and the patient journey is particularly complicated. One cycle of treatment takes around three months, but can be broken down into seven stages, each with their own medical instructions and medication. New patients are assigned to a particular specialism based on their initial test results and infertility type. Patients may also request to be assigned to a specific specialism based on their research of the clinic online or word of mouth. Once patients are assigned to a specialism, the nurses from that specialisms take over. Every day at 2.30pm the specialism nurses conduct an orientation for that day's new patients. During the orientation the nurse introduces the doctors and nurses treating them; conducts general housekeeping tasks (adding new patients to an existing WeChat patient group, give the patients their personal WeChat account; the specialism desk phone number and the 24/7 work mobile number). The nurse then describes the treatment journey using both models and flowcharts. They give the patient a patient handbook and collect the patient files given during registration and create green folders for each patients records. Finally, the specialisms generate a clinic Electronic Patient Record (EPR) for the patients.

Patients of the IVF clinic are neither completely in-patients nor out-patients: there are only two treatment steps where they are checked in as in-patients and spend the nights in the clinic (egg extraction) or the hospital (embryo transplant). Otherwise, depending on where they live, the patient will take the medicine or injection and complete tests and ultrasounds either in their local hospital or the clinic. During ovulation stimulation, patients do not need to stay in the clinic, but need to stay in the city for 12 to 21 days for their alternate day appointments and daily injections. The length of IVF treatment adds another layer complexity here. Although, a full cycle of treatment takes roughly three months, some of steps may take longer for certain patients extending the treatment length. A patient can only move on to the next step of the treatment when their tests meet all the requirements, be it progesterone level or ovarian follicle size. Hence the nurses and doctor need to keep track of patient's different treatment progress. For the patients, IVF treatment is neither as short as a typical medical

procedure, nor as long as a chronic condition that they might get used to managing. Lastly, the complexity of IVF treatment for the patients poses the biggest barrier to medical communication and adherence. As [19] found, as the complexity of dosing schedule increases, patients' adherence to medicine drops. During the IVF cycle, it is not only the dosing schedule that changes. With many factors involved, a patient's diagnosis does not remain static throughout. Conditions may develop and issues arise that call on doctors to change the treatment plan accordingly, which in turn requires patients to adhere to updated medical instructions. Further, a patient might be cured of a symptom, e.g. having blockages from fallopian tubes removed, which is a common cause for female infertility. However, the treatment is likely to only (temporarily) address the underlying issue but not necessarily offer the result the patient came to the IVF clinic for – a child. The patient journey through IVF treatment thus creates particular communication and adherence needs, ones which the nurse-facilitated WeChat groups were set up, in part, to solve.

### **A day in the life for the nurse in in IVF clinic**

The two highly skilled nurses<sup>1</sup> in each specialism handle the heavy lifting of the communication work whether that is patient-facing or internal. Doctors, in the IVF clinic decide a treatment plan, do consultations and scans, prescribe medicine, tests and other treatment during patients' visits to the clinic. The two nurses handle the patient on-boarding, patient education and explaining the treatment plan. They punch in daily in at 8am, when the patients have often already arrived. They find the files of all the patients with an appointment that morning and call patients in one-by-one for their appointments. Often patients pour into the consulting room before they are called due to the lack of space, and the nurses have to leave their task at-hand multiple times to maintain order. Meanwhile the desk phones, work mobile and their personal phones are always ringing causing further interruption. Patients calls include asking about highlighted figures in their test results, checking they are buying the correct medicine from the pharmacy, or to discuss their treatment more generally.

The consultation room is connected to a back room where the main doctor operates the ultrasound, and the associate doctor notes down medical notes and prescriptions in the paper files. After the ultrasound, the doctor quickly updates the patient on their progressions and moves on to the next patient who is already waiting by the door. The leaving patient brings their file to the nurse who orders the tests and medicine as per the doctor's prescription. Whilst patients may have many questions about their treatment, time pressure makes it difficult for nurses to deal with these in any more than a cursory way. The two nurses handle 170 patient appointments per morning on average, excluding the patients just dropping by to ask questions. As the head doctor describes, not one specialism nurse in the clinic ever has their lunch break on time. Immediately after lunch the two nurses onboard new patients and deal with unattended paperwork from the morning. Before leaving for

<sup>1</sup>All the nurses working in the IVF clinic have Bachelor's degrees, the head nurse completed a Master's degree in nursing and one of the specialism nurses was applying for a Master's degree in nursing psychology during our study.

home, they also have to plan for the next day, checking in with all the patients who are due to come in for appointment through phone calls.

