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Patient experiences of nurse-led telephone follow-up following treatment for colorectal cancer

INTRODUCTION

Colorectal cancer is the third most prevalent cancer worldwide (Parkin et al., 2005). However, mortality rates across most of Europe have decreased in recent years (Center et al., 2009). In the United Kingdom (UK), five year survival for those diagnosed at an early stage (Dukes A) is currently over 90%; those diagnosed at an early stage have a better prognosis than those who present at a later stage of disease (Cancer Research UK, 2014). However, despite most patients undergoing potentially curative surgery, 30-50% will develop recurrent disease and five year survival for advanced colorectal cancer is less than 5% (Young & Rea, 2001; Bohm et al., 1993). Incidence is strongly related to age; in the UK approximately 43% of bowel cancer cases were diagnosed in people aged 75 years and over between 2009 and 2011 (Cancer Research UK, 2014). The mainstay of treatment is surgery, although radiotherapy and chemotherapy can be recommended depending on disease presentation and stage (NICE, 2011).

Following completion of treatment, colorectal cancer patients tend to return to hospital outpatient clinics for surveillance at regular but decreasing intervals for a period of three to five years, depending on national guidelines and local hospital policy. The reported purpose of follow-up after colorectal surgery is primarily to improve patient survival by early diagnosis of recurrence as well as resolving surgery related problems and providing psycho-social support (Li Destri et al., 2006). More

intensive follow-up has been associated with improved five year survival (Jeffery et al., 2007; Tjandra & Chan, 2007). However, the most recent UK guidelines indicate that there is no consistent definition of what constitutes 'intensive' follow-up for colorectal cancer patients; no specific protocol for intensive follow up can therefore be recommended at present (NICE, 2011). Protocols for follow-up primarily focus on the most appropriate tests and investigations that will detect recurrent disease at an earlier stage and therefore improve survival (e.g. serum carcinoembryonic antigen tests CEA, CT scans, colonoscopy). However, few studies have focused on psychosocial aspects of colorectal cancer follow-up; providing patients with the information and support they need to live well beyond the cancer diagnosis.

It is estimated that there are now two million cancer survivors in the UK, predicted to rise by 3% a year (Maddams et al., 2009). Approximately 250,000 people living in the UK have received a diagnosis of colorectal cancer (NICE, 2011). The majority of colorectal cancer survivors are in phases of rehabilitation (the first year), early monitoring (up to 5 and 10 years from diagnosis), late monitoring (10 years +) and progressive illness (incurable disease but not end of life)(Maher & McConnell, 2011). Survivors of colorectal cancer are known to have specific information and support needs that are not met through traditional hospital follow-up (Nikoletti et al., 2008; Rozmovits et al., 2004; Sahay et al., 2000). The UK's National Cancer Survivorship Initiative (NCSI) calls for radical changes to the way follow-up/aftercare is provided following treatment, with a focus on providing patients with the information they need to live well beyond diagnosis, promoting supported self-management and evaluating alternative models of follow-up care (Department of Health, 2010). Given

the ageing population in the UK (and across Europe), the favourable five year survival rates for those diagnosed with colorectal cancer at an early stage and the reported success of bowel cancer screening programmes in terms of early detection (Macafee et al.,2008), it seems likely that the traditional hospital outpatient approach to follow-up will become economically unsustainable.

Whilst traditional doctor-led models of care following treatment for cancer predominantly focus on the detection of recurrence, nurse-led models take a more holistic approach and have been shown to be acceptable with positive outcomes (Beaver et al., 2009; Knowles et al., 2007; Lewis et al., 2009; Moore et al., 2002; Wells et al., 2008,). Knowles et al (2007) successfully piloted a specialist nurse-led model of follow-up for 60 colorectal cancer patients who had undergone surgery with curative intent. The study demonstrated high levels of patient satisfaction, improvements in quality of life and global health as well as potential cost savings. Knowles et al (2007) acknowledge that they were not able to conclude that improvements in health were directly attributable to the nurse-led model of follow-up but they did suggest that systematic symptom assessment and strict adherence to the follow-up protocol by the nurse specialists involved in the study may have led to the improvements reported.

