



“We don’t really do doctors.” messages from people diagnosed with occupational leptospirosis for medical professionals on infection, hospitalisation, and long-term effects

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ABSTRACT

Leptospirosis is largely an occupational disease for people working with livestock in Aotearoa New Zealand. Introduction of livestock vaccination and use of personal protective equipment has been associated with a reduction in the incidence. However, the incidence of occupational leptospirosis remains high, with significant burdens for affected families and healthcare system. For this article, a subset of thirteen participants from a nationwide leptospirosis case-control study (2019–2021) who were diagnosed with leptospirosis and worked with livestock at the time of illness were invited and agreed to a semi-structured interview. Interviewees reflected on their experiences as messages for medical professionals. The analysis of transcripts reveals widely shared experiences with infection, hospitalisation, and treatment, as well as long-term effects and recovery. Conclusions for medical professionals include that ill workers continue to have their diagnosis of leptospirosis delayed. This delay may contribute to more than half the people ill with leptospirosis hospitalised. Further, medical professionals’ communication and relationship with ill people strongly colours the latter’s experience, for good or for bad. Moreover, most interviewees experienced a recovery process that took several months of feeling tired, which undermined professional performance and emotional wellbeing.

1. Introduction

Leptospirosis is a zoonotic notifiable disease in Aotearoa New Zealand, and it is a workplace hazard in the livestock sector. It was first identified in both humans and animals in the 1950s [1]. Incidence peaked in 1971 with dairy farmers, meat workers and pig farmers identified as having high-risk occupations [2]. In the early 1980s, dairy cattle and pig vaccination programmes were

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implemented [3,4] and by 1998, the annual incidence in humans had declined significantly [5]. However, leptospirosis remains a risk for New Zealanders working in the livestock industries.

Analyses of Aotearoa New Zealand's notification data show that incidence remains highest in meat workers and farmers [5–7]. Serological surveys in meat workers conducted from 2008 to 2011 revealed risk of infection in sheep abattoirs [8]. Case studies of outbreaks in 2010 and 2015 demonstrate that the disease occurs in dairy farm workers on farms with no or incomplete vaccination programmes [9,10]. Furthermore, the animal vaccines do not cover all the strains endemic to Aotearoa New Zealand. A 2016 study of 200 randomly selected dairy cattle herds across Aotearoa New Zealand revealed that one quarter of the herds were infected with a new strain of *Leptospira* that is not included in current cattle vaccines [11]. Analysis of notification data shows that non-vaccine strains are becoming predominant [5–7].

In addition to animal vaccines, a second cornerstone for prevention of leptospirosis in Aotearoa New Zealand is the use of personal protective equipment (PPE) such as boots, aprons, and eye protection, especially by farmers and meat workers. However, a cohort study of 380 sheep meat workers from four abattoirs found that the use of PPE such as facemasks and gloves did not have a protective effect against new infection [12]. Lastly, leptospirosis places a large burden on patients as well as the healthcare system with more than 50% of leptospirosis cases being hospitalised [13] and approximately one quarter of these admitted to intensive care [14].

These analyses suggest that the epidemiology of leptospirosis is changing. To identify new infection risk factors and/or emerging sources of infection, we received funding for a nationwide case-control study with five sub-studies between 2019 and 2021. To understand the experiences and perspectives of people who have been diagnosed with leptospirosis, one sub-study identified people with high-risk occupation – i.e., livestock farmers and meat workers – from the case series and further engaged them for a semi-structured interview. These semi-structured interviews collected participants' experiences and views with the explicit purpose of communicating their lived experiences with leptospirosis to three groups of professionals: medical professionals (doctors and nurses), public health policy makers (the Ministry of Health and the national Accident Compensation Corporation) and peers working in livestock farming or meat processing plants. This article focuses on sharing the messages from the interviewees' lived experiences for medical professionals.

After detailing our methodological considerations, we present findings from an inductive content analysis of thirteen semi-structured interviews with people who have been diagnosed with leptospirosis in Aotearoa New Zealand from 2019 to 2021. With medical professionals in mind, these findings have been organised into three sections, following the chronology of the lived experience: the early stages of disease, the hospitalisation or treatment, and the long-term effects and recovery process. We hope our findings assist in improving the effectiveness of medical care for people diagnosed with leptospirosis as well as enhancing the quality of relationships between medical staff and people affected by diseases that are largely the result of their working environment.