The biggest challenge that faces the IVF clinic is the sheer volume of patients. Given that patients rarely take in much during medical consultations anyway [2, 29, 45], when there is barely five minutes to talk to them and the process is as complicated as IVF this creates real challenges. Added to this are the communication barriers created by dialects and some patients limited reading and written literacy.

### **The role of WeChat**

WeChat is used in three ways: a public-facing channel, private patient groups and for internal communication. As the focus of this paper is how chat can support the patient journey, we describe just the first two here.

#### *Public-facing channel*

The IVF clinic launched its own WeChat official account during our observations in February 2019. It uses the official account to broadcast relevant information to its followers (anyone on WeChat can follow this account). Doctors and nurses from each specialism take turns to curate themed content and send it out. Usually in one update, there is a main article, often news about IVF generally or the clinic specifically. This is followed by three articles each discussing one particular aspect of the theme in the main post. The main hospital also has an official account, through which patients can make appointments, check medical reports and pay their bills.

#### *Nurse-facilitated patient groups*

To enhance communication with their patients, the specialisms set up nurse-moderated patient groups. This is where the majority of WeChat-related work happens for the nurses. New patients are added to existing patient groups rather than having new chat group set up for each batch. This was a conscious decision: nurses learned from experience that older patients in the group would often help out answering new patients' questions when they can, as well as they can. The nurses strongly value this peer support element and described to us how the groups were set up specifically to enable this kind of support with a mixture of patients in different stages. The nurses' experience is reflected in prior research [1, 54]. However, whilst that forum created separate channels for peer and provider interaction [1], being able to communicate and share information with the nurses, *as well as* connect with peers from the *same specialism* in one single chat group is a central tenet of our setting. However, peer support is not enough on its own and managing these groups requires a tremendous amount of work from the nurses. They have to answer queries, provide reassurance, review test reports and offer counselling. In one specialism, the two specialism nurses were managing the two eldest WeChat groups of 500 members each (WeChat groups maximum size) and ten groups of roughly 100 members each. It is common for patients to stay on in these patient groups beyond their treatments (especially the ones who managed to have children) to help answer questions, provide peer support and most importantly share their experiences as '*successful alumni*'.

In addition to the patient groups, patients also send one-to-one messages to the nurses on their personal WeChat accounts. This enables patients to have a greater level of privacy than even face-to-face meetings in the clinic. As one nurse explained,

“IVF patients, are relatively more cautious and sensitive, there may be questions about mental health, and this will need be a private chat, so we will take it to WeChat, as you can see situation here: so many people around, we cannot deliver the kind of one-to-one consultation like other countries effectively, just way too many people. Too difficult, so when it comes to more private matters, we will take it to WeChat.”

And the clinic recognises the importance of clear and effective communication. As the head nurse said:

“It is important for us nurses to have enough knowledge about not just IVF but also general medical knowledge, as that’s the first step to trust, so the patient will trust you. But it is far from enough, I cannot just understand myself, I have to make sure the patients understand too, right? The medication, the treatment, the procedure, the whole process, not just IVF related, but also other issues might occur during the treatment. You need to tell them, not only how and what but also why. Then you can expect them to adhere well.”

However, while providing an additional communication channel between nurses the patients, the use of WeChat also results in added stress and work for the nurses. When asked what’s the most stressful part of the work, all the nurses and doctors we spoke to talked about “too many patients”. And indeed, it is a volume game. One of the specialism nurses reported that he received over 10,000 messages daily on WeChat. It is impossible for nurses to spare time for WeChat during the clinic’s working hours, so they have to attend to it during lunch breaks and in the evening. They cannot read each and every message, with such a large volume of messages coming through, so they have developed a number of methods to enable them to manage the work in ‘a reasonable time’. For example, one nurse described skimming through the messages in the evening would easily take him 30-40 mins. If there were messages requiring his follow-up, it would take him at least an hour. It should be noted however that all of this ‘reasonable time’ is after work, at home, when they are off-duty. In the next section we will describe the nurse’s methods for managing message volume.