Nurse-led telephone follow-up (TFU) has also been shown to be effective for colorectal cancer patients in a pilot randomised controlled trial (RCT) with those receiving TFU from a specialist nurse reporting higher levels of satisfaction with information and service than patients receiving traditional hospital follow-up (Beaver

et al., 2012). Local protocols for tests and investigations aimed at detecting recurrent disease (e.g. CEA blood tests, CT scans) were unaltered and the telephone approach focused on addressing the psychological, supportive and information needs of patients in addition to detecting signs of recurrence. The telephone intervention consisted of a structured guide containing questions about changes in health, symptoms, information and support needs (histology, treatment and side effects, genetic risk, sexual attractiveness and function, self-care, impact on social life and family concerns). The Beaver et al (2012) study provided preliminary evidence of effectiveness but to obtain more in-depth information on patients' experiences of TFU, as recommended in trials of complex interventions (Lewin et al., 2009), a qualitative study, involving semi-structured interviews with a sample of participants randomised to the telephone arm, was also conducted. This paper reports on the qualitative study that explored colorectal cancer patients views on TFU to determine what aspects were perceived as beneficial. This information is important for health care providers planning to implement this approach in practice.

AIM

The primary aim was to explore patient experiences of TFU after treatment for colorectal cancer. A secondary aim was to explore the views of the Colorectal Nurse Practitioner (CNP) who administered the telephone intervention in the pilot RCT.

METHODS

Design

A qualitative design using semi-structured interviews enabled participants to describe their experiences of TFU in depth and detail. This was intended to enrich the findings from the quantitative pilot trial that aimed to examine effectiveness of the telephone intervention. Although only one specialist nurse had delivered the telephone intervention in the pilot trial it seemed appropriate to also explore the views of the CNP on delivering the intervention and the CNP was therefore also interviewed in this qualitative study. Study participants were given the choice of a telephone or face-to-face interview. One researcher conducted all interviews which were digitally recorded, transcribed verbatim and analysed using content analysis. The study received ethical approval from the National Health Service Research Ethics Committee.

Sample

The pilot trial had recruited 65 patients; 32 were randomised to TFU. On completion of the trial, 26 patients who had received TFU were available for interview. All 26 were contacted by letter thanking them for their participation in the pilot study and asking if they would be prepared to talk about their experience of TFU with an experienced nurse researcher. Twenty one consented to be interviewed; 20 were interviewed by telephone and one face-to-face. Of the five patients who were not interviewed, three declined and two had been admitted to hospital with unrelated illnesses. All 21 patients who were interviewed had experienced telephone follow-up on at least one occasion; four participants had received two telephone appointments

prior to being interviewed. The CNP who had provided TFU for the duration of the pilot study was provided with verbal and written information about the purpose of the interview and chose to be interviewed face to face. Written consent was obtained from all participants prior to interviews.

Data Collection

Two interview guides were developed (patient and CNP) containing questions and probes relating to TFU. The semi structured format using open ended questions allowed the interviews to flow and provided the opportunity for the researcher to probe interesting and relevant issues as they arose. The patient interview guide asked patients to give their views on follow-up being carried out over the telephone instead of in hospital, how they felt about follow-up being conducted by a specialist nurse instead of a doctor, aspects of TFU that had been helpful or unhelpful, how they felt about the questions they were asked in the delivery of the intervention, whether they had experienced any problems with their appointments and their preferences for future follow-up. The CNP interview guide explored views on how TFU compared to hospital follow-up, any difficulties encountered, the perceived advantages and disadvantages for health professionals and patients, the content of the intervention and issues around future implementation. Patient interviews lasted between 20 minutes to one hour and the CNP interview lasted one and a half hours. The first four patient interviews were transcribed and analysed by all three authors to review the appropriateness and relevance of interview questions; no changes to the interview guide were considered necessary.

