

Patients' perspectives of TB DOTS treatment in Madang Province

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Abstract

This phenomenological study explored patients' behaviour towards tuberculosis and their perceptions of TB treatment provided at the health facilities in Madang Province in Papua New Guinea. This study contributes to knowledge in this field by investigating patients' perceptions through semi-structured interviews and field notes; Participants in the study were 18 TB patients (male, n=10, female, n=8) providing information on treatment in Madang, Sumkar and Bogia districts. The researcher collected data between October 2016 and May 2017 and the transcribed data were analysed according to the emerging themes using QDA Miner Lite software. Two major themes and several sub-themes emerged from the study: health systems issues (healthcare personnel, health facilities, infrastructure, and TB drugs), and patients' behaviour towards TB and treatment (traditional beliefs about TB and compliance to treatment). This study suggests that learning from the emic perspectives provides a solid framework to scale up interventions for TB control programs that meet the needs of those living with tuberculosis in PNG.

Introduction

Directly Observed Treatment Short-course (DOTS) is a TB treatment strategy recommended by the World Health Organisation (WHO) as the basis for TB treatment and prevention. It consists of five major parts: "securing political commitment, strengthening detection and diagnosis, ensuring drug availability, monitoring outcomes, and providing directly observed therapy" (Gelmana et al., 2007, p. 1396). The PNG National TB Policy guidelines (2011) explain DOT as "not making patients wait in a queue *but* actually watching the patient swallow the drugs and then recording the treatment in the treatment card" (p.17).

This DOTS treatment strategy is used globally as the mainstay of TB treatment and prevention in many countries (Iribarren, Rubinstein, Discacciati, & Pearce, 2014). When TB is diagnosed, prompt treatment and high compliance to treatment is significant. DOTS is a recommended treatment method to improve compliance and ensure that treatment is directly observed for both intensive and continuation stages (NDOH, 2011). Despite this effort, TB remains an important public health concern in many low and middle-income countries (Almeida et al., 2016; Levy, Dakulala, Koiri, Stewart, & Krause, 1998). Several studies confirm that there is little improvement in TB cases resulting from poor application of control measures and care in many countries. For

example, Iribarren et al. (2014) found that health services in Argentina had applied DOTS since 1996 but TB indicators remained high with low improvement in the last decade. A quantitative study to find barriers to successful tuberculosis treatment in Tomsk, Siberia, confirmed that TB treatment success rates had not improved during the decade, 1990–2000, despite comprehensive DOTS application in the country (Gelmanoa et al., 2007; Woith, Volchenkov, & Larson, 2012). Furthermore, another study among Danish TB patients revealed that there are low national outcomes in the completion and cure rate between DOTS and self-administration, after introducing DOTS in 1960 (Konradsen, Lillebaek, Wilcke, & Lomborg, 2014).

The health sector in PNG has implemented the DOTS strategy since 1987 as the mainstay of TB treatment and prevention (Levy et al., 1998). DOTS is a very useful treatment for TB and prevents further infection and drug resistance when applied correctly. In New York, the number of new TB cases and Multi-Drug Resistance TB was reduced considerably after implementing the DOTS strategy (Squire & Wilkinson, 1997). The National Government of PNG has supported DOTS strategy as the basis of TB treatment over the past two and half decades (Levy et al., 1998). Despite the national support and ongoing control programs, TB remains a serious public health threat in PNG (Levy et al., 1998; Marme, 2016; World Health Organization, 2006). According to WHO data (2014), PNG had a prevalence of 39,000 (529 per 100,000 population; uncertainty interval 251-908) and an incidence of 31,000 (417 per 100,000 population; uncertainty interval 304-547). These figures seem to be consistent with a total 26,170 cases of TB of all forms reported in 2014 (WHO, 2014; Marme, 2016). The available data from WHO show that only 3,617 TB cases were reported as being treated with a success rate of 67% in 2013 (Gelmanoa et al., 2007). Marme (2016) argues that while it is obvious that DOTS is an excellent treatment and prevention strategy, for as long as a difference between numbers infected and numbers treated remains, DOTS cannot be considered as an effective public health strategy in its own right.

