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- Physiotherapists' and GPs' osteoarthritis treatment knowledge and referral decisions
- Tāne Māori experiences of osteoarthritis
- Return to work after burn injury
- Orthotics for people affected by polio

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Why does Aotearoa New Zealand need an Osteoarthritis Summit?

In July this year, at the University of Auckland, a steering committee for the newly formed initiative 'Osteoarthritis Aotearoa New Zealand' hosted a gathering we called the 'Taupuni Hao Huatau Kaikōiwi Osteoarthritis Basecamp'. This one-day event included national and international presenters and attendees from across the spectrum of healthcare, from a broad range of clinical practitioners to health funders to researchers. The cause that drew people to the event was a desire to see better management for people living with osteoarthritis (OA) in Aotearoa New Zealand. During the event, we undertook two workshops to prioritise OA care delivery and research. One message that came through very clearly from these workshops is that people want cohesion in the organisation and delivery of healthcare for people with OA. A finding supported by previous papers calling for the implementation of a Model of Care to guide service delivery for OA in Aotearoa New Zealand (Baldwin et al., 2017; O'Brien et al., 2021).

The purpose of the Aotearoa New Zealand Osteoarthritis Summit initiative is to facilitate strategic planning for a national response to the growing burden of OA and to galvanise action to address this burden. It takes inspiration from the successful series of Osteoarthritis Summits in Australia, led by the prominent rheumatologist and world-leading OA expert Professor David Hunter (Hunter et al., 2019). The kaupapa aims to connect the OA research and innovative health delivery community, foster increased collaboration in OA research and innovative health delivery in Aotearoa New Zealand, and facilitate a cohesive approach to OA research and innovative health delivery in Aotearoa New Zealand from basic science to translational research and implementation by forming an OA research network and facilitating interdisciplinary and inter-institutional collaboration. The fundamental objectives of the kaupapa in Aotearoa New Zealand are to (1) co-create a National Model of Care for OA and (2) develop a list of national priorities in OA research and innovative health delivery.

Clinical services must be collaborative and responsive to the needs of all New Zealanders with OA. In a paper within this issue of the *Journal* (Dixon et al., 2021), we explore the experiences of living with OA for ngā tāne Māori (Māori men) and discuss some strategies to improve engagement. While this paper focuses on the experiences of ngā tāne Māori, some of the lessons learnt could have a broader impact. For example, we could examine the importance of whakawhanaungatanga, the value of relationship building with your patient (or community) so you can better serve their needs. We are hopeful that this notion of understanding the community's needs will underpin the Ministry of Health's development of the new Regional Networks and Māori Health Authority as part of the planned health reform in 2022. Furthermore, Dixon et al. (2021) highlight how research can inform clinical practice.

Physiotherapists have an essential role to play in the management of OA in Aotearoa New Zealand. It is a role that spans the complete spectrum of care, ranging from sports injury prevention programmes for our youth to physical activity promotion, traumatic injury rehabilitation, early symptom management, and pre- and post-operative rehabilitation. Furthermore, physiotherapists are well placed to contribute to research in all these areas and more. We had great professional engagement from physiotherapists at the Basecamp event and hope to have even greater representation at the Aotearoa New Zealand Osteoarthritis Summit in July 2022. For anyone interested in being involved in this kaupapa, you can go to the summit website: https://events.otago.ac.nz/2021-osteoarthritis-basecamp/wellington-summit

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New Zealand Physiotherapists' and General Practitioners' Treatment Knowledge and Referral Decisions for Knee Osteoarthritis: A Vignette-based Study

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ABSTRACT

Physiotherapists' and general practitioners' (GPs) treatment knowledge affects the management of people with knee osteoarthritis (OA), but little is known about the OA referral decisions and treatment knowledge of these clinicians in New Zealand. Data were collected from New Zealand registered physiotherapists and GPs (*n* = 272) using an online vignette-based questionnaire. Approximately two-thirds (63%, *n* = 172) of participants stated they would likely refer the hypothetical patient with knee OA to another profession. Participants indicated they would refer the woman between the two professions (73%, *n* = 57 GPs would refer to a physiotherapist; 47%, *n* = 92 physiotherapists would refer to a GP). However, few participants indicated they would refer the woman to other health professionals (such as 19%, *n* = 52 would refer to a dietitian). The majority of participants reported they would recommend education (98%, *n* = 267), therapeutic exercises (92%, *n* = 251) and weight-loss advice (87%, *n* = 237) as treatments for knee OA. These results indicate that first-line knee OA treatment knowledge of New Zealand GPs and physiotherapists are generally in keeping within international guidelines. However, promoting interprofessional collaboration with other health professions, such as dietetics, and providing education regarding treatments not recommended for OA is needed to meet all first-line treatment recommendations.

O'Brien, D. W., Siegert, R. J., Bassett, S., Baldwin, J. N., & Wright-St Clair, V. (2021). New Zealand physiotherapists' and general practitioners' treatment knowledge and referral decisions for knee osteoarthritis: A vignette-based study. *New Zealand Journal of Physiotherapy, 49*(3), 118–126. https://doi.org/10.15619/NZJP/49.3.02

Key Words: General Practitioners, Knee Joint, Knowledge, Osteoarthritis, Physiotherapists, Treatment

INTRODUCTION

Osteoarthritis (OA) is a chronic musculoskeletal condition that can affect a person's physical, spiritual, social and mental wellbeing (Ackerman et al., 2015; Hochberg et al., 2015; McGruer et al., 2019). Hip and knee joint OA is currently ranked as the 11th highest contributor to disability worldwide (Cross et al., 2014). In New Zealand, OA affects nearly one in 10 people, and it was estimated that in 2018 arthritis cost the country approximately $12.2 billion (Deloitte Access Economics, 2018). International evidence-based practice guidelines recommend that OA treatment options progress from conservative interventions (such as dietary changes and exercise) to invasive treatments (e.g., joint replacement surgery) (Allen et al., 2016; Bennell, 2013; Hunter, 2017). Furthermore, OA treatment should be multi-faceted and reflect the different ways the disease can affect the individual, including physically, socially and psychologically (Brosseau et al., 2016; Larmer et al., 2014; National Institute for Health and Care Excellence, 2015).

International management guidelines advocate for a staged approach to treatment progressing from first-line (exercise, education and weight loss if appropriate) to second-line treatments (pharmaceutical, aids or bracing and injection therapy) and third-line treatments (joint replacement surgery) (McAlindon et al., 2014; National Institute for Health and Care Excellence, 2015). A large component of the first-line conservative management of OA occurs in primary care; in New Zealand, this care is typically provided by physiotherapists and general practitioners (GPs) (Baldwin et al., 2017). Recent research indicates that GPs are generally the first point of care for most New Zealanders with OA (Jolly et al., 2017; Larmer et al., 2019). Furthermore, research suggests that first-line management approaches such as education, exercise and weight loss (if appropriate) are under-utilised internationally (Bennell et al., 2014; Healey et al., 2018; Hunter, 2011, 2017). The reasons for this are unclear but may include problems such as negative patient beliefs about these interventions, poor adherence or under-prescription by clinicians (O'Brien, 2018). Internationally, research has suggested that some clinicians' views contrast with international guidelines, and treatments offered frequently do not reflect the recommendations. Recent studies in New Zealand indicate similar findings from a patient's perspective (Jolly et al., 2017; Larmer et al., 2019; McGruer et al., 2019). However, little is currently known about OA treatment knowledge and referral decisions from a clinician's perspective and to what extent this knowledge and behaviour align with international practice guidelines.

There are several different methods for exploring clinical practice. Clinical vignette is one method for measuring clinical knowledge and self-reported behaviour, and has been previously used in this population (Holden et al., 2008). Clinical vignettes are cost-effective and allow for data to be collected efficiently from a wide range of clinicians (Evans et al., 2015; Peabody et al., 2004). However, caution should be applied when considering the findings, as clinical vignettes are prone to response bias (participants providing answers they believe the researcher wants to hear or believe are 'correct') and may not reflect actual clinical practice (Evans et al., 2015).

This study aimed to investigate the referral decisions and treatment knowledge of physiotherapists and GPs about New Zealanders with knee OA.

METHODS

Study design

This study was a cross-sectional, observational study with data collected via online questionnaires. Ethical approval to conduct this study was obtained from the Auckland University of Technology Ethics Committee (reference number 16/284).

Participants

Clinicians were eligible to participate if they were registered and practising in New Zealand as either a physiotherapist or GP, had treated a patient with knee OA in the past 6 months, were living in New Zealand at the time of data collection and had sufficient English language skills to complete the survey.