DATA ANALYSIS

Two researchers independently reviewed and analysed all transcripts using the interview guide as a framework for analysis (Ritchie & Lewis, 2003). Content analysis techniques were used to analyse the data and concept networking was used to link the relationships and associations of the themes that captured the content and meaning of the data (Miles & Huberman, 1994, O’Leary, 2004). Where appropriate, the numbers of participants whose data supported a theme or sub themes were counted and the results reported descriptively (i.e using terms such as “all” and “most”). Reliability and trustworthiness was established through discussion of any discrepancies between the authors and re-examination of the original data until consensus was achieved (Shenton, 2004). By carrying out the data collection and analysis in a systematic and comprehensive way, and ensuring transparency in reporting at all stages of the research process, we could subsequently ensure that the interpretation of findings would be well supported by the evidence generated (Richie & Lewis, 2003)

RESULTS

The characteristics of the patient sample are outlined in Table 1. Both men and women were represented in the sample and a typical participant was retired and over the age of 65 years. All patients found TFU to be a positive experience and all stated a preference for continuing with TFU. Three main themes emerged from the patient interviews; 1) accessible and convenient care, 2) personalised care, and 3) relationship with the specialist nurse. The themes from the CNP interview were 1) knowing the patient, 2) the benefits of TFU and 3) the challenges of TFU.

Insert Table 1 here

Patients' Views

Accessible and convenient care

All participants commented on the convenience of TFU; no travel, no car parking problems and no long waiting times in hospital clinics. Positive comments were made about the punctuality of telephone appointments; appointments were on time with no waiting involved. Participants appreciated being able to schedule their day knowing that their appointment would last approximately 20 minutes, with the timescale largely dependent on their information needs at the time of their appointment.

"I haven't got a car so I'd have to take two buses you see to go to the hospital. When I get to the hospital I have about an hour and a half wait in the waiting room. And I go see the doctor, two minutes and I'm out again."
(ID09)

"I thought it was quite good actually, because it saved all that problem of having to go to the hospital and queue, as you know. Wait around and probably there for a half an hour, an hour, a lot longer than you should be. And well a lot easier all the way around actually, I thought." (ID08)

TFU was also viewed as more economical as participants did not have to take time off work, pay for travel and car parking or make arrangements for care of dependents. A number of participants had co-morbidities and altered bowel function and had found the journey and time spent at the hospital to be fraught with difficulties, particularly if they were prone to involuntary emissions or had difficulties with colostomy bags. TFU allowed participants to focus on their information needs and concerns in a familiar and relaxing environment over which they had control. Most participants chose to have their telephone appointments at home while others chose to be telephoned at work. The punctuality of the telephone calls ensured minimal disruption to participant's daily lives. One participant was a long distance heavy goods vehicle driver and was able to conveniently pause his journey for his scheduled telephone appointment. Another participant was able to continue with a planned holiday as she could take the telephone call on her mobile phone during her holiday period.

“Well it was good for me really, ‘cos I didn’t have to keep taking time off work to go to the hospital. They just used to ring me up on my mobile and while I was out at work, and I could speak to them there rather than having to keep going in. And when I didn’t feel there was anything wrong with me, it seemed a waste of time going into the hospital anyway like. I’m driving about all day so I just pulled over. They were pretty prompt on ringing.” (ID03)

Personalised care

Participants viewed the telephone appointments as personalised and relaxed. They felt unhurried with time to ask questions and felt comfortable talking to the CNP about personal issues over the telephone. Participants reported a degree of privacy that was not available in the busy hospital outpatient department, which enabled them to talk more freely.

“I mean she’s so good that she could even ask me things of a sexual nature with my after-care, without me being embarrassed. She handled it superb, because one of the hardest things to do for a man is to talk about how he performs... She went through it like an absolute veteran. The training she’s had to deal with, shall we say, awkward subjects which is good.” (ID01)

The structured nature of the intervention was seen as helpful and the questions were considered relevant, prompting some participants to ask questions they might not have considered at hospital visits. Telephone appointments provided an opportunity for participants to learn more about their health and to develop strategies for dealing with difficulties they were experiencing.

“I preferred it. Yeah. Because she (CNP) was able to tell me sort of little details. Like how much of the bowel they'd removed, and how far the cancer had gone. And of course I wouldn't have asked things like that, but she offered the information... I think when you're in a hospital appointment, you're conscious that other people are waiting outside sometimes...” (ID15)

Some participants commented that the repetitive and structured nature of the telephone intervention enabled them to prepare in advance and to think through questions that they might want to ask. Most felt that the private nature of the telephone consultation made them feel as if the nurse was focussing on them without being distracted by other patients waiting in a busy clinic.

“They’re looking after you only, there’s no one else, and it’s been that way right from the beginning. Your own personal nurse, put it that way.” (ID08)

None of the participants reported anything lacking in their care by not attending hospital for follow-up although two participants thought it would be useful to have a combination of hospital and TFU. One participant commented that she missed the informal support of meeting with other patients at hospital visits.