### Work in WeChat groups

Given the number of patients in each group and across all groups, the nurses set up a few house-keeping rules to optimise their work. To easily identify the patients who send messages, nurses request the patients to set their patient group alias as their real name plus treatment stage and to update their alias accordingly as they move on, e.g. *Meili Xu – Fresh Cycle* and *Xiao Wang – Ovulation Stimulation*. These aliases are useful for the nurses as well as the peers to contextualise a patient’s posts. While providing answers, the nurses (and sometimes patients) can use the stage of treatment named in the alias

to determine the best answer or diagnosis. The nurse also described how this could help patients decide how much to trust an answer by their peers based on the peer’s treatment stage.

During the orientation, nurses also requested the patients to @ them, if they wished the nurse to reply to their questions. However, patients often mentioned the nurses name without inserting the @, which increased the chances of their messages being overlooked. Every day the nurses first look for the message directed @ them, whether that’s a question needs their answer, a test report to review or an appointment to be arranged. Ironically, unlike Slack or Twitter which separate out all the @ message for a user, WeChat does nothing with @ messages except indicate that you were mentioned! Nonetheless using @ helped because it looks very different from any Chinese character, so is easy to spot when skimming through the messages! This then is “*purely manual work*” as the nurse put it, to go through 10,000 messages looking for @ signs. Looking for directed messages is a collaborative task for the two nurses in a specialism. Whilst they prioritise answering messages directed at them, if they catch any unanswered messages for the other nurse, they will answer them too. There is no formal division of tasks i.e. whose turn it is to answer those messages first but it is a lightweight way of reducing the number of missed messages.

### Typology of messages

Typically, when patients post in these groups, they either direct questions to the nurses (other patients might still answer) or post for peer support.

#### *Medication related questions*

The questions on medication range from general queries about dosage to their reaction (or non-reaction) to a medicine. Dosage questions were common and often answered by peers. For instance, one patient messaged “*Nurse B, could you take a look [referring to an image of the handwritten prescription] how do I take Femoston?*” Another patient replied stating the usage being external, once per day. The patients in these groups share a high confidence in the quality of answers from their peers and they often direct questions to peers instead of the nurses, e.g. “*Dear all, the two [pills of] Progynova per day, do I take them together or separately?*” another patient quickly replied “*Either is fine, though I take them together.*” The initial poster replied with thanks and no other posts on this were seen. Similarly, another patient posted to the group “*Hi, is Deltacortone Prednisone?*” and immediately received an answer from a peer confirming the two names refer to the same medicine. Images are often used to help illustrate their questions on whether the medicine at hand is correct. Apart from general questions there are also more specific questions related to either the patient’s reaction or treatment plan. Such as a patient asking whether she should take another pill if she had thrown up 40 minutes after taking one.

As described, IVF treatment is complicated and so is the medication. Throughout the treatment, the patients, according to the treatment stage, need to take different types of progesterone which often have similar names i.e. Femonston and Duphas-ton. And for Femonston, there are two forms, one yellow and

one pink, patient at different stages are prescribed different coloured pills to either apply externally or take internally. Due to the progression through different treatment stages, often when patients get familiar with the medical instruction for a stage, they move on to the next. Thus, to remember their specific prescription and adhere to it is no easy task for the patient which both results in and is reflected by these questions in the WeChat group.

#### *Sending test/ultrasound reports*

Since many patients are remote, they undertake frequent blood tests and ultrasound scans in their home clinics. Patients send the image of their reports alongside text message to the nurses in the chat group. Nurses use this to monitor patients progress and pass this information to the doctor if necessary. As images are regularly cleared out from WeChat groups, nurses keep a notebook of anything from reports which needs to be shared with the doctor.