Measures/questionnaires

The survey comprised two sections: 1) demographic and occupational characteristics and 2) referral decisions and treatment knowledge about knee joint OA.

Section 1 collected demographic data about the participant, such as occupation and gender, as well as data about occupational characteristics, such as duration of practice and geographical location of the practice. Additionally, the occupational characteristics included questions about OA-specific practice such as, 'In your current job, how many patients do you see in your clinic/department with OA?' and 'What are the criteria that you typically used to decide that a person has OA of the knee joint?

The vignette used in the current study describes a 'typical' person presenting in a primary care setting for treatment of their knee OA, as well as a series of practice-based questions (Appendix A). The original vignette was based on the research records of an anonymous patient who had clinical knee OA, and the questions were based on those used by Holden et al. (2008), altered for use with both physiotherapists and GPs. The questions sought to understand how the practitioner believed they would manage the person. Before the survey was administered, all questions were tested for face validity and readability. Three clinical researchers with experience in OA research and survey design read the questionnaire and provided feedback about survey length, appropriateness for the New Zealand context and readability.

Procedure

The anonymised survey was advertised through several channels: physiotherapy continuing education courses, the Physiotherapy New Zealand Conference, the Royal New Zealand College of General Practitioners e-newsletters and the local primary healthcare organisation. Data were collected between 1 September and 1 December 2016 via SurveyMonkey® (https://www.surveymonkey.com). Participants were required to read the online participant information sheet and respond to the items in the questionnaire. Submission of the questionnaire constituted informed consent to participate. No identifying information was collected, and participants could not be identified or traced.

Data analysis

All data were analysed using SPSS version 24.0 (IBM, USA), with the alpha level set at $p < 0.05$. The use of the online platform limited missing data because participants were directed by automatic prompts to complete any missed item or question. Only complete data sets were analysed. It was not possible to calculate the total return rate for the survey, as participants completed the study online and it was unknown how many potential participants saw the study advertisement but chose not to participate.

Demographic and occupational characteristics

All data describing demographic and professional characteristics were categorical. For each category, the total number of scores was described using descriptive statistics. Data from GPs and physiotherapists were presented together and separately to allow comparison between the two professions. Categories that represented a small number of participants were collapsed into a single category, called 'Other'. Group equivalency between the two professions for demographic and occupational characteristics data were assessed with chi-square tests (Pallant, 2011). The Yates correction for continuity was reported where data were represented as a two-by-two assessment (Pallant, 2011).

Clinical vignette data

All data were categorical, so the total number of scores for each category were counted and converted to a percentage score of the total number of people who answered the question. Data from GPs and physiotherapists were presented as a single group and separately to allow comparison between the two professions. Group equivalence of the vignette question data between the two professions was assessed by Chi-Square tests. Where data represented a two-by-two test, the Yates' Continuity Correction was reported (Pallant, 2011).

RESULTS

Demographic and occupational characteristics

In total, 295 clinicians participated in this study and completed the demographic and occupational characteristics section of the survey (Table 1). The dropout rate from those who started the survey was 7.8%, and 272 participants completed the clinical vignette. Approximately 70% of participants were physiotherapists. More female (62.4%) than male participants completed the survey, irrespective of profession. The duration of practice ranged from less than five years to over 20 years in both professional groups. Significantly more physiotherapists than GPs had completed pre-registration qualifications in New Zealand (X^2 (1) = 7.65, $p = 0.0001$). Participants from both professions came from a range of geographical and employment settings. Significantly more GPs worked in private practice, whereas more physiotherapists worked in the public system.

General OA patient referral decisions

Table 2 shows that GPs saw significantly more people with knee OA more frequently than physiotherapists (X^2 (3) = 27.67, $p = 0.0001$). Additionally, a significantly higher percentage of GPs indicated that they would commonly refer people with OA to other health professionals (X^2 (1) = 16.39, $p = 0.0001$). Most commonly, participants indicated that they would refer patients with OA to orthopaedic surgeons, radiographers/sonographers and Green Prescription. Significantly more GPs indicated that they referred patients to these professions than physiotherapists did (orthopaedic surgeons: X^2 (1) = 26.95, $p > 0.000$; radiographers/sonographers: X^2 (1) = 32.48, $p = 0.0001$; Green Prescription: X^2 (1) = 11.61, $p = 0.001$). Conversely, a much smaller number of participants indicated that they usually referred patients with OA to other professions such as dietitians or psychologists.

Vignette referral decisions and treatment knowledge

Data from 272 participants were analysed (Table 3), and the results of the vignette questions are presented for the whole sample and the individual professions. The findings show that significantly more GPs indicated that they would refer the person described in the vignette to another clinician (X^2 (1) =

Table 1

*Participants' Demographic and Occupational Characteristics (*N *= 295)*

Characteristic	All		GPs		Physiotherapists	
	n	%	*n*	%	*n*	%
Participants	295	100	87	30	208	70
Gender						
Male	111	38	39	54	72	35
Female	184	62	48	55	136	65
Duration in practice						
< 5 years	60	20	9	10	51	25
6–10 years	63	21	20	23	43	21
11–15 years	38	13	11	13	27	13
16–20 years	38	13	8	9	30	14
> 20 years	96	33	39	45	57	27
Location of pre-registration qualification						
In New Zealand	217	74	54	62	163	78
Elsewhere	78	26	33	38	45	22
Location of clinical practice						
City	197	67	54	62	143	69
Town	63	21	17	20	46	22
Rural	35	12	16	18	19	9
Employment setting						
Public	51	7	4	5	47	23
Private	218	74	74	85	144	69
Both	15	5	6	7	9	4
Other [a]	11	4	3	3	8	4

Note. For clarity, percentages are rounded to the nearest whole number. GP = general practitioner.

[a] Other employment settings included: aged care (*n* = 1), community care service (*n* = 2), hospice care (*n* = 1), Māori health trust (*n* = 2), occupational health service (*n* = 1), primary health organisations (*n* = 2) and university clinic (*n* = 2).

Table 2

Participants' OA Patient Referral Decisions

Characteristic	All (*n* = 295)		GPs (*n* = 87)		Physiotherapists (*n* = 208)	
	n	%	*n*	%	*n*	%
Frequency of treating patients with hip and/or knee osteoarthritis						
≥ 1 per day	81	28	35	40	46	22
1–3 per week	121	41	43	49	78	38
1–3 per month	66	22	8	9	58	28
1–3 in the past 6 months	27	13	1	1	26	13
Usually refer patients with osteoarthritis to a(n)						
Orthopaedic surgeon [a]	190	64	76	87	114	55
Radiographer/sonographer [a]	130	44	61	70	69	33
Green Prescription [a]	120	41	49	65	71	34
Dietitian	57	19	18	21	39	19
Occupational therapist	44	15	14	16	30	14
Personal trainer [a]	39	13	4	5	35	17
Orthotist	37	12	8	9	29	14
Psychologist	15	5	3	3	12	6
Physiotherapist	N/A		64	74	N/A	
GP	N/A		N/A		93	45
Other [b]	31	11	5	6	26	13

Note. For clarity, percentages are rounded to the nearest whole number. GP = general practitioner; N/A = not applicable.

[a] Indicates a statistically significant difference between the GPs and physiotherapists.

[b] Other practitioners that participants indicated they would refer to included arthritis nurse educator (*n* = 1), community exercise programme (*n* = 7), hydrotherapy (*n* = 2), osteopath (*n* = 2), personal trainer (*n* = 4), podiatry (*n* = 7), practice nurse (*n* = 6) and sports doctor (*n* = 2).

15.54, $p = 0.0001$). Both physiotherapists and GPs indicated that they would most commonly refer the person described in the vignette to the other group's profession, respectively. Considerably fewer participants indicated that they would consider referring the patient to another profession such as a dietitian, orthopaedic surgeon or pharmacist. Very few participants indicated they would refer the patient to a pain specialist (2%) or a psychologist (< 1%).

Most indicated they would provide *advice and education* (98%) and *therapeutic exercise* (92%). In contrast, very few participants indicated that they would suggest intra-articular injection (7%) or opioid-based analgesics (2%). GPs' and physiotherapists' answers differed significantly for many (8 of 11) of their chosen treatment modalities for the person. Most of these significant differences reflect differences between scopes of practice of each profession.

Almost every participant (99%) indicated that they would provide the patient with advice as part of their treatment (Table 3). The highest number of participants indicated that they would give the person advice about weight loss (87%), pacing activities (81%) and analgesic use (72%). Significant differences occurred between the two professions for six of the 11 advice categories; again, these differences reflected differences in scopes of practice. Significantly more physiotherapists expected to see the person described in the case study more times for her OA (X^2 (4) = 76.04, $p = 0.0001$).