2. Materials and methods

2.1. Towards transdisciplinarity and a mixed methods approach

The five sub-studies framed within the nationwide case-control study were predicated on research disciplines that ranged from microbiology to epidemiology to social work, applying research methods that varied from sequence typing *Leptospira* in laboratories to surveying hundreds of people via the phone to interviewing farmers at their kitchen tables [15]. Such disciplinary and methodological diversity is increasingly seen when dealing with complexity in practice-based or practice-oriented research [16,17]. Inevitably, this collaboration triggers methodological conversations about multi-, inter-, cross-, and transdisciplinarity, often depicted as positions on a continuum rather than clearly demarcated [18–20]. Based on the positive and enriching engagement with each other and with representatives from key stakeholders outside academia – such as District Health Boards and Māori health advisers, Trade Unions, and General Practitioners – we found ourselves coming closer to a transdisciplinary research approach as we progressed in time [21].

In terms of research methods, interdisciplinary teams often seem to land on a mixed methods approach, combining quantitative and qualitative methods [16,22,23]. Bamberger & Mawby's definition of mixed methods as “judicious combinations of QUAL and QUANT methods” [24] appeals to us. Within the wider methodological framework of our research project, the quantitative data collection methods with probability sampling and control groups provided valuable broad insights that were generalisable to wider populations. However, our quantitative methods also had limitations. They explored questions that we as researchers had identified; they did not explore questions or take perspectives from people diagnosed with leptospirosis. Moreover, quantitative methods reveal patterns in observable facts, rather than depth of understanding complexity in factors, diversity in views, and the importance of context. This is where qualitative methods such as interviews with the people who had been diagnosed with leptospirosis can complement or enrich the quantitative research findings, because they assist in “providing an in-depth understanding of complex phenomena while focusing on the experiences and perceptions of research participants and taking into consideration contextual factors” [25]. In the field of medical research, the emerging field of narrative medicine [26,27] equally underscores the importance of storytelling and story-listening “to augment scientific understandings of illness” [28].

The study received national ethics approval from the Health and Disability Ethics Committee, reference number 19/STH/80. The study also received local ethics approval and consultation with Māori (the Indigenous people of Aotearoa New Zealand) from the 20 District Health Boards (DHBs) in Aotearoa New Zealand.

2.2. Purposive sampling and sample

A total of 80 people diagnosed with leptospirosis were enrolled into the case-control study between July 2019 and July 2021. Of these, 61 were working in high-risk occupations on livestock farms or in the meat processing industry. From these 61 people, the

research team invited 13 people, using profile criteria such as having participated in the initial survey and the six-month follow-up survey, as well as mobility criteria such as residing within a two-day travel radius from the university and responding to evolving Covid-19 lockdown regulations. All 13 people invited for an interview accepted and were interviewed, which resulted in a non-probability purposive sample of 21% of the people enrolled in the research and diagnosed with leptospirosis in the high-risk occupations.

Logically, non-probability purposive sampling places limitations on findings' representativeness and generalisability [29]. However, this sub-study's purpose was "to find people who can and are willing to provide the information by virtue of knowledge or experience" [30]. This "voluntary nature ... supports the purposive sampling approach, it does not mitigate against it" [31]. In this context, we are genuinely grateful to the thirteen people who gifted us their experiences and reflections – a reminder that the original meaning of data derives from the Latin 'datum', i.e. something gifted [32]. Table 1 shows that the interviewees in the sample include people from different genders, ethnicities, age brackets, and occupations. Arguably, voices from all groups of people most likely to be affected by leptospirosis can be heard in our analysis of these interviews.

2.3. The semi-structured interview method

In an introductory letter and reiterated in a telephone conversation prior to the actual interview, the prospective interviewees were informed that the purpose of the interview was to hear from them what lessons could be drawn from their lived experiences with leptospirosis for relevant third parties. We asked the prospective interviewees to reflect on their experiences with leptospirosis as messages to three specific third parties: medical professionals such as doctors and nurses; public health policymakers; and their peers such as farm workers meat workers. In this article, we will analyse the responses, interviewees' messages, to medical professionals. Specifically, we informed prospective interviewees in advance that one question would be: "Regarding your illness, and your messages to medical professionals: What can you tell me about your health experience with leptospirosis?" This type of question characterises a semi-structured interview. Semi-structured interviews are generally positioned between structured (or closed) surveys with pre-determined categories of answers and, on the other side, unstructured interviews that have no list of questions and are effectively open conversations. Semi-structured interviews are most commonly used in exploratory research, when researchers seek to identify unknown unknowns, as they are "the most useful because [they] ... may yield unexpected information" [24].

We would add that semi-structured interviews can not only yield unexpected information, but also information about what is probably important or remarkable to interviewees. For example, when asking interviewees about their experiences with leptospirosis, five interviewees chose to talk about their loss of appetite, but we did not ask or prod, "What was your appetite like?" If we had asked that systematically, it is quite possible that more than five interviewees would have nodded, 'Ah yes, that too' and we could have concluded loss of appetite was a widely shared experience. However, we would not have been able to argue the loss of appetite was an important symptom for a noticeable proportion of infected people.