According to the nurses, reports are one of the most common message types, and the only type where the peers cannot provide support, as the reports are sent and reviewed for diagnostic purposes. When patients send out their test/scan reports they specifically direct it to the nurses, however, this does not mean the patient will always remember to @ the nurse, rather they will simply mention the nurse i.e. “Nurse A” or “Nurse B” in their text message. Though these messages are meant for the nurses, other patients do seem to read these messages and the reports. For example, patients may post questions about particular figures in reports, or offer support such as “Don’t lose faith yet.” Three things are striking in terms of reports. Firstly, the nurses strictly discourage comparing tests report in the group between patients as one of the chat group housekeeping rules, however, we did not see it violated, so did not see any enforcement of group chat guidelines in our data set. Secondly, this type of messages are directed at the nurses and they make up the majority of the messages in the WeChat group that require the nurses monitoring and more importantly a reply. Lastly, as we described in the above section, given the patterns of how and when the nurses check WeChat group messages, they often reply in bulk to all the patients (@ each patient individually) who were waiting for a response: the most common response being “Please call the specialism”<sup>2</sup> suggesting the matter is too complicated to discuss over message. Sometimes nurses may give instructions to individual patients in the group. As one nurse showed us, they had given three responses to reports, each to a different patient included instructions for one to continue with local monitoring, one should drop by the clinic next week and one should redo and resend that days test. Thus, whilst WeChat is used to communicate information to the nurses, in the form of reports, it is not used for giving complicated medical instruction.

#### *Protein input/output self-monitoring*

When the patients enter the ovulation stimulation stage, they also send out a self-monitoring daily input and output report as the input-output volume serves as an indicator for the nurses to monitor if the patients display Ovarian Hyperstimulation Syndrome (OHSS) tendencies. Patients usually send out an

image or screen shot of their self-monitoring report of the day before every morning around 8am to the group. The patients are required to detail the time and amount of each input/output, when the nurses look at these reports, however, they only check if the total amounts are within range the details are reviewed only if the total amounts indicate potential issues. Though the nurses do check these self-monitoring reports, they rarely reply to this type of message because of volume of work, except for very occasional motivational messages. It is impossible for patients to know for sure if the nurses have checked these reports, which may hinder their adherence given the lack of acknowledgement or reassurance [14, 16].

#### *Emotional support – passing on the good ‘luck’*

Most clinical studies on the effects of infertility treatment conclude that early intervention is needed that addresses, predicts, and normalises the stresses and emotional sequelae of infertility [10]. Nurses describe the most significant element of peer support in these groups is the emotional support they provide for one another, especially when it comes from the successful alumni sharing the hardship leading to their positive outcome. Whenever a success story is shared, a special phrase – “*Jie Hao Yun*” (to continue/receive the good luck/pregnancy) – was sent by many patients together with their congratulations. In Chinese, both the characters for pregnancy and luck is produced Yun, “*Jie Hao Yun*” which usually means to continue the good luck thus has the meaning of receiving the good luck to have a good pregnancy here. The very presence of these successful alumni in these groups are also considered the best testament of inspiration and hope for other patients, and its positive emotional effect whether through their success stories or the messages of encouragement is not to be underestimated in light of the well documented emotional effects of infertility [15, 25]. After one alumnus shared the news of delivering twin babies in the group, one patient first congratulated the poster, then expressed her frustration with her recently failed embryo transfer. The alumnus then disclosed that the successful pregnancy and delivery was in fact the result of the third embryo transferring attempt and she encouraged the frustrated patient to have faith in herself, in the treatment and in the specialism. Another alumnus joined in to share her journey which was also far from smooth, saying “*to endure the pain but maintain positive*” was hard but necessary, as “*it was all worth it*”. Peers also support each other by sharing solidarity with frustrations and triumphs as ‘sisters in it together’. As well as providing some support for patients during an emotional and stressful journey, nurses find such posts useful as an indication of patients ongoing psychological state. They describe this as being particularly important because of the risk medical professionals in China face of litigation or even violent incidents from unhappy patients.

#### *Sharing non-medical information*

In addition to the emotional support, the patients also post in the chat group to ask their fellow patients for tips, recommendations and treatment norms (e.g. how long it takes to move from one stage to another). When patients need to temporarily relocate to be near the clinic they post in the group to ask for accommodation recommendations and look for potential housemates. Other non-medical information seeking/sharing

<sup>2</sup>Hence the title of this paper.

also includes information about where to get the particular needles required for the progesterone injection, how many days each stage of the treatment takes so they can plan their days-off from work and which physical exercise that is recommended by the clinic.

#### *Trading medicines*

Another common practice is to trade medicines with peers. Since it is hard to predict how long a patient stays in a stage, the doctor often prescribe medication for longer period of time to be safe especially when the patients are remote and have less easy access to pharmacies. Therefore, some patients may end up with excesses of one medicine from the current stage and in need of another one for the next stage. When this happens, the patient will post in the group of what they have extra and what they need so other patients can trade with them, or simply buy the extra medicine off them.