DISCUSSION

The findings of this study suggest that first-line knee OA treatment knowledge held by the GPs and physiotherapists in this study are in line with core treatments recommended in best-practice guidelines (McAlindon et al., 2014 [Osteoarthritis Research Society International]; National Institute for Health and Care Excellence, 2015), and is influenced by their respective professional scopes of practice. While both groups suggested they would commonly refer patients with OA to the other group (i.e., GPs to physiotherapists or vice versa), referral to other health professions appear limited and may indicate the need for a Model of OA Care in New Zealand to facilitate better collaboration between healthcare professionals (Baldwin et al., 2017). Furthermore, this limited collaboration is reflected in patients' experience of OA treatment in New Zealand (Jolly et al., 2017; Larmer et al., 2019; McGruer et al., 2019). It was interesting to note that some participants indicated they would consider applying treatment modalities or advice that is not supported by best practice guidelines, such as acupuncture and rest (National Institute for Health and Care Excellence, 2015).

Table 3

Vignette Beliefs And Referral Decisions

Characteristic	All participants (*n* = 272)		GPs (*n* = 78)		Physiotherapists (*n* = 194)	
	Answered 'Yes'					
	n	%	*n*	%	*n*	%
Would you be likely to refer this patient to another health care professional? [a]	172	63	64	82	108	56
Would you refer this woman to a...?						
Dietitian	52	19	14	18	38	20
Orthopaedic surgeon	38	14	8	10	30	16
Pharmacist	32	12	5	6	27	14
Support group	28	10	9	12	19	10
Podiatrist [a]	24	9	2	3	22	11
Rheumatologist	17	6	2	3	15	5
Acupuncturist	10	4	1	1	9	5
Exercise physiologist	10	4	4	5	6	3
Occupational therapist	10	4	3	4	7	4
Pain clinic	6	2	0	0	5	3
Osteopath	1	> 1	0	0	1	> 1
Psychologist	1	> 1	0	0	1	> 1
Chiropractor	0	0	0	0	0	0
GP	N/A		N/A		92	47
Physiotherapist	N/A		57	73	N/A	
Once you have made your diagnosis, would you suggest...?						
Advice and education	267	98	75	96	192	99
Therapeutic exercises [a]	251	92	63	81	188	96
Ice or heat [a]	138	51	20	26	118	61
Manual therapy [a]	137	50	6	8	131	67
Prescription of simple analgesics [a]	126	46	76	97	50	25
Strapping or bracing [a]	89	33	7	9	82	42
Acupuncture [a]	70	26	4	5	66	34
Prescription of non-steroidal anti-inflammatory drugs [a]	67	25	39	50	28	14
Rest [a]	30	11	8	10	22	11
An intra-articular injection of steroids or similar [a]	20	7	16	21	4	2
Prescription of opioid-based analgesics [a]	6	2	5	6	1	> 1
Would you offer any advice as part of your treatment?	270	99	78	100	192	99
Would you offer any advice about...?						
Weight loss	237	87	69	89	168	86
Pacing activities [a]	220	81	42	54	178	91
Analgesics [a]	196	72	65	83	131	67
Heat or ice [a]	159	58	28	36	131	67
Increasing level of activity [a]	150	55	32	41	118	61
Using a walking aid	132	48	32	41	100	51
Nutrition	105	39	27	35	78	40
The use of knee supports [a]	90	33	18	23	72	37
Rest	48	18	9	12	39	20
Avoiding painful movements	40	15	12	15	28	14
Reducing activity levels [a]	28	10	2	3	26	13
How often would you be likely to see this woman?						
Once [a]	6	2	4	5	2	1
2–3 times	86	32	52	67	34	18
4–5 times	91	34	18	23	73	38
6–7 times	50	18	1	1	49	25
> 7 times	39	14	3	4	36	19

Note. For clarity, percentages are rounded to the nearest whole number. GP = general practitioner; N/A = not applicable.

[a] Indicates a statistically significant difference between the GPs and physiotherapists.

Demographic characteristics

Participants included clinicians with a range of different experience levels, frequency of treating people with knee OA, employment settings and geographical locations. However, the small sample sizes (approximately 4% of New Zealand registered physiotherapists and 1% of GPs completed the survey) means that the findings cannot be considered representative of the treatment knowledge or self-reported referral behaviour of each profession. Considerably more physiotherapists participated in the study than GPs. Previous research has referred to the challenges of recruiting GPs to studies of this nature, citing causes for low research recruitment rates as survey fatigue and high workloads (Cottrell et al., 2015, 2017). It is possible that the length of the survey in the current study was a barrier to GP participation and future research needs to address these challenges to enhance recruitment of GPs.

OA patient referral decisions

Participants most commonly reported the three professions or services they refer people with OA to as radiology, orthopaedic surgery and Green Prescription (a publicly funded community-based exercise and activity service). These findings are not surprising. First, X-ray is still considered a critical diagnostic tool by some clinicians, despite current contradictory evidence and recommendations that suggest that imaging is unnecessary (National Institute for Health and Care Excellence, 2015). Imaging correlates poorly with symptoms and, in some cases, is harmful because it reinforces a purely mechanical view of the disease (Bunzli et al., 2019; O'Brien et al., 2019). Second, surgical joint replacement is common and effective for reducing pain (Hochberg et al., 2015; Leskinen et al., 2012).

In contrast, only a few participants indicated they would refer people with knee OA to dietitians, psychologists and occupational therapists. A high body-mass index score is a known risk factor for developing OA and an aggravating factor with OA (Barrow et al., 2019; Hochberg et al., 2015). Therefore, it would seem logical that referral to dietitians to help with weight loss, when appropriate, would be beneficial. Similarly, many people with OA describe the impact of the disease on their mental and emotional wellbeing (Bijsterbosch et al., 2009; Brembo et al., 2016; Sharma et al., 2016). Thus, engaging the services of a psychologist could be beneficial for these people. Limitations of activities of daily living and mobility are common, as is chronic fatigue (Hegarty et al., 2016; Murphy et al., 2013; Palmer, 2012). Hence, a benefit may be obtained from occupational therapy services to facilitate pacing and coping and the prescription of functional aids (Stukstette et al., 2012).

Three factors may explain the findings of clinicians' referral practices. First, GPs and physiotherapists may see little efficacy in these services or have a limited understanding of what these professions could offer people with OA. This limited knowledge is known to affect the referral of people with OA to conservative treatment programmes (Chevalier et al., 2004). Second, the current funding model in New Zealand does not typically facilitate referral for people with OA to these services because patients have to pay for these services. Cost and funding models are known to affect how clinicians in primary care services practise and refer (Stokes et al., 2017). Furthermore, Stokes et al. (2017) found that the current primary care funding model in New Zealand has led to the fragmentation of care for people living with chronic multi-morbidity. Third, the findings may be due to inadequate or limited communication between health professionals. If GPs and physiotherapists do not regularly practise with clinicians from these professions, they may not consider including these professions in an integrated or collaborative approach to OA treatment (Hall, 2005; Westby & Backman, 2010).

Vignette referral decisions and treatment knowledge

The results show that the participants supported first-line treatment practices in keeping with current best-practice recommendations for the treatment of people with knee OA (Fransen et al., 2015; McAlindon et al., 2014; Merashly & Uthman, 2012). *Advice and education* and *therapeutic exercise* were the most popular interventions considered appropriate for the person described in the vignette, findings that are similar to previous research using this vignette (Holden et al., 2008). Moreover, this finding suggests that participants perceive value in therapeutic exercise for people with moderate knee OA. The most popular advice categories were *weight loss*, *pacing activities* and the use of *analgesics*. Again, these results imply that participants were conscious of the known benefits of these interventions (Atukorala et al., 2016; Bliddal et al., 2014; Mills et al., 2019; Poitras et al., 2010). Several significant differences were seen in the recommended treatments and advice given between the two professional groups (GPs and physiotherapists). However, most of these differences can be explained by differences in the scope of practice of each profession. For example, significantly more GPs advocated prescription of medication, whereas more physiotherapists advocated treatment such as pacing, therapeutic exercises or manual therapy.

There were three areas where the findings suggest knowledge that differed from clinical best practice. First, a notable percentage of participants indicated they would recommend management approaches (acupuncture [26%] and rest [18%]) not supported by current evidence (McAlindon et al., 2014 [Osteoarthritis Research Society International]; National Institute for Health and Care Excellence, 2015). These findings may suggest that further professional training is needed among GPs and physiotherapists to ensure consistent, best-evidence management is provided to people with OA in New Zealand.