Because semi-structured interviews approximate conversations, their fruitfulness, "rests considerably on the relationship, rapport and level of trust established between researcher and the researched" [33]. Our interviews were conducted by two researchers, one of whom has more than a decade of professional experience in veterinary practice on farms and in the meat-processing industry while the other has over 30 years of experience with leptospirosis research and development of cattle vaccines. Interviewers and interviewees connected quickly through their personal introductions, choice of words, and short anecdotes about working in commercial livestock production.

2.4. Data analysis

The duration of the semi-structured interviews varied from 20 minutes to just over an hour and all interviews were, with interviewees' verbal consent, audio recorded. An anonymised selective transcript was made of parts deemed to be the essential answers or comments to the question, leaving out repetitions or obviously unrelated side-tracks. These selective transcripts varied in volume between 2400 and 10,100 words, averaging 4700 words. These selective transcripts were sent to each interviewee, with the request to edit any text the interviewee deemed necessary. Interviewees were given two weeks to do so with the explicit understanding that if they did not comment or communicate, we would assume they considered the selective transcript a correct and quotable record of the interview. We received no comments or edits.

We took the thirteen selective transcripts as raw data for a content analysis. A content analysis of text is often explained with a reference Berelson's seminal definition: "a research technique for the objective, systematic and quantitative description of the manifest

Table 1
Sample by gender, ethnicity, and livestock industry sector (n = 13).

Gender	Age Category (years)	Ethnicity	Industry sector
4 women	2 < 30 years	9 European	4 Dairy farming
	1 30–39 years		
	2 40–49 years		
9 men	4 50–59 years	4 Māori	5 Meat-processing
	4 > 60 years		

content of communication” [34]. In our analysis of the transcripts, we made three important choices. First, our content analysis focused on the manifest content of ‘what was said’; we did not explore a more interpretative analysis of latent content of ‘what was meant’. Second, our content analysis was an inductive one (as opposed to a deductive one); we did not search for comments on pre-conceived categories or themes, but instead searched for recurring themes as they emerged from the transcripts [35–37]. And finally, as is common in qualitative content analysis, we decided that an issue was a recurring theme when about one third of the thirteen interviewees (i.e., four, or 31%) mentioned such a theme. We argue such a theme reflects more than the experience or view of a few self-selecting individual interviewees and is likely to have relevance for a noticeable section of all people who have been diagnosed with leptospirosis in Aotearoa New Zealand. We will share in this article three quotes as illustrations of each identified theme. These quotes are minimally edited for readability and brevity.

2.5. Strengths and limitations

An important strength of this research based on a series of semi-structured interviews is that it offers an in-depth analysis of common lived experiences of people who were infected with leptospirosis in their work with livestock on farms or meat processing plants. Rather than being guided by questions of the researchers, the emerging patterns of recurring comments reveal the experiences of people eager to share – not only experiences with infection and recovery, but also, and importantly, how they perceive and feel about their treatment and hospitalisation in the hands of medical professionals. This focus is a strength as it offers medical professionals some specific messages, framed as conclusions for further research, action, and reflection, from the people they have treated for leptospirosis. One of the limitations of this research is that in using purposive sampling, the findings are not immediately generalisable to the wider population of people working with livestock and at risk of infection. However, as we note in the conclusions, in several respects our findings confirm those from research based on probability sampling.

3. Results

3.1. Acute leptospirosis

From the analysis of the interview transcripts, we identified three recurring themes regarding acute leptospirosis. First, interviewees commented on the first symptoms and most shared similar experiences. Second, interviewees had very diverging experiences with the efficacy of their initial self-medication using painkillers. And third, interviewees seemed to have similar psychological response of profound distress when the symptoms of leptospirosis became worse.

3.1.1. First symptoms

Almost all interviewees – eleven of thirteen (85%) – reported their infection’s first symptoms were feeling somewhat unwell with a minor fever. They often described feeling like coming down with a flu, and then fluctuating between somewhat better or worse for the next two to five days, before their symptoms of feeling unwell increased quite dramatically in a matter of hours, always with a much increased, high, fever.

I woke up through the night and something wasn’t quite right ... just felt like the flu ... the headache was, the headache was something else. So just really worked half days, because I could only do that and slept the rest ... then started that next day at a temperature of 40 and started vomiting ... (#1)

[Spouse:] It was a Thursday ... he got home in the afternoon, he said, “I feel like I’m coming down with something” ... he got sicker and sicker ... Friday night you vomited ... Tuesday, he thought, “I think I’m feeling happier”. But he wasn’t. And so Tuesday evening I made an [doctor’s] appointment for the next morning. (#4)

It just felt like the flu at first. And that went on well for about three to five days or something. I felt like I had the flu ... But then the day I went to hospital, I was just like I couldn’t breathe properly. (#11)

Five of the thirteen interviewees (38%) reported losing their appetite for food, though most kept taking fluids, even if spouses sometimes had to insist.