There is a growing number of studies conducted on tuberculosis due to its global significance and investigated in many different contexts (Dong et al., 2007; Gelmanoa et al., 2007; Konradsen et al., 2014; Krishnan et al., 2014; Marme, 2016; Squire & Wilkinson, 1997; Woith et al., 2012; Yukselturk & Dinc, 2013; Zelnick, Gibbs, Loveday, Padayatchi, & O'Donnel, 2013). This phenomenological study adds to the literature by exploring the lived experience of TB patients and their behaviour towards DOTS treatment and support by health services in Madang Province, PNG. Healthcare settings that offer TB treatment and prevention activities to improve treatment outcomes need clear information of specific behaviours of patients that influence effective TB treatment, and their experiences of taking treatment at these health facilities (Gelmanoa et al., 2007; NDOH, 2010).

The National TB Program in PNG has generally improved its data management and case reporting since 2008. The PNG National TB Policy (2011) emphasises that the TB program needs additional effort despite this improvement in the last few years. This study aims to investigate the patients'

perspective of TB DOTS treatment and support services and how these services can be leveraged in PNG health facilities. As very little evidence exists about patients' behaviour towards tuberculosis and treatment services in PNG, this research study explores those behaviours and recommends measures to improve the treatment services.

Research questions

The aim of this research was to explore patients' behaviour towards tuberculosis and their perspectives of TB treatment in health facilities. To accomplish this aim, the following research questions guided the study.

1. What are the patients' perceptions of tuberculosis?
2. What are the personal, systemic and everyday practical issues that influence effective tuberculosis treatment and support services in Madang Province, PNG?
3. What can be done to improve or leverage tuberculosis treatment and support services in health facilities in Madang Province, PNG?

Methodology

This qualitative study used a standard phenomenological approach to investigate the lived experiences of TB patients and their perceptions of TB treatment provided at the health facilities. The study sample consisted of 18 (m=10, f=8) TB patients on treatment at the health centres in Madang, Sumkar and Bogia districts of the Madang Province.

After being granted ethical approval by the Faculty of Medicine and Health Sciences Research Committee of Divine Word University, the participants for the study were purposively selected, using maximum variation sampling technique and key informant strategies. The criteria for the inclusion were to be TB patients on treatment for more than two years or had completed TB DOTS treatment through health facilities and were willing to share their experiences. Patients who were very sick were excluded from the study to avoid adding stress to their condition. The participants were identified by consulting health workers of the health facilities and community leaders. All 18 participants were interviewed with permission to record their narratives. The researcher collected data between November 2016 and May 2017. The transcribed data were translated from *Tok Pisin* (local language) to English, and analysed according to emerging themes using QDA Miner Lite software. The researcher reduced bias through bracketing, ongoing reflection and member checks (Zelnick, 2013).

Results

a. Sociodemographic characteristics of study participants

Table 1: Social and demographic characteristics of study participants

<i>Sociodemographic characteristics</i>	<i>Madang district</i>	<i>Bogia district</i>	<i>Sumkar district</i>
<i>Age</i>			
<i>18 – 25 years</i>	1	3	2
<i>26 – 35 years</i>	2	3	2
<i>36 – 55 years</i>	1	1	1
<i>56 + years</i>	0	0	2
<i>Gender</i>			
<i>Male</i>	3	4	3
<i>Female</i>	3	3	2
<i>Employment status</i>			
<i>Employed</i>	0	0	0
<i>Unemployed</i>	6	7	5

The participants' sociodemographic data provide useful insights that could influence TB to develop and impact on individuals' ability to access health services at the health facilities. The study sample consists of 18 participants (10 male and 8 female) who were TB patients on treatment at health facilities. The majority (n=13/18, 72%) of the study participants were between 18 and 35 years of age. Of the sample, there were more younger people contracting tuberculosis than older people. If this trend continues, it could have adverse long term effects on the local society (Almeida et al., 2016; Gelmanoa et al., 2007).

Unemployment affects all social and educational strata and all age groups (Almeida et al., 2016). All patients in this study were unemployed. This may lead to delays in seeking medical care resulting in more problems and expense, and poses greater danger for TB transmission in the community (WHO, 2006). Furthermore, Woith et al. (2012) explain that unemployed people are at a greater risk of contracting TB. They argue that employed people with high levels of income had better and improved nutrition and had healthier living standards.