Second, very few participants specified that they would refer the person to a dietitian, despite 86.9% of participants indicating the importance of providing advice about weight loss. Obesity is a known risk factor for developing knee OA (Barrow et al., 2019; Silverwood et al., 2015). Furthermore, weight loss is known to reduce disease progression in people with knee OA (Van Manen et al., 2012). Therefore, this result is somewhat surprising, and the reason for this finding is unclear. Possible explanations for these findings may relate to the limited funding of dietetic services in New Zealand, the perception that any healthcare professional can provide weight-loss advice, or that effective weight loss is too challenging for people with knee OA. Again, this finding suggests that considerably more research is needed in this area of OA treatment.

Third, 14% of participants indicated that they would refer the patient to an orthopaedic surgeon, despite limited conservative treatment options being trialled first. While this is a relatively small percentage, it is still notable given that surgery is only considered appropriate after all conservative treatments have been attempted (National Institute for Health and Care Excellence, 2015). Furthermore, 64% of participants indicated they usually referred people with OA to an orthopaedic surgeon. The reason for these findings is not apparent, but the results may reflect a perception that joint replacement surgery is inevitable for people with OA or the limited state-funded conservative treatment services available to people with OA in New Zealand (Baldwin et al., 2017; Bunzli et al., 2019; O'Brien et al., 2019).

Strengths and limitations

A strength of the study was the adaptation and use of an existing clinical vignette (Holden et al., 2008), which allowed for comparison with previous research.

The study had several limitations. Twice as many physiotherapists as GPs completed the survey. Therefore, the findings may be biased towards physiotherapists' beliefs and may not represent GPs' beliefs. The sample size was relatively small, meaning the findings may not represent the knowledge or practice decisions of the wider population of physiotherapists and GPs in New Zealand. The high survey dropout rate (7.8%) may reflect survey fatigue and indicate that the survey was too long for some participants. Finally, while the clinical vignette provides insight into clinicians' knowledge and practice, the results may be biased by participants inadvertently reporting socially desirable responses. Therefore, the reported data should be considered with caution as they may not reflect actual clinical practice.

CONCLUSION

Treatment knowledge of a sample New Zealand GPs and physiotherapists reported providing care for people with knee OA that was mainly in keeping with current first-line evidence-based recommendations. However, few participants indicated they referred to other health professionals such as dietitians, and a proportion of practitioners support the use of treatments not recommended by best-practice guidelines. Systems need to be developed to facilitate greater referral practices between clinical services to assist weight loss, where appropriate, and the management of the psychological symptoms of OA. Furthermore, these findings add to the growing evidence that signals New Zealand needs a Model of OA Care.

KEY POINTS

1. The first-line knee OA treatment knowledge of New Zealand GPs and physiotherapists is generally in keeping with international treatment guidelines, particularly in terms of core treatments of education, exercise prescription and weight-loss advice.
2. Engagement with services to support weight loss for people with knee OA merits greater consideration.
3. Some participants indicated using treatments or providing advice not supported by current evidence (acupuncture or rest).

DISCLOSURES

No funding was obtained for this study. There are no conflicts of interest that may be perceived to interfere with or bias this study.

PERMISSIONS

This study was granted ethical consent by the Auckland University of Technology Ethics Committee (reference number 16/284). There was no mechanism of identifying people who participated in the study, and the participant information explained that by submitting the questionnaire electronically, they were consenting for the data to be used for the study. No additional permissions are required for this manuscript.

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Appendix A

CLINICAL VIGNETTE (CASE STUDY)

A 66-year-old woman presents to your clinic with a 6-year history of left knee pain, which was of insidious onset and has gradually worsened over time. She is a retired shop manager and usually enjoys gardening, but this has become difficult due to her knee problem. Her general health is good, despite being overweight and having mild hypertension. She also has pain in both hands.

Today, she rates the intensity of her knee pain as 6 out of 10. Descending stairs, bending and rising from sitting all aggravate her knee pain. She has some difficulty walking and has started to use a cane outdoors. Her knee is stiff first thing in the morning and after staying in one position for too long. She finds some relief from an anti-inflammatory gel and takes up to three 200-mg ibuprofen tablets per day.

Despite not having a radiograph, she feels her problem is due to arthritis, as her father had this. This is the first time that she has consulted with a health professional about the problem, and she is optimistic about its outcome. On examination, the left knee has a mild effusion and a valgus alignment. Flexion is limited and the quadriceps femoris muscles are weak. The joint line is tender on palpation. No other examination findings are remarkable.

The Lived Experiences of Ngā Tāne Māori with Hip and Knee Osteoarthritis

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ABSTRACT

Osteoarthritis (OA) is a debilitating condition affecting an individual's quality of life in multiple ways. However, little is known about the experiences of tāne (men) Māori living with OA in Aotearoa New Zealand. We aimed to explore the lived experiences of ngā tāne Māori with OA. This qualitative study was guided by tikanga and kaupapa Māori philosophies. Interviews were conducted in a semi-structured method, with seven tāne Māori living with OA. Key themes were identified and developed from the data through thematic analysis, and were informed by Tā Mason Durie's Māori health frameworks, Te Whare Tapa Whā and Te Pae Māhutonga. Four themes developed from the data and were named: (1) *The interface of masculine embodiment and mana,* (2) *Taha whānau and connection as central to ngā tāne Māori wellbeing*, (3) *The benefits of taha wairua (spiritual wellbeing),* and (4) *Te urutau kia uru ki te punaha tiaki hauora: Adapting to access the health-care system.* OA places a significant burden on ngā tāne Māori and their whānau, impacting on all aspects of hauora (health). The unique lived experiences and impact on wider whānau of Māori living with OA indicates the need to consider te ao Māori (Māori world view) when developing clinical services and a Model of Care for OA.

Dixon, T.-W., O'Brien, D. W., Terry, G., Baldwin, J. N., Ruakere, T., Mekkelholt, T. & Larmer, P. J. (2021). The lived experiences of ngā tāne Māori with hip and knee osteoarthritis. *New Zealand Journal of Physiotherapy, 49*(3), 127–133. https://doi.org/10.15619/NZJP/49.3.03

Key Words: Aotearoa New Zealand, Beliefs, Experiences, Tāne (men) Māori, Osteoarthritis

INTRODUCTION

Osteoarthritis (OA) is a common joint disease that affects the health and wellbeing of approximately one in 10 people living in Aotearoa New Zealand and costs the country an estimated $12 billion annually (Deloitte Access Economics, 2018). People with OA often experience pain, joint stiffness and weakness, which can affect their mobility, independence, function and mental wellbeing (Hall et al., 2008). Research suggests that ngā tāne (men) Māori suffer higher incidence and prevalence rates of OA than non-Māori males (Ministry of Health, 2019), although Jansen et al. (2009) state Māori may be underestimated in statistics. Māori are more likely to undergo total joint replacements at a younger age, present with greater preoperative comorbidities and have more postoperative complications than non-Māori (Pai et al., 2010; Singleton et al., 2013).

OA can affect all aspects of a person's sense of hauora (health) including taha hinengaro (mental and emotional), taha tinana (physical) and taha whānau (social) (Durie, 2004; Gignac et al., 2008; Hawker et al., 2011; Jolly et al., 2017; Kao & Tsai, 2012; McGruer et al., 2019; Smythe et al., 2012; Smythe & White, 2017). International guidelines state that management of the disease should be patient-centred and address the multifaceted nature of the condition (National Institute for Health and Care Excellence, 2021). Furthermore, a call has been made for a New Zealand Model of Care for OA that details how, when, where and with whom the management of OA should happen (Baldwin et al., 2017; O'Brien et al., 2021).

Māori perspectives have historically been under-reported in research in Aotearoa New Zealand and few studies have employed kaupapa Māori methods that facilitate mana-enhancing practice (Smith, 1999). McGruer et al. (2019) explored the lived experience of ngā wāhine (females) Māori with OA, and found that OA inflicts a substantial burden on the physical, mental, spiritual and family wellbeing of Māori. The authors argue that primary care practitioners must consider spiritual and family wellbeing when providing care for Māori with OA (McGruer et al., 2019). However, it is unclear if the findings also represent ngā tāne Māori. Therefore, we aimed to explore the perceptions and lived experiences of ngā tāne Māori living with OA in Aotearoa New Zealand.

METHODS

Study design

This study used a qualitative method and was informed by the kaupapa Māori philosophical framework for research (Smith, 1999).