I’ll lay on the couch and my wife said do you want anything to eat and like I got no appetite. And that went on for Sunday and Monday, Tuesday in bed. (#2)

[Spouse:] And then he went off wanting to eat about Saturday ... Friday night you vomited. That’s right. So, you know, no food, just fluids. And then he was having trouble drinking enough really. (#4)

I didn’t eat for weeks ... you just take fluids. She [spouse] tries to force something down you, it’s just soup but I didn’t want to. Just give me some water. (#10)

Five of the thirteen (38%) of the interviewees detailed how they felt very sleepy in the first few days after the first becoming ill with leptospirosis.

So just really worked half days because I could only do that and slept the rest. (#1)

I felt just completely awful, and I went back to sleep, and I ended up sleeping like 15 hours straight. (#6)

I was falling asleep and like what do you call it lethargic ... I was very sleepy yeah. (#11)

3.1.2. First actions taken by ill people

Five of the thirteen interviewees (38%) commented on taking painkillers in the first few days of feeling poorly; probably quite a common response to the early symptoms of fever and headache. However, while these painkillers helped some interviewees in the first days, others experienced little relief.

I got up and took Panadol. And that was what stopped the shaking because I just got into the shakes that I just couldn't stop. The only thing stopping it was Panadol. (#3)

Really severe headaches and taking panadol. But they weren't doing much. (#4)

[Q:Did anything help with the pain at all?] No, no. (#9).

3.1.3. Psychological and emotional response by ill people

About half the interviewees (seven of the thirteen, 54%) expressed feelings of serious concern and emotional distress. Some interviewees connected feelings of not knowing what was happening to them to profound fears of dying. Others explained their emotional distress was caused by feeling a loss of control or having hallucinations. The comment 'I wouldn't wish this on my worst enemy' came up repeatedly.

I thought, "What the hell's wrong with me?" ... It was just like, "real shit at one stage. I just wanted to die ... never in my life ... (#2)

I just didn't know what it was ... wouldn't wish this upon my worst enemy, this kind of disease. Things are going through my head and I just it was just too much to think of. (#10)

I've seen things running around, you know dragons like ... Those hallucinations: you are really freaked out. (#13)

3.2. Hospitalisation and treatment

Our analysis of the transcripts revealed three recurring themes in the interviews that related to the hospitalisation of people infected with leptospirosis. First, several interviewees shared stories about the difficulties they experienced in getting a diagnosis of their infection. Second, those interviewees who were admitted to hospital for their infection shared experiences in finding themselves in an intensive care unit (ICU) quite quickly. Third, when discussing their interaction with medical staff, interviewees had quite diverging experiences.

3.2.1. Getting a leptospirosis diagnosis

Five of the thirteen interviewees (38%) commented on difficulties in obtaining a leptospirosis diagnosis, either when they approached their GP or when they were taken into the hospital.

[Spouse:] It wasn't typically COVID at all, not a sore throat and cough ... And the health line woman said it would be worth getting COVID swab. So, he ... got a COVID swab ... [Four days later, after another GP visit] The doctor said, "... could be viral ... might be bacterial. You should start on antibiotics." [Spouse insists on hospital visit] I went in and picked up the referral letter ... it took quite a long time to get the lepto diagnosis. It took almost five days. (#4)

It was very hard to get diagnosed. Yeah, very conflicting on some results. Some said, "Perhaps" and some said, "No" and then I'd be sent off to the different hospitals and different people said different things. No one could really agree on whether I did or didn't have lepto ... A result came in, but it wasn't enough of a positive. (#9)

They couldn't pinpoint it straight away. So, they did blood tests, urine tests and they thought then that I had a urine infection ... I stayed overnight, had medication and then it wasn't until like a week later ... they said it wasn't a urine infection, you've got lepto. (#11)

However, and in contrast, two other interviewees commented on how nursing staff observed from clothing or demeanour that interviewees were farmers and therefore the symptoms might be indicative of leptospirosis and started testing for leptospirosis with urgency:

I kept going back going to the hospital ... I had lymph node infection under my left arm ... They said, "You've got a skin infection." [A couple of days later] In the middle of the night off we go, in for the third visit. One of the nurses said that she sees I'm a farmer. "Has anyone ever tested you for lepto?" I said, "No." She tested me and basically, I had lepto. (#5)

They [nurses] just looked at me and said, "What do you do for a job?" When I told them, they said, "You got lepto, we will get that all sorted out now." (#12)

3.2.2. Hospital admittance

About half of the interviewees (seven of the thirteen, 54%) ended up in the Emergency Ward of the hospital. Generally, these interviewees experience a rapid deterioration. Some were moved to ICU for up to four days, and then up to 19 days in the General Ward before being discharged.