“I did miss the camaraderie that you get from other patients. And, of course, what tends to happen when you go on hospital visits is that you tend to be there at the same time as the other people who had their ops [operations] with you.” (ID14)

Relationship with the specialist nurse

All participants commented that they had developed a trusting relationship with the CNP even though less than half of participants had actually met or spoken to the CNP before commencing TFU. Of those who had not met the CNP, four commented that they would have liked to have put a “face to the voice” but that it had not affected

satisfaction with care. Participants appreciated the ability of the CNP to empathise with their situation and they appreciated her interpersonal skills, in particular the ability to listen.

“She was a very caring person and she’s a person who listened to your problems...her personality still came hard over the phone. She spoke to me like a friend... It was just her whole attitude seemed to be... I just felt I was able to talk to her.” (ID20)

“She listens carefully to what you have to say. She thinks about what you’ve said, and then she comes back with a response... she makes you feel that you’re the person that she’s interested in, which comes across.” (ID01)

Participants had confidence in the ability of the CNP to provide support and meet information needs and acknowledged the CNP’s knowledge and competence. The CNP was able to provide the information needed such as tips for securing colostomy bags, identifying dietary habits that might be causing problems, assisting with access to additional resources and referring to other services if necessary. Participants commented that they felt able to talk to a nurse about intimate bodily functions in a way that they could not talk to a doctor and a number commented that the CNP had more knowledge than medical doctors about the particular difficulties they were facing.

“They knew what you go through... For instance I had this problem and that is absolutely horrendous ... especially now having a colostomy bag on, a stoma bag. So when you say to the doctor about it they, you know, they don't quite understand. Where obviously the specialist nurses will understand what you've got to go through.” (ID 06)

“Quite happy. I did feel that I perhaps gleaned more information, I didn't feel rushed or anything. And I'm sure that I sort of gleaned more information from my colorectal nurse than I would have perhaps done in a clinic situation.” (ID14)

Colorectal Nurse Practitioner views

Knowing the patient

The CNP commented that getting to know the patient was a critical factor in her ability to provide personalised care and she would prefer to have met all participants prior to commencing TFU. The CNP had initially found it harder to get to know patients and build a rapport over the telephone than face-to-face and had to hone her listening skills to identify non visual clues.

“I think initially I found it quite hard with a lot of the patients that I haven't met before, that was one of the things that I felt hard over the phone, because you couldn't sort of visualize that person and I found that hard. You had to sort of rely a lot on your listening skills which I found quite tiring in the beginning. I think from my nursing perspective, sometimes... I'm used to like

seeing people in the flesh, because I used to think well you can get a lot by visually seeing people if they'd lost weight, 'cos they may over the phone tell you "Oh I'm fine. I'm fine." And then when you see them, they look absolutely ghastly." (CNP)

One of the ways the CNP got to know the patients was through her diagnostic skills which were dependent on visual or olfactory signs but with TFU she was reliant upon the descriptive skills of patients or their carers.

"But sometimes some people think that because this is the first time they've had a stoma or whatever, they don't know what's right or what's wrong. And it's only sometimes when you see them face to face, or you're looking at them, or you can get a smell, or some kind of non-verbal thing... Whereas again over the phone, it's one of those things you can't necessarily assess. But saying that I mean I have had one person who over the telephone consultation I felt she described what I felt was a hernia and we got her to come the next day and it was a hernia. She did describe it well... I suppose patients have got to take some responsibility for their own health." (CNP)

Even though the CNP felt that she became more proficient and thus more comfortable with telephone consultations over time, she thought she would like to see the patient at least once prior to the commencement of TFU.