Kaupapa Māori philosophical framework

The kaupapa Māori research model is Māori-centred, with outcomes aiming to benefit Māori. Kaupapa Māori research is defined as "to engage in a dialogue about setting new directions for the priorities, policies, and practices of research for, by and with Māori" (Smith, 1999, p. 183). It places Māori values, customs and protocols at the centre of the research methods, and is vital in attaining an accurate interpretation of te ao Māori to ensure mana-enhancing approaches to research practice (Jones et al., 2006).

Participants

The study was advertised via social media and flyers as well as through the primary researcher's (TD) whānau, community contacts and snowball sampling. Participants were recruited from the Bay of Plenty region. Participants were included if they identified as tāne Māori, were over the age of 35 years and met the American College of Rheumatology criteria for hip or knee OA; knee, hip or groin pain; stiffness for less than 30 min; knee crepitus; bony tenderness and enlargement of the knee; and no unusual, palpable warmth (Kolasinski et al., 2020). Participants were excluded if they had difficulty verbally communicating in either English or te reo Māori; had suffered a significant injury in the past 3 months; had had a total joint replacement; or had a disability or medical condition other than OA that substantially affected their daily function.

Procedures

Participants were interviewed face to face by TD in a location of the participant's choosing. Upon starting, karakia (ritual chant or prayer) was undertaken, the consent form was filled out and whakawhanaungatanga (process of building relationships) established. The interviews followed a semi-structured style in both English and te reo Māori. TD utilised the domains of te ao Māori to ensure tikanga (Māori customs) where karakia, whakawhanaungatanga, manaakitanga (process of showing respect), aroha (love and compassion) and pono (honesty) were included. These tikanga practices safeguarded the research process, results, researchers and participants (Jones et al., 2006). The questions were open-ended (see Appendix A), aiming to explore the participants' personal experience of OA and their experience of health services. Five of the seven participants asked that their interviews not be recorded – two of the participants did not want their voices to be loaded onto any shared networks and no reason was given for the other three participants. Interviews that were not digitally recorded were instead transcribed by TD, from extensive notes written during the interview, then further developed and transcribed immediately following the interview to aid in the retention of important details. The remaining two interviews were recorded and transcribed verbatim.

Data analysis

Analysis was guided by the six steps outlined by Terry et al. (2017) for reflexive thematic analysis. Consideration of te ao Māori informed and shaped the process of developing themes throughout the research process. The first step involved familiarisation, making casual notes on the content of the interviews. Inductive codes were then generated, informed by the research question at both semantic and latent levels (the latter often using concepts from mātauranga Māori to inform codes). From this, themes were developed, tested and reviewed by returning to the interviews to determine whether they accurately gauged the data collected, then the final report was produced. Each of the six phases of thematic analysis were carried out by the primary researcher, with findings presented to the wider research team. Following this, the themes were refined by a second member of the research team (GT) and again presented to the research team to ensure that meaning had been retained.

Theme development was informed by the Māori health frameworks, Te Whare Tapa Whā and Te Pae Māhutonga. Te Whare Tapa Whā (Durie, 1998) uses the four walls of a whare (house) that represent the elements that symbolise good health and wellbeing. Te Pae Māhutonga is a health promotional framework, also proposed by Durie (2004). A constellation, Te Pae Māhutonga or Southern Cross, has traditionally guided Māori on their ocean voyages. The stars that make up Te Pae Māhutonga symbolically represent the components of Durie's (2004) health promotion framework: Mauriora, Waiora, Toiora, Te Oranga, Nga Manukura and Te Mana Whakahaere, which served historically as a guide for generations of Māori.

RESULTS AND DISCUSSION

Seven tāne Māori participated in the study and their ages ranged from 49 to 75 years. Five participants had knee OA and two had hip OA. Symptom duration ranged from 6 months to 40 years. Four participants lived rurally and three lived in an urban area. All participants indicated taking medication for their OA and four stated that they used rongoa (traditional Māori medicine) to treat their OA. Four themes developed from the data and were named: (1) *The interface of masculine embodiment and mana,* (2) *Taha whānau and connection as central to ngā tāne Māori wellbeing*, (3) *The benefits of taha wairua (spiritual wellbeing),* and (4) *Te urutau kia uru ki te punaha tiaki hauora: Adapting to access the health-care system.*

Theme 1: The interface of masculine embodiment and mana

This theme explored the different beliefs ngā tāne Māori expressed regarding their mana, in relation to their 'manliness' or masculinity, and how this was impacted by OA. Central to this theme was the relationship of masculine identity to both taha tinana and taha hinengaro, and the inseparability of these within te ao Māori. Taha hinengaro allows people to think, communicate and feel, generating awareness of the self (Durie, 1998) – but this includes experiences and expressions of the physical body. Within Western men's health literature, this interface has been understood as *experiential embodiment* (Robertson et al., 2010). This is an area underexplored within Western biomedicine, where the body and mind are often treated as separate (Robertson et al., 2010), something that can impact ngā tāne Māori negatively. For the men in this study, taha hinengaro seemed to be a primary point of reference for understanding the experience of OA. However, how this manifested in their roles and responsibilities (toiora) as tāne Māori was also referred to throughout the interviews.

Frequently, the sensation of whakamā (an event or experience that brings shame or embarrassment) was present for ngā tāne Māori when talking about their experiences of OA (Te Karu, 2013):

> It's just annoying to be honest. A lot of things have changed … The things I used to be able to do, I just can't … I can't run anymore, I can walk but I struggle to keep up with people … It's tough because I'm still relatively young … It just bothers me feeling like people are looking at me with pity. (Participant 5)

Participants commonly expressed attitudes associated with the dominant ideals and values of Aotearoa New Zealand: strong, hard-working, rising above adversity and, most notably, humility (Phillips & Hulme, 1987). Participants spoke of being a "man's man", and having a "she'll be right" attitude, drawing on the powerful imaginary figure of the 'kiwi bloke', who epitomises what an Aotearoa New Zealand man should look like and aspire to be (Terry & Braun, 2009). A predominant feature of this whakamā was the reluctance to be vulnerable. Ngā tāne Māori seemed to struggle with a concern for burdening others and the disempowering feeling of pity from whānau and friends. This had significant effects on their mana. Mana as an expression of spiritual power and potentiality within a person (Tate, 2010), seemed at risk due to their experiences. This was spoken about by some of ngā tāne Māori specifically in relation to their masculinity:

> I can't bring myself to get too emotionally involved, I've always been a man's man and just gotten on with life. My kids are all doing really well with my moko's [mokopuna/grandchildren] so I don't want to be annoying them. (Participant 2)

> I've never really thought about it … I'm definitely a man's man, I've always just done things a certain way and was brought up with my dad's 'life isn't fair' way. I don't really talk about these things because we were basically raised to be staunch and all. (Participant 5)

In contrast, some ngā tāne Māori articulated their mana or masculinity as not defined by their physical capacity alone, and were more willing to be vulnerable and accepting of change: "Having ailments is a natural thing. Your maleness isn't judged on whether you're limp winged or have any other physical defect" (Participant 3).

Despite these differences in ngā tāne Māori, there was a distinct sense that they were answerable to these masculinity concerns, whether or not they identified strongly with them. This meant that ngā tāne Māori would often make reference to manhood and masculinity when speaking about OA and its impacts, whether or not this was raised by the interviewer.

Much of this kōrero related to changes in toiora (role expectations and changes) and the modelling of skills and behaviour to their whānau. This often meant that the elements of their identities that gave them a sense of meaning were increasingly being located in the past, rather than the present.

> I really miss my hunting … that's what I miss the most. Getting my boys and the dogs, then just spending a day or two out in the bush with them. It's priceless those moments … They're memories I will cherish forever; it's the time I spent with my boys bringing them up and teaching them the life skills that were passed down to me. It's whakapapa really my boy. (Participant 6)

This kind of embodiment has been described as pragmatic embodiment – or the ways the body enables certain roles (father, worker, rugby player) to be taken up (Robertson et al., 2010). For ngā tāne Māori like Participant 6, this was inextricably tied to their bodies. For some ngā tāne Māori, their roles had changed as they aged, and so the need for physical expression of masculinity was lessened: "When I go and help with the marae and that, it doesn't really affect me. Although, I've got to sit down a bit … I still partake in that sort of thing it hasn't stopped me doing that" (Participant 4).