Day four, straight to the medical centre ... straight in an ambulance ... Things got a bit hazy for me once I got to ED ... and then I started sort of just convulsing ... [in ICU for] four days ... [in hospital] for two weeks. (#1)

My recollection is very poor ... for that whole period ... [Spouse:] They put up fluid straight away, they put antibiotics up straight away without knowing what it was ... And they did a brain scan because he was starting to be a bit confused ... Well, bang, bang, bang, right there from the emergency department. And then he got settled in for the night and spent five nights there. (#4)

The next day, about nine o'clock, I rang the hospital ... and said, "I can't even swallow the tablets" ... they said, "Come down and see us," so we went down to the ambulance ... They shoved me in an ambulance and took me down to Invercargill ... Four days in intensive care. It was hard ... Then I got sent back ... to Gore where I ended up spending the rest of the 19 days in hospital. (#13)

3.2.3. Interaction with medical staff

Aside from the difficulties several interviewees experienced in seeing medical staff getting their leptospirosis diagnosis, about half of the interviewees (seven of thirteen, 54%) were explicitly appreciative of the care they received from medical staff during their early treatment. An analysis of these comments suggests two types of actions by medical staff are specifically appreciated. First, several interviewees appreciated medical staff telling them openly and upfront what is likely to happen, or medical staff being honest when they do not know.

The doctor said, "Well, this is what's gonna happen," and that's what did happen ... He said this is gonna take a while ... And he was really good. (#2)

Yeah, all staff, medical staff have been really good [Spouse:] Yep, quite good information from the younger doctor at the follow up appointment. (#4)

The doctor said to me, "I don't really know anything much about lepto because you're going to be the second person I have seen with it." ... I accepted that. (#5)

A second type of action by medical staff that interviewees commented on in positive terms comprises an overall appreciation of medical staff caring and showing interest.

The whole Palmerston North Hospital ... They were all real good ... especially in terms of care, they were so good. (#1)

All sorts of doctors ... always been good, I can't fault them. Women doctors are better than male doctors; they make you feel more comfortable ... They usually have a laugh and hear me out. (#7)

They had better doctors there [in Invercargill]. (#13)

Next to these appreciative comments, five of the thirteen interviewees (38%) shared critical or dismissive comments when reviewing their experiences with (other) medical staff. Here too, two types of actions by medical staff can be distilled from the interviews. First, there was resentment about poor follow-up or poor communication by medical staff.

I had to go back. It was a month later. Yeah. And did another test but I can't remember if it was blood or urine. But follow up, I never heard of it. (#3)

When I went to the doctor's they originally mucked up my bloods here so, then I had to go back the next day ... takes a couple of days for those results to come in so like I didn't have any treatment ... it's quite frustrating because I'm pretty sure I went to the doctors early. (#6)

I went to the doctor, and they did tests. The doctor said, "You've got leptospirosis and you should have come earlier." (#7)

A second type of action of medical staff that interviewees were critical about was medical staff saying they do not know exactly what causes the interviewee's symptoms or underestimated the seriousness of the symptoms.

The doctors there were convinced that I didn't have it. They said, "You won't have this" And then I got a call the next day saying I do have lepto. Yeah, it was not a good time ... Yep, it is who you get, they were just like, "Nah, no, no, it's not lepto". (#6)

You know something's wrong but getting an answer as to what is too hard ... there's nothing worse than hearing from a doctor that they can't find anything wrong. Hearing, "It could be this, but we can't prove it." (#9)

The local doctor here said, "Oh with your high temperature, I should have known it was an infection". But he never did anything on the Monday, you know. (#13)

3.3. Long-term effects and recovery from leptospirosis

In most interviews, the recovery and long-term effects from leptospirosis took up a substantial part of the interview. For many, the infection had been a very impactful experience in their lives and often still ongoing. Our analysis distilled six recurring themes. First, all interviewees commented on the duration of their recovery. Second, interviewees shared feeling physically tired for prolonged periods and, third, for some these feelings of tiredness or exhaustion continued to affect them if they engaged in physical activity beyond an identifiable tipping point. In a fourth and fifth set of recurring comments, some interviewees speak about the significant effects the infection has had on their overall attitude to health and their outlook on what is important in life. Lastly, taking yet another step back, once ill with leptospirosis, most interviewees place their experiences in the context of local community experiences with leptospirosis – with “dairy farm fever” [38] – dating back two or three generations.

3.3.1. Duration of recovery

All thirteen interviewees volunteered comments on the duration of their recovery from leptospirosis. Many interviewees explained it had taken them weeks or months to recover to a health condition that resembled their health prior to the illness. The shortest recovery period mentioned was two weeks, but that was an outlier.

Fortnight of ... recovering from it ... I couldn't say I've had anything since, I've had nothing really since that would be attributed to it. (#3)

Probably the first six to twelve months after I got it, it was pretty awful but, as of now I'm relatively fine. (#9)

It took a couple of months, that was hard ... the first few months we were pretty worried about you know the being kind of slow thing, but I came back pretty quick, really, I think. (#13).