#### *Urging for medical adherence*

One of the prime purposes of all the efforts to establish better communication between providers and patients is to the improve patient's medical adherence. During patients visits to the clinic, the nurse repeatedly tells them *"please read the patient brochures and please listen to the doctor."* In the WeChat groups due to time pressure they mostly reply with concise, direct answers, but occasionally they post encouraging messages to acknowledge the patient's good adherence and rally them to keep up the efforts, e.g. *"Good work recently, continue!"*

Additionally, though the doctors are not members in these chat groups, they still do have a presence. In addition to receiving updates from the nurses, the doctor also asks *patients* to post instructions on their behalf. One patient posted the same message 3 times in a row, highlighting the absolute importance of the message, *"!!! Passing on what the doctor said this morning: all patients, whether you are waiting for embryo transferring, not yet arrange for transferring or have done the transferring: All of us are located remotely, the travelling back and forth is not easy, and the ovulation stimulation, embryo defrost and transferring are incredibly hard, so we need to strictly adhere to the medical instructions, so we can hope for the best outcome. It is the most responsible we can be for ourselves. [...] whatever difficulty in the treatment we might face, the doctor is here for us, but if there is undesirable outcome because we didn't adhere to the doctor, she cannot do much to help. Please pass this on to your peer patients, your spouses and family."* The proximate presence of the doctor in the chat group and the very presence of the nurses not only creates a clear provider-patient communication channel but also helps in urging the patients to adhere to medical instructions.

#### **Working around issues with WeChat**

Retrieving content generated and shared over time or related contents that showed up over time is a known difficulty in chat [33]. In this setting due to the sheer number of messages it is extra difficult. Information posted in the chat groups disappears in the long stream of messages, there is no means of threading so interactions may be interspersed with multiple messages. Add to this that there is no way to directly view @ messages, not to mention patients often forgetting to @ the

nurses. It is therefore no surprise that both nurses and patients may miss messages. As a result, group members develop practices to try to compensate for this.

#### *Timed message post*

We have already mentioned the use of @, and how the two nurses will cross check unanswered questions for each other. Patients too have learned to time their messages according to the nurse working patterns. For instance, patients often send out the test/scan report as soon as they receive it in the morning, however, the nurses don't normally start responding until lunch or the evening. When patients see nurses responding to others whose posts were after theirs but not to their messages, they may send their reports again @ the nurse, or simply ask *"reply to mine too, please!"* Other times, when patients realise the nurse they have directed the message to was not responding, they resend the message @ the other nurse. Of course, whilst this plays on the usefulness of chat for immediate communication [33] it adds yet more messages to the chat stream.

Since nurses usually respond to all patients in bulk, often with the same instruction – to call the specialism – patients may also miss the reply to them. In which case, nurses repeat their response. Both nurses and patients are noticeably accommodating of such missed messages.

#### *Group regulations*

It can also be hard for nurses to keep track of one conversation in the long chat stream. It is not a rare case that the two messages in one conversation between a patient and a nurse are messages (as many as 40!) apart. This is because is a patient posts in the morning, and nurses reply in the afternoon or evening, other patients will have posted their reports and queries or coordinate with others to exchange medicines. Patients too are likely to be subject to the overload in messages and they strictly regulate what gets posted. Immediately after one patient posted a link to a game, another patient protested dropping the nurses' name in her protest.

#### **DESIGN SUGGESTIONS**

These nurse-facilitated patient groups, just by the sheer volume of messages, seem to provide a useful extension of the nurse-patient communication. However, they are not without problem, resulting in extra work for nurses, undertaken during their downtime. We recognise and acknowledge the precarity raised by [38] of shifting patients from well adopted platforms with limited functions to new platforms with the potential of more functions. We believe that some additional functionalities could help order and organise the content and therefore reduce the burden on the nurses. To this end we propose the following set design solutions for WeChat, primarily aiming to make the work of the nurse-facilitator easier and more effective.<sup>3</sup> See Figure 1.