For those whose identities were tied up in their physicality, this was something that seemed to be a longstanding component of their lives. Ngā tāne Māori spoke of the comparisons between the freedom of youth and their current experience of their bodies:

> It's all part of life. I was just a kid, I still am young at heart even though I'm an old fart and can't do much anymore … We would go up the hills and roll down them, run down to the beach and build huts and play rugby in the mud. (Participant 6)

These conversations and comparisons seemed to be confronting for some participants. This could indicate a reliance on their bodies for a positive sense of self. Several ngā tāne Māori had not previously considered, or had and disregarded, the implications of their physical ailments on their mental wellbeing. This may highlight a challenge when supporting ngā tāne Māori to express their vulnerabilities.

> I do sometimes get a little bit, well maybe more than a little bit … How do I put it? Not depressed. Oh, actually a little bit of that I think … You know, putting up with the pain. It's

> hard to say … You know, when I feel and look at my bad knee I think, Jesus what's going on. (Participant 4)

Taha tinana considers our autonomy over our physical health and how we manage the challenges presented to this and is strongly related to our mental wellbeing (taha hinengaro). Turning to whānau for support in times of need is common; so, it is essential we consider the nuances of taha whānau and the role of connection.

Theme 2: Taha whānau and connection as central to ngā tāne Māori wellbeing

Whānau in te ao Māori is tremendously important. Durie (1998) argues the concept of whānau is unique, as it organises Māori culture and is foundational to Māori identity. There are two elements that characterise taha whānau. First, whānau is the principal support system. Second, self-reliance and an insistence on independence, not turning to whānau for support in times of need, is viewed as immaturity rather than strength. As Durie (1998) states, "Interdependence rather than independence is the healthier goal" (p. 72). This idea is extended to connection to whenua (land) and whakapapa (genealogy), and the support these offer ngā tāne Māori and their sense-making concerning OA.

'Mauri', means life force, in things or objects both living and inanimate. In essence, 'mauri ora' expresses the importance of a healthy cultural identity, to realise inner potential and to seek one's identity and facilitation into te ao Māori (Durie 1999; 2004). For many Māori, urbanisation has limited access into te ao Māori. Many Māori have become alienated, as cultural ties have been damaged through the confiscation of whenua, generational loss of te reo Māori, colonised suppression and institutionalised racism (Jones et al., 2006). The loss of cultural identity and its impacts on wellbeing were evident among some participants in the dataset:

> I was brought up in the city but we used to go out to the farm back home all the time when I was growing up … I was beaten when I was younger for speaking Māori even though it's my native tongue. (Participant 2)

All participants discussed how important their whānau were and the crucial role they played in their lives. However, several ngā tāne Māori struggled or were reluctant to engage emotionally with whānau about their OA. This could indicate the breakdown in mauri ora, with some ngā tāne Māori unwilling to open up in fear of becoming a burden on others, emphasising again the challenge ngā tāne Māori have with vulnerability: "I don't really talk about it with them … It's just become the norm now really, me being a cripple. My kids and I joke about it so it's not too depressing" (Participant 5).

Some ngā tāne Māori appeared to have strong connections with whānau and whakapapa, speaking of their whānau as Durie (1998) describes: "family is the primary support system for Māori, providing care and nurturance, in physical terms as well as culturally and emotionally" (p. 86). Muriwai et al. (2015) further argue that those who strongly identify solely as Māori, with strong cultural adeptness, have lower psychological distress. Our data supports this notion, for instance: "My whānau support me 100 percent, they are the reason I am who I am. Their opinions are the only opinions that matter most to me. If anything, they help me through each and every day" (Participant 7).

Ngā tāne Māori in this study discussed how their roles had changed within their whānau and society due to ageing. It is a natural human instinct to seek acceptance and to have a place of belonging within society (Oetzel et al., 2019). Hence, the endeavours of te oranga is to find that sense or place of belonging, in order to participate in society (Durie, 2004). Ngā tāne Māori felt their ability to participate in society or with whānau had become limited due to their OA. These limitations include the changing dynamics as a pāpā (father) or koroua (grandfather), and the inability to work full-time or at all, drive, stand at the marae or simply hang the washing.

> I used to be able to help the boys at mahi [work], but now I have to drive the truck around to all the areas and just wait for them as we go through each paddock or bush … I can't go out hunting like I used to as well, because my knee just hurts too much. (Participant 1)

When speaking of these changes, ngā tāne Māori allowed out a part of their compartmentalised emotions. These were raw, special moments, which showed they had the capacity to express their vulnerabilities: "I tell you what though, the thing I really miss is actually being able to run around with the kids" (Participant 5).

> The main thing I miss the most is being able to ride my horse … I can't ride him like I used to … My knee bloody kills me when there in the stirrups, it just jars-up and crunches with every stride. It's the worst pain. (Participant 1)

Ngā tāne Māori have struggled with the changes brought on by OA, including choosing to be independent from whānau, living and working alongside whānau or seeking a spiritual connection. Hence, taha wairua needs to be discussed, as Māori culture is infused intimately with the spiritual world.

Theme 3: The benefits of taha wairua (spiritual wellbeing)

Taha wairua encapsulates the unspoken energies that surround us. It is intertwined with the past, present and future and provides the important connections Māori have with their whakapapa and te ao Māori (Durie, 1998). Waiora is one's capacity to balance and harmonise one's relationship with one's environment. Durie (1999, 2004) emphasises the significance of environmental protection and the relationship with te ao Māori, and how it is crucial for the health and wellbeing of Māori. The two important factors required to bring balance with the spiritual realm are tikanga and āhuatanga Māori. If tikanga Māori are 'Māori customs' then āhuatanga Māori are 'Māori traditions', and co-exist with one another. Āhuatanga Māori in particular is key, as it encompasses the characteristics of Māoritanga that connect the deep emotional and spiritual bonds unique to Māori (Mead, 2003).

Typically, Māori are raised under tikanga and āhuatanga Māori. Our results suggest that rural ngā tāne Māori appear to have a stronger connection to their wairua compared to urban ngā tāne Māori, which could be due to the effects of urbanisation: "I'd go for drives to the bush where I used to go hunting … to listen to all of Tāne-mahuta's children singing their songs and let my thoughts drift away. Sometimes I'd fall asleep" (Participant 1).

In comparison, Participant 7 was from an urban setting: "Never tried rongoa … I wasn't brought up around that stuff. If we were sick or got injured we went to the doctors, that's just the way it was" (Participant 7).

Some urban-raised ngā tāne Māori mournfully expressed they had not been back to their papakāinga (ancestral homelands) in many years, which resulted in them feeling disconnected from their whenua, iwi and tīpuna (ancestors): "If I'm feeling a bit down about something, all my whānau live back home so I don't really have that many people to talk to. I'm divorced now and the kids are all grown up" (Participant 2).

Urbanisation has profoundly impacted the upbringing of Māori and their access to te ao Māori. Many Māori who feel disconnected from their wairua become more socially isolated and have experienced generational marginalisation in the Aotearoa New Zealand healthcare system (Jansen et al., 2009). Participants in this study have experienced different types of healthcare treatment; hence, it is critical to discuss these experiences.

Theme 4: Te urutau kia uru ki te punaha tiaki hauora: Adapting to access the health-care system

Numerous studies have argued Māori marginalisation in the Aotearoa New Zealand health-care system, and the disparity between the biomedical/Western and Māori models of health (Elers, 2014; Wilkins, 2009). Ngā tāne Māori in this study reported contrasting experiences of the healthcare system. Ngā tāne Māori with a stronger sense of identity, support and belonging appeared to have had positive experiences – especially if their medical professionals' practices matched their expectations:

> Oh, the good thing they do here is they treat you like whānau. They always make sure we are okay, they would contact you and make you feel at home here, which [I think is] different to what it's like in the cities. (Participant 4)

However, others reported stories of institutional racism and marginalisation, for instance:

> I grew up in a pohara [poor] neighbourhood and the doctors treated us like we were from a third world country … I got annoyed one time when my mum was sick. The doctors saw all the pākehā patients who arrived after us … I was 12 or 13 at the time and I threw my marbles at him when he came out and we left. We moved to another doctor after that and we've had the same family doctor ever since. (Participant 7)

Furthermore, some discussed the disconnect between the pākehā/biomedical approach, which traditionally they felt focused on the physical symptoms of health, and the holistic approach of te ao Māori. This divide in Aotearoa New Zealand healthcare institutions was perfectly summarised by Participants 1 and 3: "Never really been a big fan of doctors boy. Everything to do with the pākehā way of life is just different to our life. Not to say one is better than the other, just different" (Participant 1).