In fact, at the time of the interview, eight of the thirteen interviewees (62%) looked back several months or more than a year after their leptospirosis diagnosis and felt they still had not fully recovered.

[Talking 15 months after their leptospirosis diagnosis] It's horrible. I talked to the doctor and, yeah, they're going to ... try to sort it out, because I'm just constantly tired and I can like fall asleep, and like one minute, if I close my eyes, right now, I could be straight asleep ... Quite frustrating. (#6)

Right up till now I still get tired ... I had lepto, like that's over 12 months ago. (#7)

I still have headaches ... I'm not quite sure whatever I have, whatever I got, or whatever I do now, or whether it's lepto or not or the after-effects of lepto or if I have still got lepto in my system. (#10)

3.3.2. Feeling tired

As some of the quotes above already noted, most interviewees talked about being tired persistently as the most prevailing feature of their recovery period. Ten of the thirteen (77%) interviewees explained in detail how this prolonged tiredness during their recovery period negatively affected their personal wellbeing and their professional performance. Also, as elaborated above, seven of these ten interviewees talked about tiredness not in the past, but in the present time. In addition, a couple of interviewees reported that the persistent tiredness made them ask their GP to test them again, but these tests did not detect leptospirosis.

They said, “you won't work for two months.” ... I couldn't do anything physical; I had no strength and just still sleep a lot ... You do a little bit and then ... your tank is just empty ... I sort of plateaued-off ... and mentally, mentally it was an issue for me. And still is. (#1)

I guess it must be over because of my blood [tests] ... Though I was thinking the other day, I should go and have a general blood test again. Yeah, I do feel tired all the time ... I don't think I have any lepto left in me. I've been going to the doctor's for a month, but I haven't got nothing specifically for that tiredness. (#5)

With the children you know, you play, you interact then all of a sudden, you're out of breath in no time. Even at work ... the freezing works, same place where I caught it, all the workmates there have noticed the big change in me. That I have slowed right down instead of how I was. (#12)

3.3.3. Feeling all right, until a tipping point

Reflecting on their recovery process, four of the thirteen interviewees (31%) shared how they had discovered they could exert themselves physically (almost) as much as they could before the infection with leptospirosis, but that unlike before, they had learned the hard way not to exert themselves beyond a certain point. If they did exert themselves beyond that point, their recovery could take days.

And that was like ... once you've gone too far, it's too late. (#1)

I don't overwork myself. No, no. I work within myself and know that. (#2)

About 70% of the time, I'm all right, but if I overdo it work-wise, it just triggers something in me. I just hit the wall and lose it for days. (#8)

3.3.4. Effects on attitude towards health and disease

When talking about their experiences with leptospirosis and the long recovery period, eight of the thirteen interviewees (62%) made explicit references to their identities – generally described as rooted in a rural culture, a farming environment – as a source of strength and attitude to adversities such as disease.

We just battled through, just carried on working ... We just soldiered on through the night ... We don't really do doctors. (#1)

You just don't get to throw in the towel ... No, it was just hard. (#9)

Being a farmer, you don't disturb anybody ... You just put up with it, you know you will come right ... you have to get out and go on like stop bloody feeling sorry for yourself ... And there was no one else to do it, so you just had to. (#13)

At face value, such comments could be considered as a dismissive 'shut up and toughen up' approach that largely ignores a problem or people affected by problems. Perhaps an appeal to the strong and independent stereotype depicted by New Zealand's 'Southern man or woman'. However, it is worth noting that some of these interviewees also – and often in the same breath – acknowledged mental health aspects of their leptospirosis, and the community or colleagues around them.

It is what it is and, you know, you don't want to get in that downward spiral ... the depression ... because it's like a brain injury, really ... You have got to be positive. Man, there's a lot of people worse off out there. (#1)

A real good guy and one who really cares about staff ... he goes out of his way to make sure things are right ... He's actually quite good at reading me, he knows. Quite often, he'll say to me, "You seem a bit down" ... it seems to help. (#7)

3.3.5. Effects on outlook on life

Six of the thirteen (46%) interviewees shared how their long – and often ongoing – experience with leptospirosis had altered their overall disposition towards other people or their outlook on life, mostly in a negative way. Some interviewees reflected on how they had become short-tempered towards loved ones – "I was grumpy as shit," to which the spouse added: "Yeah, grumpy" (#1). Others noted their outlook on life sometimes became dark, or how they felt deeply insecure by not knowing if their reduced physical abilities were a drawn-out-but-temporary effect of leptospirosis or an effect of irreversible but natural aging.