In addition, financial and other economic burdens may act as barriers to TB treatment and support services at the health facilities. Personal and structural issues including transport costs to health facility to collect medications, low-income, demand of competing family/personal needs, and increasing cost of living. These are important factors affecting compliance with TB treatment and support services (Skinner & Classens, 2016).

These issues are expressed in the following excerpts.

Participant 5: "There is no car in the village so I walk several hours to the health centre to collect my supplies. Most of the times, health workers go to town to collect new supplies and are not around to help me so I return home with no supplies. This has affected my treatment and takes time go back to the health centre to get my supplies."

Participant 9: "I come from... (name of place withheld) which is far from the health centre. I do not have "wantoks" (relatives) to support me with money and food. When I started taking the medicine, it increased my appetite and I've started eating a lot now. I usually feel hungry after taking the medicine because we take plenty of medicine every day. The health centre supplied milo this month but not food and this has helped us a bit."

Empirical evidence reveals clear connection between tuberculosis and poverty and it is uncertain which factor causes the other. Ali et al. (2013) concluded that the majority (85%) of TB patients in Eastern Uganda in Africa lacked adequate income, housing, food, water and sanitation. This conclusion leads to the discussion of a positive association between tuberculosis and poverty. Poverty is a major issue affecting TB control efforts worldwide and requires combined efforts to address this problem (Ali et al., 2013; Berezovskii et al., 1991). In Papua New Guinea, the National TB Policy (2011) and National Health Plan 2011-2020 clearly outline TB management protocols. Both these policies identify poverty reduction strategies as important towards accomplishing TB control and prevention programs and ultimately addressing international health goals such as Sustainable Development Goals by 2030.

b. Health system issues

Health care personnel

Health care workers are key people in any health care system. In the PNG health care system, doctors play a significant role in providing specialised clinical health services. The doctors' existence in rural health services could contribute to improvement in specialised clinical health services such as TB control. However, this study found that there were no doctors employed in rural health services in Madang Province. Doctors were located in urban centres. The participants' experience indicated that availability of medical officers at a health facility should be an essential step towards improvement in TB diagnosis and treatment. Several patients' behaviour towards different health facilities highlighted the important role doctors could play in a health care system.

Participant 5: "There is no doctor employed at the health centre to make proper diagnosis and give proper treatment so I requested to transfer to Madang General Hospital. When I got admitted there, there were many doctors so they did proper diagnosis and treatment."

Participant 6: "Despite lack of money and food, I was serious about my health problem and requested nurses to refer me to Modilon General Hospital, because there are doctors in town but not at the health centre."

Participant 15: "I requested the nurses to transfer me to Madang General Hospital because I want doctors to make a proper diagnosis and give me proper treatment so I can get better quickly. I do not want to stay at the health centre and wait for the results to come."

These comments highlight the notion that recruiting and retaining doctors and qualified health personnel in all rural health facilities is important for successful TB control and TB prevention programs.

Health facilities infrastructure

Health infrastructure is another key element of the health care system. A well-resourced and supportive infrastructure may improve the health outcomes of TB patients. Participants stated that adequate TB wards and infrastructure are important for patients with tuberculosis. This study found that there are inadequate facilities in health centres to manage tuberculosis effectively including x-ray, laboratory, TB wards and sputum tests. Consequently, early diagnosis and treatment are delayed for several weeks in rural health centres and patients request referral to a major health facility for further investigation and treatment. These issues are expressed in the following excerpts.

Participant 17: "I personally requested to go to the major hospital because there are no proper facilities like sputum testing and x-ray at the health centre."

Another participant reported that the health centre did not have a separate ward for TB patients. All patients were admitted into the same ward.

Participant 12: "The health centre has only two general wards (male and female) and all patients are kept in those two wards which are overcrowded. Patients with TB are not separated from other patients."

This situation directly obstructs the TB control program as other patients in the ward and visiting relatives are at risk of contracting TB at the health centre. This study correlates to the theory of nosocomial infections theorised by the World Health Organisation (2006) which discovered that high numbers of nosocomial infections occurred in health facilities. They argue that patients with tuberculosis and aging people are potentially at greater risk of contracting TB. Health centres may act as TB hotspots and increase TB transmission rather than contain it (Marme, 2016).