> Our people are not used to talking about their mamae [pain]. Perhaps, our medical professionals would need to learn how to get that information out of us rather than write 'now okay we'll give you this for that, and this for that. All right, thank you very much. See you later, good day.' Then they walk out and pay $50 for that service. (Participant 3)

OA has made a significant impact on ngā tāne Māori. To others, they present the dominant ideals that are perceived to epitomise what an Aotearoa New Zealand ngā tāne Māori should be. However, many spoke about struggling to come to terms with their condition(s) and become accepting of these changes, in private. Durie (1998) advises considering all dimensions collectively and not independently. But this is difficult to achieve with ngā tāne Māori with ill-health or injury. Throughout each dimension, a major issue became evident: the inability for some participants to accept change and unwillingness to express their vulnerabilities.

Strengths and limitations

A strength of the study was the guidance of kaupapa Māori throughout the research process; the key utilisation of the Māori health frameworks informed the data analysis and theme development. Having the primary researcher (TD) and a second member (TR) of the research team identify as Māori and understand tikanga and kaupapa Māori protocols was fundamental to implementation of concepts of te ao Māori. A limitation of this study was the small sample size, which should be considered when interpreting the results. Additionally, only two of the seven interviews were digitally recorded at the request of participants. Therefore, some communications may have been lost due to recall limitations.

Clinical and research implications

Physiotherapists and researchers should consider the process of whanaungatanga as a method of building rapport when undertaking research with or treating ngā tāne Māori. This change could be something as simple as committing time at the beginning of the session to understanding what is important to your patient/participant and sharing something about yourself. For more guidance, please see *Person and whānau centred care / seeing the patient as a person / ethnicity Māori* (Darlow & Williams, 2018) on the Physiotherapy New Zealand website.

CONCLUSION

This is the first kaupapa Māori-informed study of the lived experience of hip and knee OA by ngā tāne Māori in Aotearoa New Zealand. The findings emphasise the multifaceted and integrated nature of hauora Māori. The physical and emotional burden of OA has impacted on ngā tāne Māori perceptions of themselves, and caused some to question their masculinity. Furthermore, OA impacts the relationships and roles of ngā tāne Māori within both their whānau and in society. The unique lived experiences and wider whānau impacts of ngā tāne Māori living with OA supports the need to consider the necessities of te ao Māori into clinical practice and future OA models of care.

KEY POINTS

1. OA can affect the ability for ngā tāne Māori participation with whānau, which can in turn impact their sense of self-worth and mana.

2. OA affects ngā tāne Māori relationships and roles within both their whānau and in society.
3. Physiotherapists should consider the process of whanaungatanga to build rapport when treating ngā tāne Māori.

DISCLOSURES

There are no conflicts of interest that may be perceived to interfere with or bias this study.

PERMISSIONS

This study was granted ethical approval by the Auckland University of Technology Ethics Committee (reference number 18/389).

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APPENDIX A

INDICATIVE QUESTIONS

Can you start by telling me about the history of your [knee/hip] pain?

What, if anything, has been the impact of your [knee/hip] pain on your life?

What, if anything, have you done about your [knee/hip] pain?

How do you manage your knee/hip pain on a day-to-day basis?

Has your [knee/hip] pain affected your relationships with other members of your whānau? If so, how?

Has your [knee/hip] pain impacted on your [physical/ mental/ spiritual] health and wellbeing? If so, how?

How do you feel about your [knee/hip] pain, now and into the future?

What is your knowledge of osteoarthritis in terms of the condition itself?

What are your thoughts about medication/pain relief in relation to your knee/hip pain? (Talk about different kinds of medication and how they are used).

What sorts of traditional/complementary/alternative approaches do you use? How have you found these?

There are a number of ideas about Kiwi masculinity (being stoic, self-reliant, etc.). How do you relate to these?

How does being a guy influence some of your thinking about pain and management of pain?

What has been your experience of doctors and other health practitioners (broadly defined) prior to OA?

Has the experience of having OA impacted on how you relate to doctors and other health practitioners? If so, how?

Supporting People Experiencing a Burn Injury to Return to Work or Meaningful Activity: Qualitative Systematic Review and Thematic Synthesis

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ABSTRACT

Qualitative studies contain in-depth information about facilitators and barriers to successful rehabilitation. This systematic review synthesised findings across qualitative studies to inform vocational rehabilitation practices for people who have experienced burn injury. PRISMA guidelines were used to determine inclusion criteria for the review and develop a comprehensive search strategy. Four databases were searched and results screened. Included studies investigated experiences of return to work (RTW) or meaningful activity in a burn injury population. Quality of included articles was examined using the CASP framework for qualitative research. Thematic synthesis was used to analyse the qualitative results. Six studies met inclusion criteria. Five analytic themes were identified regarding experiences of vocational support and ability to RTW after burn injury: addressing the complex impact of burn injury; personal connections as vital support; skilled and specialised healthcare as central to RTW; value of knowledge; and considering the work environment. No included studies investigated meaningful activity other than paid work. Findings support structured vocational rehabilitation, psychological interventions, social support, intensive rehabilitation and patient, clinician and workplace education as key in facilitating RTW after burn injury. Additionally, coordinated care is likely to improve vocational outcomes. Research is needed on supporting return to meaningful activity.

Van Bentum, J., Nicholson, J., Bale, N. & Fadyl, J. K. (2021). Supporting people experiencing a burn injury to return to work or meaningful activity: Qualitative systematic review and thematic synthesis. *New Zealand Journal of Physiotherapy, 49*(3), 134–146. https://doi.org/10.15619/NZJP/49.3.04

Key Words: Burns, Qualitative research, Rehabilitation, Systematic Review, Vocational

INTRODUCTION

Survival rates following burn injury have notably improved worldwide due to medical and surgical advances (Espinoza et al., 2019). Quality of life following burn care is now the focus of most burns research (Espinoza et al., 2019). Return to work (RTW) is a key rehabilitation goal and is identified as a valid indicator of post-burn injury physical and psychosocial health (Espinoza et al., 2019). RTW is defined here as engaging in work in any capacity after health-related impairment. Achievement of RTW or meaningful activity helps people who have experienced burn injury regain a sense of normality and is an indicator of community reintegration (Johnson et al., 2016; Mason et al., 2012).

The Burn Registry of Australia and New Zealand (BRANZ) recorded 437 admissions to Aotearoa New Zealand inpatient burns units between 2018 and 2019 (Tracy et al., 2020). Scald, contact and flame burns remain the most common mechanism of injury and the vast majority of injuries happen in the person's own home (Tracy et al., 2020).The trend of severity of burn injuries remains stable, with the majority of injuries being less than 10% total body surface area (TBSA) (Tracy et al., 2020). In New Zealand, the current criteria for a person who has experienced an acute burn injury to attend a regional burn unit includes, but is not limited to, a TBSA greater than 10% in an adult or 5% in a child, burns to specific areas such as face, hands or perineum, electrical or chemical burns, or burns with inhalation injuries (Counties Manukau Health, 2021). The current criteria for admission to the national burn unit includes, but is not limited to, burns greater than 30% TBSA, full thickness burns to face, hands, genatalia or perineum, significant inhalation injury, and significant electrical or chemical burns. Specialised burn-experienced physiotherapists are part of the treating multidisciplinary team (MDT) at the national burns unit and the regional burn units. The rehabilitation pathway may differ between individuals, depending on the severity and mechanism of the injury, patient demographics and existing co-morbidities, resources available at their hospital of admission, and support provided by the Accident Compensation Corporation (ACC). ACC guidelines state that burn injury rehabilitation must be carried out in a designated District Health Board (DHB) facility but do not provide specific rehabilitation processes, therefore permitting the treating therapist to provide rehabilitation and RTW strategies at their discretion (Accident Compensation Corporation, 2016).

A 2012 systematic review by Mason and colleagues estimated that 28% of individuals experiencing burn injury never RTW. Although New Zealand statistics were not included in this review, it is reasonable to infer that New Zealand burns patients face similar challenges to what is reported in this review (Mason et al., 2012). In New Zealand, 99% of burns patients' health-related costs are funded by ACC, which is a no-fault personal insurance scheme for accidental injuries (Tracy et al., 2019). ACC funds medical costs, post-discharge support and also vocational rehabilitation and 80% wage compensation. Wage compensation and vocational rehabilitation continues until the person is work-able, determined by a RTW or an assessment that the person could work in a suitable job according to both medical and vocational criteria (New Zealand Accident Compensation Act, 2001). According to ACC statistics, weekly wage compensation costs for people with burn injuries between 2018 and 2019 were $5,315,779 (personal communication, April 6, 2020). Therefore, burn injuries pose not only significant healthcare costs, but delayed RTW following injury also creates an additional economic load due to productivity loss and compensation claims.