“I think I feel I always like to see that patient, even if it's just once. Just meet them face to face and then afterwards it wouldn't bother me about using telephone follow-up. I just feel it's a bit more (pause)it's a bit more personal if you've met someone face to face.” (CNP)

Benefits of telephone follow-up

The perceived benefits outlined by the CNP were similar to those reported by patients and she recognised that telephone consultations were more convenient for patients and fitted into their lifestyle:

“I think it fitted in a lot better with people's lifestyles. I had a young guy, he... I think he's a wagon driver, so he could fit in his consultations whilst he was working... he'd pull over... I could ring him, do the consultation and then he'd go back to work. And another one I think I had, I rang her whilst she was on holiday in Devon, another I think, working overseas, so it fitted in really well with their lifestyles I think.” (CNP)

The CNP perceived that patients were relaxed with her and that their carers or partners felt comfortable enough to join in with the consultation:

“I was having three-way conversations... You know it was on speakerphone and the wife was chipping in and listening and things like that so... One couple was still in bed I think when I was...They thought it was lovely. And

they're really relaxed with me and everything. And I think that's a positive, isn't it really?" (CNP)

Challenges of telephone follow-up

There were a few challenges expressed about telephone consultations. Most were overcome as the nurse gained experience and confidence over time. Consultations initially took longer, patient assessments were more difficult (if the nurse had not met the patients), and although the CNP had been involved in developing the intervention guide she found the structure inhibiting until she became familiar with the format and flow of the questions. Telephone consultations were initially tiring and required more concentration; fewer could be done in a day than face-to-face consultations in the clinic.

"Telephone clinic, I only allow sort of four slots ... I think it's just the concentration that you've got to put in and listening for the cues while speaking, it is quite mentally exhausting. I don't think you could do a huge follow-up clinic. Just 'cos it's purely relying on your listening skills." (CNP)

"I got to start enjoying it a lot more and relax more in myself... I think it's probably my own time management skills, and... I think in the early days when I started doing it, the consultations were quite long, ...the next time I rang them, these are a lot shorter. But I felt I had to build up that... Because I'd never met them visually and face to face, I felt I had to spend that bit longer on the phone, building up that rapport." (CNP)

The CNP acknowledged that not all patients would be suitable for TFU due to difficulties with hearing and memory or other cognitive difficulties which made assessment and monitoring more difficult. However, the CNP did perceive that nurse-led TFU could be offered to most patients after treatment for colorectal cancer.

DISCUSSION

The NCSI in the UK has called for alternative models of follow-up care to be evaluated, emphasising the importance of providing patients with the information they need to live well beyond diagnosis and treatment (NCSI, 2013). TFU is one approach with proven effectiveness and has been advocated by a major cancer charity in the UK (Macmillan Cancer Support, 2012). Other approaches, such as primary care follow-up by general practitioners (GP), may be equally effective and acceptable to patients and health care providers. For example, GP follow-up has been found to be effective for patients diagnosed and treated for breast cancer (Grunfeld et al., 1996) and melanoma (Murchie et al., 2010). However, cancer follow-up, for many cancers, has remained firmly rooted in secondary care. Hence, clinical nurse specialists have a key role to play in improving patient experiences of their care during and following treatment (NCSI, 2013).

The nurse specialist role is key to the success of TFU. The continuity of care, ability to develop a rapport and establish a trusting relationship, combined with expert knowledge and relevant information ensure that the nurse specialist is uniquely placed to provide follow-up service provision for people treated for colorectal

cancer. The findings from this study are markedly similar to those reported from a study of nurse-led TFU for breast cancer patients (Beaver et al., 2010) and indicate that specialist nurses in different specialist areas can provide a quality service to cancer patients at all stages of care and treatment.

The successful delivery of the intervention requires a level of skill that is associated with the specialist role. General nurses communicate by telephone with patients on a regular basis but this is usually in response to a specific question or query or the need to provide specific information rather than the delivery of a complex intervention. A period of training was provided for the CNP in the current study and this is recommended prior to implementation of this approach in practice. The training included a detailed examination of each item of the intervention, looking at what concerns may arise and how the CNP would address those concerns. Vital aspects of the intervention were also emphasised; for example asking all questions at each consultation as issues may become important at different time points. Avoiding making assumptions about patients' needs was also emphasised during training (for example, not assuming that older patients would not need information about sexual function). Despite training, it is likely that the delivery of the intervention may alter outside the remit of a research study and the fidelity of the intervention has important implications for implementation (Hasson, 2010). It was not within the remit of this study to examine intervention fidelity but future studies should examine the long term delivery of TFU to ascertain what changes are made to delivery over time and how this may affect outcomes.