TB treatment drugs

Treating tuberculosis with drugs is a common medical intervention in all health settings in PNG. In addition, early detection, diagnosis and treatment of TB results in good treatment outcomes. Poor management of TB results in unnecessary deaths and disabilities in children and adults and causes multi drug resistance TB which is very costly to manage with poor outcomes. The majority of the participants testified that they are protected when drugs are available at the health centres. They expressed high levels of confidence in taking medication as an important step towards curing TB and preventing complications. They reported that high compliance with TB treatment protocol is essential and helpful.

Participant 22: "There are drugs at the health centre and when I got admitted I was given these drugs after doctors confirmed the diagnosis. I feel better after taking the medicine."

Participant 18: "When I was admitted to the health centre, health workers give me the right medicine. I know that it will help me cure TB so I take them faithfully every morning. I developed nausea and joint aches but did not stop taking the drugs and continued taking them. I am very happy now when I see improvement in my health status."

c. Patients behaviour towards tuberculosis and treatment

Traditional beliefs on causes of tuberculosis

Traditional beliefs about the causes of diseases are common in PNG. With over 800 languages, PNG is famous for its diverse cultures. Thus, beliefs about causes of ill health are still an important part of the society. Participants narrated that traditional sources, including sorcery and witchcraft, caused TB when they noticed blood discharging from the mouth. According to the participants, villagers associated any unusual phenomenon to a traditional cause. They would seek traditional treatment before going to a health centre. They would seek medical help only after their attempt with traditional healers was unsuccessful. This results in delays to early diagnosis and treatment. This next excerpt highlights this issue.

Participant 12: "When I started getting sick with TB, I saw blood coming out from my mouth and nose. I thought right away that this was caused by sorcery or witchcraft in my village so I looked for village doctors to seek treatment and help. After some weeks, I did not get better and my condition got worse so I decided to go the health centre for a medical consultation. When they checked my sputum and chest, they told me that I had TB."

On the other hand, some participants gave diverse explanations and interpretations of the causes of tuberculosis. They associated TB to other

known diseases including pneumonia, *sot win* ('short wind', asthma), and *skin cold* (malaria) and some even claimed that TB was not infectious. This statement shows that they lacked adequate knowledge and understanding of the causes and prevention of tuberculosis.

Participant 13: "I was sick for several weeks with fever, cough and sot win (short of breath) and I thought it was just malaria, or pneumonia or asthma. I reported to the health centre several times and was treated with antibiotics and antimalarial drugs. After several weeks, the symptoms did not subside and my condition deteriorated so the health workers admitted me and ordered a chest x-ray. After the x-ray, they confirmed that I had TB and started me on treatment. I am feeling better now with the TB treatment."

These responses highlight that cultural influences may obstruct efforts for tuberculosis control and prevention programs. Communities develop their own explanations for tuberculosis, putting them at risk of developing further complications and transmitting the disease to others. A systematic approach to health education plays a major role in the effort against tuberculosis.

Compliance with TB treatment

Adherence to TB treatment is an effective prevention and control method. Studies done overseas have proven that DOTS treatment is effective where there is a high level of compliance with treatment. All participants stated that strict adherence to prescribed treatment was necessary and very helpful. They claimed that drugs were a conduit to full recovery and alleviated complications. Patients affirmed that despite suffering mild side effects including nausea and joint aches; they continued to take the medications as scheduled. They maintained that to discontinue medication would only hinder improvement in their health status. Others claimed that unless adequate drugs were available at the health centres, patients could die from complications.

In contrast, participants maintained that due to the complex nature of TB, patients may easily believe in other social causes rather than bacteria. They recommended health education and awareness in communities as vital to educate people who are at risk of contracting tuberculosis to seek early medical treatment at the health facilities. Other participants indicated that issues such as lack of adequate supply of food may challenge their abilities to take the prescribe treatment. The following narratives reveal this statement.

Participant 5: "I always take the medicine faithfully, I never miss a dose and as a result I saw changes in my physical health and feel better. So I would highly recommend to those with tuberculosis that if they want to get better, they must take all the prescribed medicine faithfully."

Participant 8: "I got the medicine I need, so the medicine helps a lot with my disease. I take all medicine faithfully as prescribed."

Participant 3: "I believe in the medicine health workers give me and it has helped me."

Participant 4: "It is important to take medicine. I feel better when I started taking medicine at the health centre. It motivates me when I see changes in my body and am gaining weight so I take the medicine faithfully."