#### **@ Message tab and pre-edited messages**

An immediate time saver for the nurses would be to enable them to see all the messages directed at them. We therefore

<sup>3</sup>Prototype link <https://xd.adobe.com/view/a9153651-b406-483c-4fe3-33c9d5cb08e3-df24/>





Figure 1. Screenshots of design suggestions mock-up

propose a separate @ tab where the nurses have easy access to these messages. Since the patients don't always remember to insert @ when they message the nurses in the group, we also propose name detection being incorporated, similar to Facebook's mention function: as soon as patients type the nurse name, they will be suggested to insert @.

Further, considering the clear patterns of the responses from the nurses, we propose a pre-edited message template in the @ tab too, so the nurses can choose from their most use responses "Please call the specialism" "Continue monitoring test in local hospital" "Please come in for an appointment at...". In addition, motivational responses could be added, enabling the nurses to recognise and encourage patients without increasing their messaging burden.

Currently the two nurses respond to patients collaboratively. We would hope this function would not remove this work, but just reduce the burden of looking for their own messages.

### Leader board tab

Currently the nurses look through thousands of patient messages for posting patterns. They look for most active users and the content of those messages, such as if a patient repeatedly talks about one matter. We propose a leader-board which ranks the most active users of that day, with the numbers of messages they have sent. This could be enhanced by sentiment analysis [52] of the messages to provide an initial sentiment estimation. Such a function could help nurses get an overview of the day's activity and for example check the messages of patients posting a lot or displaying distress.

### Test/Scan Report tab

This separates out the all the messages of test/scan reports, again to better access to this type of message, which form the bulk of nurses work, not to mention reducing the messages in the main chat stream.

### Input/output report tab

Nurses could send out a table (similar to a Google form or Kaizala survey) which the patient fills in directly instead of sending images or screen shots of the report. In addition to seeing the individual report, the nurses can see an aggregated summary of all total amounts of each patient and only look at detailed report from a patient when they spot an issue.

### Medicine exchange

To facilitate medicine exchange, a completely separate space for patients to post and exchange medication could be created. This would further declutter the main chat stream, and nurses can choose to check only if they wish.

### Related Articles

Often patients questions on medicines and treatment are answered in the articles the clinic send out through its official account, this is a tab where the links to the articles are listed so the nurse can choose to send related articles to support their answers.

### Feasibility

Whilst these designs are technically feasible, they are currently not legally feasible on WeChat. WeChat maintains sole control of group chat data and does not permit data scraping from chat groups. There are therefore two options for moving forwards. Firstly, and most preferred, is for WeChat to incorporate these designs. In the latest launch of the Group Manager mini program for example, people can separately post and store images or send out simple polls. We aim to present our ideas to WeChat. Secondly, another chat app, such as Telegram or Kaizala, could be used which does support analysing messages and building on top of the API. This would however introduce the problem of migrating users from WeChat to a new app, which is no easy feat [33].

### DISCUSSION

Studying the use of WeChat in the context of the clinics daily operations helps us understand this emerging use of chat in healthcare work. These nurse-facilitated groups were widely used and it is clear patients and nurses find them useful. We extend understandings of the facilitation work for healthcare providers in these groups in particular how WeChat provides little support for nurses dealing with so many messages. We describe the interplay between facilitation and peer support. For example, nurses rely on peer support to answer some questions, but discourage discussion of test results.

### Hierarchy, facilitation and adherence

Previous research suggests that creating online communication channels between healthcare providers and patients disrupts the traditional provider-patient hierarchy [1]. However, this claim does not stand true in our case, despite peer support and nurse facilitation being combined in a single channel. Indeed, patients respect the hierarchy which is reflected in the way the nurses are approached for advice and how they are addressed: both in the clinic and in the chat groups nurses are sometimes addressed as 'Daifu' (doctor in Chinese) or 'Laoshi' (teacher in Chinese) which both demonstrate respect and authority, and

is an indication that the hierarchy transcends the boundary of the digital and the physical. This is perhaps unsurprising given that the WeChat group is just one part of the clinic's treatment program. Similarly, patients invoke the hierarchy by mentioning nurses' names when discouraging irrelevant posts to the chat. Finally, messages are posted by patients on behalf of the doctor, where the doctor is invoked to encourage adherence, although the doctor himself does not take part in the group. Indeed, this abstinence also represents the hierarchy, as the doctor only involves himself in consultations, with nurses left to run these groups. Research suggests that patients adhere better in 'supervised environments' [34] and these WeChat groups become supervised digital environments. Within which it seems likely that this extension of the patient-healthcare worker relationship of respect outside of the clinic could play an important role in supporting adherence.