The CNP in this study found the initial consultations challenging and would have preferred to have met the patients she was telephoning prior to the first call. An initial meeting would establish rapport and allow patients and specialist nurses to put a 'face to the voice'. A period of learning and adjustment is also required before nurses feel comfortable with delivering the intervention. The CNP in this study noted that earlier calls were longer but that call duration reduced as she became more comfortable and familiar with the delivery of the intervention.

The informal costs of caring for colorectal cancer survivors have been shown to be considerable; a high economic burden for families and/or carers (Hanly et al., 2013). Study participants welcomed the convenience of TFU and arguably saved money on travel, car parking and time out of work but it is not clear if there would be cost savings for the NHS. It could be speculated that cost savings could be made if consultations were not overly long and the nurse delivering the intervention was employed at a pay band that did not exceed that of a junior doctor. However, we did not attempt to carry out an economic evaluation of TFU for colorectal cancer. Other studies have demonstrated cost savings when using telephone contact with NHS patients instead of face to face consultations (Donohue et al., 2014, Gordon et al., 2014, Graham et al., 2013, Pinnock et al., 2005, Uppal et al., 2004). Further research is needed with a larger main trial to examine the economic costs of TFU for colorectal cancer to patients and the NHS in more detail.

In the current technological age, and at a time of austerity, it seems unlikely that regular face to face contact with health care professionals in hospitals clinics

following treatment will continue. The number of cancer survivors increases markedly each year (Maddams et al., 2009) and secondary care services are stretched to accommodate the growing numbers (Okera et al., 2011). In this study we used the telephone as a convenient medium for communication but advances are being made in the use of different technologies to communicate with patients. In the UK, 86% of adults have used the Internet; 99% of adults aged 16-44 have used the Internet and 33% of adults aged 75 years and over have used the Internet (Office for National Statistics, 2013). Hence, access to technology is increasing rapidly.

There is evidence from other areas that modern technologies are being used effectively (Ekeland et al., 2010). Ekeland et al (2010) report on examples of the effective use of technology in online psychological interventions, programmes for chronic heart failure that include remote monitoring, home telemonitoring of respiratory conditions and web and computer-based smoking cessation. Text messaging has increased adherence to medication in young people with diabetes and has also shown effectiveness in smoking cessation programmes (Bennett & Emberson, 2011; Franklin et al., 2006). A recent systematic review evaluated evidence on the clinical safety, patient acceptability, cost effectiveness and impact on quality of life from advances in technology where it had been applied to cancer follow-up. (Dickinson et al., 2014). As yet, the 'technology' in the cancer field has primarily involved TFU but as technology advances at a rapid rate it seems likely that other technologies will be developed and evaluated. However, at present the telephone may be considered a useful interim means of providing a high quality and convenient service to patients that aims to meet their individual needs for

information and support. As we move forward in an ever increasingly technological age it is likely that new and innovative means of providing follow-up will be forthcoming, responsive to future generations of highly computer illiterate individuals.

Exploring patient views on TFU provided valuable information on what patient's valued about their care following treatment. Overall, participants in this study were positive about TFU and had few negative comments, despite having to forego clinical examinations and face to face contact with a doctor. All participants were willing to continue with TFU, which gives a further positive message that this is an acceptable form of service delivery. This study has focused on colorectal cancer patients but other studies on TFU for other cancers have also reported positive findings (Beaver et al., 2009; Booker et al., 2004; Sardell et al., 2000).

Limitations

This was a small scale qualitative study and findings are not generalizable beyond the study sample. All study participants had been part of a pilot trial and entered the trial fully accepting of randomisation to either hospital or TFU. Consent to participate in the trial may indicate that the sample were favourable towards TFU and this may have produced biased reporting during interviews. We did not interview patients randomised to the hospital arm and they could have had equally positive views of hospital follow-up. Only one nurse specialist was interviewed; the individual personality and capabilities of the individual nurse could have impacted on findings.

Conclusion

TFU delivered by a specialist nurse was favourably received by patients diagnosed and treated for colorectal cancer. This form of service delivery was perceived as highly convenient by patients, having distinct advantages over hospital follow-up. Continuity of care was an important factor in building a trusting relationship between patient and nurse. The telephone intervention was designed to meet information needs and the structured nature of the intervention was welcomed. Training in the use of the intervention by specialist nurses is recommended and it may be useful for specialist nurses to initially meet eligible patients face to face to establish rapport before implementing TFU in practice.

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