I actually went through a stage there ... I was talking to somebody a while ago ... they said, "You actually were in a really dark place, like ... we were worried you were going to actually do something to yourself." My wife said to me that I did say a couple of times, "I wish I could just die." (#7)

Other days it is just like ... I can't be bothered ... Before I caught lepto I was just racing around like anything. That really, really, scared me. (#12)

I'm 60 now ... You kind of think you just slow down anyway. You just haven't got the same energy kind of thing. So, yeah, I've got age as well. So, can you tell me what are the on-going effects with it [leptospirosis]? (#13)

It is worth noting, however, that two of the interviewees who shared concerns about their changed outlook on life also reflected on how their darker experiences had led them to re-prioritise or re-value life and life choices.

Man, it's changed my life ... it's just the way you look at things ... You look at enjoying the kids more, and fish, and hunt, and duck-shoot more, you know, do all the things that we really enjoy doing. (#1)

I can sit in my lounge, when I'm having a bad day, and one of my grandchildren walks in and looks at me and comes up and gives me a cuddle and you think, "Oh, I haven't got anything to moan about really". (#7)

3.3.6. Local community knowledge

The analysis of the interviews also revealed how much the long-term effects of leptospirosis go beyond the individuals affected: people's experiences with leptospirosis become part of local community knowledge. Nine of the thirteen (69%) shared stories of how people in their family or local community had experienced leptospirosis in the past, often many years ago. While this theme suggests leptospirosis is a well-embedded element in the historical knowledge around health and disease of rural communities, a closer look at these stories reveals that many people became aware of the historical presence of leptospirosis in their environment only after they had been diagnosed with it themselves. Arguably, having leptospirosis triggers people to explore or remember these stories of others, or others are triggered to share these stories with people who have been diagnosed with leptospirosis.

The comments by the nine people who talked about others' experiences with leptospirosis can be divided into two categories. A first category comprises a cluster of experiences in a past that is many years ago and generally related as 'hear-say' from secondary sources. A second category includes close or personal experiences by people in the immediate environment of the interviewees. Both are treated by the interviewees with comparable levels of credibility and respect. First, a few quotes to illustrate 'hear-say' experiences with leptospirosis in the wider local community, or decades in the past.

My grandfather had it ... and so my uncle had to leave school to run the farm, you know ... they were like, 13, or 14 ... it has been around for a long time. (#1)

Some of the stories we've heard since telling people I have had lepto, they are just so different from mine ... you know just about every dairy farmer from decades ago, 30–40 odd years ago, has had lepto and just about and much worse experiences than I had – right? (#4)

I am from a farming background, and I knew about it. A lot of the older people around this area have had it, they tell me their stories about it. (#8)

In the second category, we grouped experiences with leptospirosis in the interviewees' more immediate professional or personal environment; often family members, friends, or colleagues who have had leptospirosis, formally diagnosed or not.

The guy rang me up ... and he said, "Oh, can you come and commentate down at the shearing at the Carterton show." And I said, "Sorry mate, I have got lepto" and he says, "Holy shit", he says, "You won't be going anywhere." And then he told me he had it. It hospitalised him and he was down for nine months ... I think I was really lucky ... I was a month and a half. It still affects my mate now. I worry it might affect me as I get older though. (#2)

So, I've learned that my case is quite a mild case compared to others, because my uncle's had it before and he was sick for like six months and I was like thank gosh I was not like that. (#6)

They just told me their stories. Like one of my workmates, he was crook for about a year to really fully come right. Yep. So, when he sees me back at work and I told him I had lepto he was like, "What?!" And then, when I started getting into hot flushes and stuff he said, "Yep, yep, that's a part of it, that'll be it." (#11)

4. Conclusions

The inductive content analysis of thirteen interviews from a purposive sample of people who have been diagnosed with leptospirosis in Aotearoa New Zealand provides one of the first in-depth descriptions of the experience of this illness from the patient's perspective. It offers medical professionals several conclusions for further research or suggestions regarding how to improve the effectiveness of medical care and the relationships with people who are mostly infected in their working environment. Following a chronological approach, looking at the illness first, the interviews confirm findings from other research [9,39,40] that most people with leptospirosis initially report feeling somewhat unwell, thinking they had a cold or flu with a fever. In addition, we found people who were infected reporting that initially, they noticed a loss of appetite and felt an increased need to sleep.

While painkillers clearly reduced these symptoms for some, others report no benefit at all. This finding may relate to the fact that different strains of *Leptospira* may present diverging symptoms, perhaps a phenomenon for further research. Importantly, this feeling somewhat unwell often takes a sharp turn for the worse after this initial period, with rapidly increasing fever. These worsening symptoms trigger a fear of dying in some people. Until this point, none of the interviewees reported seeing a doctor, or even considered doing so, expecting the feelings of unwellness would pass with time. An often-noted stoical attitude among rural workers of '*We don't do doctors*' probably drives further delays in seeking healthcare and would suggest to medical professionals that when they do present it is consistent with considerable concern and significant illness. As a first conclusion for medical professionals, the biphasic pattern of the non-specific symptoms of a febrile illness, as described by the interviewees in this study, should prompt a clinical diagnosis of leptospirosis in persons working in an environment exposed to animal urine. Rural workers with this disease are more likely to present concerned when they have become significantly more unwell in the second phase of this illness.