### **The work of chat**

Like [1] suggests, the aim of digital forums such as chat should not be to replace in-person communication between patients and providers. Whilst providing extra staff might be the best solution, WeChat has already been adopted to extend limited clinic time, and for the nurses to reduce the number of phone calls they receive throughout the day (also found in [1, 55]), which are more disruptive of their work. Our design suggestions aim to facilitate the work of the nurse, making managing message volume easier rather than, for example, automating replies with a chatbot. We believe the nurses play a vital role in the interaction and understanding the state of their patients is crucial for high quality care. Nonetheless, the work of moderating such groups needs to be taken seriously by any healthcare organisation wishing to deploy such groups. Sun et al. in their study of one-to-one patient-provider messaging portals, with low active users (32), recognised the potential burden this messaging work could bring to health care providers impacting on both the quality of communication and care [48]. We build on this by showing how messaging unfolds in *high volume* patient-peer-provider *groups*, how these groups support the treatment program and explicate the work that nurses must do to manage these messages. Such work needs to become a recognised part of the providers workload, with adequate time and staff set aside for it, rather than additional work down out-of-hours. This was managed in the online forum, through dedicating extra staff [1], creating a team consisting of senior nurses who do not have night shifts and limiting the facilitated chat time to 30 minutes per day [21]. However, when such work is carried out on personal devices, it is easy for it to seep into personal time as [5] noted. In the IVF clinic, nurses anyway have to bring the emergency work phone home to be reachable outside of working hours. Thus how nurses view their work and boundaries between personal and work time is a research topic in itself.

### **Patient-centred care**

These nurse-facilitated patient groups make care more accessible, providing reliable information and emotional support from peers. Research has found these to be important to patients [9]. Further they help healthcare professionals get a sense of patients' satisfaction with the treatment program which

may otherwise be hidden. However, there is an ongoing dichotomy between delivering patient-centred care and adding to the workload of already stressed medical professionals: nurses in China, in our case. Good design is essential for developing provider-patient communication tools which balance the precarious tension between providing better access to care and requesting extra work from medical professionals. We hope our design suggestions are a starting point on this road.

A second concern is privacy. In addition to the regulatory perspective about sharing patient information in chat [4, 23], we want to draw attention to a more contextualised understanding of privacy from the patients' perspectives in Chinese healthcare. Patients in the nurse-facilitated chat groups share their test/scan reports, physical reactions to treatment and experiences that are both deeply personal and emotional. This does not mean they lack an understanding of privacy; as one nurse described for more private matters, patients would move to a one-to-one chat. Our study echoes [54], who found that patients in a Chinese online community for diabetes established their friendships with one another with a "*high level of trust and less concern about personal information sharing*". To criticise or discard the usefulness of these chat groups from a privacy regulatory standpoint would miss the whole picture. What counts as privacy in regulations is not necessarily what concerns the patient, as has been discussed outside the healthcare context [12, 42].

### **CONCLUSION**

In this paper we build on research suggesting that chat is a useful tool for provider-patient-peer interaction to support and extend healthcare services. This may be especially important in the Global South where the sheer number of patients creates a barrier to effective patient-provider communication, and where chat apps have been widely adopted and incorporated into daily life and work. We contributed to this growing body of research by revealing the work nurses must do to manage such chat groups, which highlights a tension at the heart of patient-centred healthcare. We described how nurses (and patients) created innovative workarounds for some of the problems of chat, and proposed some design suggestions for facilitating their work. Whilst these suggestions have not yet been implemented, we hope they provide inspiration for designers of chat apps for patient-provider-peer interactions. Our future work will focus on examining the issues we discovered but which remain unaddressed in this study. Whilst some of our findings and designs might be specific to this clinic and WeChat e.g. using chat for medicine exchange, others may generalise. For example, the burden for nurses of chat facilitation; the value of peer support; or how chat impacts on both the quality and practice of healthcare. Certainly, patient-provider chat groups are springing up rapidly, suggesting the importance of investigating further their impact and their design in a variety of medical settings, from TB treatment to mental health care.

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