Participant 6: "When I first got the disease, I saw blood coming out from my mouth. I thought this was caused by sorcery so I looked for glass-man (traditional doctors) for treatment. After some time, my condition got worse so I reported to the health centre. They did some tests and confirmed tuberculosis and started me on treatment. I took all the prescribed medicine faithfully and now I feel better and my health is improving."

Participant 7: "I feel hungry when I take the medicine. I take lots of medicine and don't have food to eat because I don't have relatives to supply food."

Discussion

This article has demonstrated how complex issues influence TB patients' behaviour towards TB and challenges their abilities to access health services at the health facilities. While the data presented in this study are from a limited sample of TB patients, those patients represent diverse villages within three districts of the Madang Province. Despite the limitations, the patients provide information that is relatively consistent with other studies in terms of patient behaviour and perceptions towards TB. The data provide the basis for further studies into patients' perspectives ON the challenges of providing TB services.

Health system issues

The patients have identified numerous health system issues that affected their capabilities to obtain health services at the health facilities in the districts. They highlighted that an adequately resourced and supportive health care system is a prerequisite to effective implementation of TB control and prevention programs in PNG. Wynne, Richter, Banura and Kipp (2013) claimed that inadequate training for health care workers and inadequate financial support for TB programs in Western Uganda in Africa had placed a massive financial burden on the patients and effectively inhibited TB control programs. Additionally, ineffective treatment at the health centres obstructed patients' ability to seek early treatment (Wynne et al., 2013).

Furthermore, participants' expressed concern over the lack of diagnostic facilities, including laboratory and x-ray, at the health centres to make early diagnosis possible. Wynne et al. (2013) study of healthcare workers and

patients' perspectives of challenges in tuberculosis in Western Uganda, found that lack of diagnostic capabilities of health services had affected the TB program resulting in low levels of successful outcomes.

Murray (2006) and Wynne et al. (2013) agreed that modernising the health system is a major challenge to TB control programs in Africa. The diagnostics equipment used for TB is obsolete and usually ineffective. Murray explains that health facilities use out-dated sputum smear microscopy that lacks competency to detect pulmonary or smear negative TB and is ineffective in children and people with HIV. Furthermore, most health facilities lacked laboratories to detect Multi Drug Resistance TB (Murray, 2006).

The health care workforce is another significant health system issue affecting TB control programs. Zelnick et al. (2013) argue that the capacity of health services to deliver the required level of essential health services depends on the existence of medical, nursing and allied health workers who have the necessary qualifications, skills and experience. They describe how the lack of qualified health workers has affected TB programs in Ghana. Despite successive attempts to increase staff strength, managers complain about insufficient staff to implement programs (Zelnick et al., 2013). Several authors (Workneh, Bjune, & Yimer, 2016) agreed on break downs in health systems including infrastructure, drugs, finance and staffing which often results in incomplete or insufficient management of tuberculosis.

The findings in this study show that the health facilities in the three districts (Madang, Sumkar and Bogia) where this study was conducted, were inadequately resourced and supported. Consequently, they are hindered to implement key national health policies such as the PNG National Health Plan 2011–2020, PNG National Health Service Standards 2011–2020, National TB Management Policy (2011), and WHO Policy on TB Infection Control Practices in Health Care Facilities (2009), to combat communicable diseases like TB. This situation may adversely affect patients' abilities to get access to TB treatment services at the health facilities leading to treatment default and failure, and ultimately poor national TB outcomes. From this evidence, it is likely that national and international health policies may not be implemented as anticipated leading to low national health outcomes. Thus, there is a need to conduct research to evaluate the extent to which the National Health Plan 2011–2020 is implemented in the Madang Province and more broadly in PNG.

Patients' behaviour towards TB and treatment

Traditional causes of TB

Health beliefs and attitudes towards disease are global phenomena and are usually associated with other social systems often with adequate explanations. These beliefs cannot be easily dismissed as mere superstitions and may serve as barriers to effective TB programs. Moloantoa's (1982) study of traditional attitudes towards TB showed that people's health beliefs are closely connected with set practices. For example, the South African people's beliefs and

attitudes towards health and illness are linked with social norms and practices such as kinships, relationships and religion (Moloantoa, 1982). Furthermore, the WHO (2006) supports that traditional medicine is deeply embedded in spirituality and religion and is a common barrier to health service delivery in many parts of the world.