Moving to the next period, with interviewees' sharing experiences in care and hospitalisation, we found a noticeable number of people with leptospirosis experienced difficulties getting tested for leptospirosis or getting a conclusive diagnosis. This finding underpins a second conclusion in two successive parts. First, medical professionals' understanding of the tests required to confirm a diagnosis of leptospirosis can be improved as different tests are performed depending on how early or late a patient presents after being ill [41]. Second, with improved understanding, medical professionals can better inform the patient of the nature and timing of those tests to reduce their frustration and delays in confirming diagnosis. Making a prompt clinical diagnosis with clear organisation of confirmatory tests could contribute to reducing hospitalisations. In this research, about half of the interviewees were hospitalised as an emergency, often spending several days in ICU. These findings are consistent with other quantitative research on leptospirosis in Aotearoa New Zealand [13,14].

Looking back, people infected with leptospirosis have rather diverging views on their interactions with medical staff: some are very appreciative, others are clearly less impressed. For both views, medical staff providing clear communications and showing a caring attitude – or falling short of expectations in these fields – are the two critical elements of the relationship. Medical staff communication and effect on the resulting patient relationships is well detailed in a number of studies [42,43]. Our study would add as a third conclusion that to improve the relationship with rural workers affected by leptospirosis, medical professionals need to show care and communicate clearly, both in the acute and follow-up setting, about expectations of the illness and addressing fears experienced by even the most stoical rural patients.

The period of recovery and suffering long-term effects is what gets most detailed attention in the interviews. With a couple of exceptions, most interviewees shared that their recovery was a long or on-going process of many months, sometimes exceeding a year. These months were characterised by continuous feelings of tiredness, affecting their professional performance and personal wellbeing.

Visits to a doctor seldom, if ever, provided a diagnosis or a pathway for treatment. Some interviewees noted they managed their physical exertion carefully; if they crossed a line, they had come to expect a recovery of days. For others, the symptoms were so long-lasting, they were left wondering if their decreased physical abilities were temporary effects of leptospirosis or signs of aging. A fourth conclusion from this analysis therefore points to the need for further research into these persisting symptoms after an acute infection of leptospirosis and in particular the phenomenon that some people have discovered their personal tipping point in physical activity. Perhaps the quickly growing body of research into “long Covid” may provide valuable cues [44,45]. Relatedly, this conclusion also suggests medical personnel undertake more in-depth explorative engagement with people who feel tired many months after a confirmed leptospirosis infection.

A fifth conclusion from the interviews builds on the finding that having experienced – or still experiencing – the effects of leptospirosis, about half the interviewees commented this changed their views on health and choices in life. For a few this entailed positive choices, but for many interviewees and their family these changes were darker. In fact, mental health issues resulting from long leptospirosis led some people who had been infected, as well as their family or colleagues, to open conversations about depression and mental health – uncommon in many rural families where ‘*stop feeling bloody sorry for yourself*’ (#13) is also a prevailing attitude. In addition to these changes in the outlook on health and life, our analysis of the interviews also shows that as people are diagnosed with leptospirosis, a majority of them also (re-) discover that leptospirosis has been part of their rural communities for several generations. Some of their loved elders and respected ancestors had suffered the long-term effects. Combined, these recurring themes support a final conclusion for medical professionals: people diagnosed with leptospirosis often have long-term effects and they may increasingly be open to, and benefit from, conversations about the mental health aspects of their on-going symptoms. In addition, we believe such conversations could have increased effectiveness if they relate explicitly to their rural community’s deep knowledge and experience with leptospirosis.

Author contribution statement

Gerard Prinsen: Conceived and designed the experiments; Analyzed and interpreted the data; Contributed reagents, materials, analysis tools or data; Wrote the paper. </p>

Michael Baker: Jeroen Douwes: Analyzed and interpreted the data; Wrote the paper. </p>

Jackie Benschop: Julie Collins-Emerson: Conceived and designed the experiments; Performed the experiments; Analyzed and interpreted the data; Wrote the paper. </p>

Ahmed Fayaz: Stuart Littlejohn: Analyzed and interpreted the data. </p>mmcl

Shahista Nisa: Polly Yeung: Conceived and designed the experiments; Analyzed and interpreted the data; Wrote the paper. </p>

Tanya Quin: Analyzed and interpreted the data; Wrote the paper. </p>

Data availability statement

Data will be made available on request.

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Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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