Venkatraju and Prasad (2010) emphasise that TB patients give different explanations from health care professionals of the causes of their health problems within the general categories of natural and supernatural origin. They demonstrated strong existence and beliefs of the folk theories of diseases or traditional medicine as theorised by WHO (2006) including sin, wrath of deity, witchcraft and evil eye (Venkatraju & Prasad, 2010). Folk medicine started from primitive people's behaviours and actions towards natural phenomena where magic and witchcraft are regarded as important causes of health problems. In addition, peoples' efforts to find solutions to health problems were the basis for folk theories/traditional medicine by many people. In 2006, a report by World Health Organisation indicated that 80% of the world's native population use traditional medicine.

In a neighbouring country, Vanuatu, some people believe that factors causing TB include: food, sharing utensils, kava, alcohol consumption, smoking, and physical and spiritual influences. In addition, patients often access traditional healers before seeking medical treatment and this has caused delays in diagnosis (Viney et al., 2014; WHO, 2013).

Traditional beliefs in sorcery and witchcraft are common in many parts of PNG and believed to cause many types of diseases, death and disabilities. Amelda (2013) and WHO (2006) agree that beliefs in sorcery are deeply rooted in PNG's culture and play a key role in culture and religion of PNG's diverse cultures and linguistics. PNG beliefs in sorcery and witchcraft are so ingrained in many parts of the country that the Australian colonial government started the Sorcery Act in 1971 to make sorcery act illegal in PNG (Amelda, 2013).

The findings of this research verify the theory proposed by anthropologists many centuries ago about disease being caused by magic, witchcraft or by a number of different social and cultural factors: sorcery causing a spell on someone, and disease from poor housing and smoking. A recent ethnographic study among 139 countries by Lynch and Medin (2006) affirm similar explanations. For example, the Zande of Central Africa believe that jealousy or angry neighbours practising witchcraft causes disease/illness. Many industrialized nations such as the United States and other nations also develop various explanations for illness including negative thinking and other psychological phenomenon (Lynch & Medin, 2006).

High compliance with treatment

All patients in this study classified compliance with TB treatment as the key strategy to reduce tuberculosis and prevent further transmission among the community. Tuberculosis is a chronic disease requiring long- term treatment.

Adherence to treatment is one of the most difficult and challenging tasks for the tuberculosis control and prevention program. Liam, Lim, Wong and Tang (1999) explain that patient education and motivation is necessary for successful completion of TB treatment. They cited that poor compliance with treatment is a primary cause of both defaulter and incomplete treatment leading to failure of many TB control programs (Liam, Lim, & Tang, 1999).

PNG National TB Management Protocol (2011) offers clear directions for the diagnosis and management of tuberculosis in PNG. According to this policy, early diagnosis and prompt treatment without unnecessary delay is essential for a successful TB program. TB treatment play a key role by “curing patients and alleviating suffering, preventing deaths and disabilities from its complications, stop transmission in the communities and prevents development of drugs resistance TB”. Furthermore, the DOTS treatment strategy becomes effective if applied correctly. The TB Management Protocol (2011) states that, the best way to make sure of the correct application of DOTS is to watch the patients as they take the prescribed medications. Thus, treatment and adherence in TB management includes Directly Observed Treatment (DOT), ensuring continuation of treatment, and managing patients who interrupted their treatment program.

Conclusion

Understanding the emic perspective of issues influencing TB treatment is critical to monitor the provision of tuberculosis treatment services in Madang Province and more broadly in PNG. Investigating these issues is important to monitor and evaluate tuberculosis control programs to find barriers and problems influencing effective provision of TB treatment services. Many contexts, issues and factors exist to influence TB control programs including DOTS treatment services leading to unnecessary deaths and disabilities among adults and children. The findings generated in this study are useful for healthcare providers, policy makers and health managers at district, provincial and national levels to scale up tuberculosis treatment services that meet the needs of those infected with tuberculosis. There is a need for further research on barriers and facilitators to effective TB prevention and control practices in PNG from the perspective of those infected with tuberculosis. In addition, implementation research is required to assess the extent to which the National Health Plan 2011–2020 is being implemented in the districts and more broadly in PNG.

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