Returning to work requires people with burn injury to overcome persistent injury-related challenges including tissue contractures, pain, weakness, psychological issues, scarring and insecurities over altered physical appearances (Mason et al., 2012). A 2010 systematic review reported time to RTW following burn injury in the USA, China, Australia and Sweden as ranging from 4.7 weeks to two years (Quinn et al., 2010). This research illustrates the variable and often lengthy RTW experience. Vocational rehabilitation (VR) employs a MDT approach aimed at optimising RTW among individuals experiencing a health-related impairment (Escorpizo et al., 2011). In New Zealand, physiotherapists are involved in VR for people with burn injury both in early intervention as staff on burns units and as specialised VR providers. This often involves teamwork among occupational therapists, VR counsellors, psychologists, social workers, case-managers and medical staff (Esselman, 2011; Gobelet et al., 2007). Physiotherapy contribution is crucial; therefore, research in this field is significant to physiotherapy practice. However, with limited research on effective practices specifically in relation to VR, it can be challenging for physiotherapists to decide on best use of time and resources. Comprehensive VR programmes are individualised and include interventions like vocational training, guidance, education, goal setting, job placement and vocational counselling (Gobelet et al., 2007). Successful VR has obvious benefits for people with burn injury while generating positive social and economic effects through the prevention of long-term sickness and disability (Waddell et al., 2008).

Despite the importance of social and work reintegration following burn injury, there is limited literature or guidelines detailing intervention protocols that facilitate RTW. Therefore, supports likely differ between burns units. Additionally, the clinical trial evidence in this area is still extremely limited. Our search identified only one randomised controlled trial published since 2005 that specifically investigated RTW after burn injury (Wiechman et al., 2015). This study, conducted in the USA, compared an expanded delivery model of burn care to standardised outpatient care, and there were some concerns about risk of bias. At present, the most productive avenue is to examine experiences reported in the qualitative literature to identify promising interventions for further testing. The authors aimed to address this need through a systematic review of qualitative literature related to supporting RTW or meaningful activity after burn injury. Meaningful activity was defined as any physical, social or leisure activities important to a person.

Qualitative studies are designed to explore complex lived experiences and social processes, and therefore they are specific to the context in which they were conducted. When multiple qualitative studies are synthesised, it is possible to retain the nuanced understanding of a phenomenon that is enabled by qualitative research, while generating insights that cut across the different study contexts (Flemming et al., 2019). This type of review can also be used to identify possible interventions for future testing (Levack, 2012). There are several methods of conducting synthesis of qualitative studies. For this study, we selected thematic synthesis (Thomas & Harden, 2008) based on guidelines published in the *Cochrane handbook for systematic reviews of interventions* (Higgins et al., 2019) – an approach appropriate for the type of research question, and capable of producing well-developed themes.

METHODS

The research question this review addressed was: What does qualitative research evidence indicate is useful to support an individual experiencing burn injury to RTW or meaningful activity?

Definition of terms for database search and screening for inclusion

We employed a pre-planned database search strategy across four databases, specifying keywords and subject terms adapted for each database. The key definitions that structured our search are outlined below. Specific keywords used are presented in Table 1.

Table 1

Search Terms

Population terms	"burn* patient*" OR "burn* injur*" OR "burn* rehabilitat*" OR "burn* model*" OR "burn* care" OR "burn* survivor*"
Intervention terms	"return to work" OR "rtw" OR "return to employment" OR employment OR "work reintegration" OR "work re-entry" OR "work resumption" OR "vocational rehabilitat*" OR "meaningful activit*" OR "meaningful occupation*"

Note. Population and intervention terms were combined in the search with AND.

Included populations

The review included studies where participants were 16 years of age or older, who had experienced burn injury. A burn injury was defined according to the BRANZ definition, encompassing contact with hot objects, hot liquids or steam, chemicals, electrical current, fire or flame, radiation, radiant heat, flashes of energy produced by explosive material or friction-type movement of a surface against the skin (Tracy et al., 2019).

Included interventions and related outcomes

Included interventions involved any type of support aiming to assist people who have experienced burn injury to remain in or RTW or meaningful activity. Studies were excluded if there was a lack of discussion of or focus on RTW or meaningful activity. RTW was defined as engaging in work in any capacity after health-related impairment and return to meaningful activity was defined as engaging in any physical, social or leisure activities important to that person.

Included study designs

All qualitative study designs except qualitative systematic reviews were considered eligible for inclusion. Relevant study designs included, but were not limited to, grounded theory, qualitative descriptive, ethnography, critical, post-structural or Indigenous methodologies. Other qualitative systematic reviews including evidence synthesis were excluded due to potential double-up of study data with original studies.

Timeframe

A 15-year search timeframe was chosen for study eligibility to ensure appropriate relevancy accounting for changes in job market conditions and policy environments over that time.

Sources of research reports

We searched four databases in February 2020 for peer reviewed articles published between 1 January 2005 and 27 February 2020. The databases were CINAHL, MEDLINE, SPORTDiscuss and Scopus. We also conducted a manual search of reference lists of included articles.

Study quality

As thematic synthesis synthesises the findings across studies, it was important that all data included for synthesis was considered trustworthy. To this end, studies included for data extraction were required to meet critical methodological quality criteria. These criteria were appropriate methodology, design and data collection, and sufficiently rigorous analysis, including a clear statement of findings – each mapping onto a specific question in the critical appraisal tool (see below).

Study screening

The team involved in study screening and subsequent quality assessment included two final-year trainee physiotherapists (JvB, JN), a senior burns physiotherapist (NB), and an experienced qualitative researcher with expertise in both qualitative synthesis and vocational rehabilitation (JF). Initially, two review authors (JvB, JN) independently considered the titles and abstracts from the studies identified and screened for relevance to the research questions. All studies that had any possibility of meeting inclusion criteria for topic and population at title and abstract screening were included for full text screening, and methodology/study type was not screened until full text stage. The same two authors conducted full text screening, also independently before discussing consensus. Disagreement or uncertainty about relevance for inclusion was discussed with the senior author, and involved consideration of full study reports. The screening process was managed using Rayyan software (Ouzzani et al., 2016).

Quality assessment

Two review authors (JvB, JN) independently assessed for methodological quality using the Critical Appraisal Skills Programme qualitative checklist (Public Health Resource Unit, 2002). Section A (six items) assesses the study design as it affects validity of results. Section B (three items) addresses the reporting of results directly. Section C addresses external validity. As with screening, uncertainties and disagreements were discussed with the senior author and resolved by consensus. Each item was scored ‘yes’, ‘no’ or ‘can’t tell’. Where an item scored ‘can’t tell’ and it was critical to our inclusion criteria for quality (see quality inclusion criteria above), study authors were contacted for clarification.

Data extraction

Two authors (JvB, JN) independently extracted key information from all included studies including full citation, authors, year published, country, sample size, methodology (such as grounded theory), intervention (where relevant) and study findings. Extracted data was compared and any disagreements were handled in the same way as for screening and quality assessment. The data for analysis for each study was the extracted text from the ‘results’ or ‘findings’ and ‘discussion’ sections.

Thematic synthesis

Included qualitative data was synthesised using methods of thematic synthesis outlined by Thomas and Harden (2008). Thematic synthesis is an established method used to inform practice recommendations through development of analytic themes, which presents data in an accessible form. This method was selected as it meets the review’s objective of identifying patterns within existing qualitative literature to make informed conclusions.

The first stage involved two authors (JN, JvB) independently coding the results, quotations and discussions of each study, line by line, according to meaning and context. Codes were placed into Google Docs for cross-review. Codes were checked alongside the original text to confirm consistency of interpretation and to identify whether additional levels of coding were required (Thomas & Harden, 2008).

The second stage involved identifying similarities and differences between codes to develop descriptive themes that capture and describe patterns in the data (Thomas & Harden, 2008). Codes with the same meaning were combined into new codes. All codes were then placed into Miro (www.miro.com), an online whiteboard. Similar codes were arranged together into hierarchical tree structures. From this, the study team developed five descriptive themes.

The final stage involved generating analytic themes that expanded beyond the original data and addressed the review question. The team discussed each theme with the aim of describing an overarching meaning in the context of inferences for appropriate support. At this stage, ideas became more abstract and analytic themes superseded the prior descriptive themes. Both the in-depth knowledge of the descriptive themes from the prior work and the depth of experience within the research team in relation to burns rehabilitation and vocational rehabilitation were crucial to this stage of analysis. Results presented below are the result of the analytic theme stage of analysis. That is, they go beyond the findings of the original study into interpretation only possible with synthesis of multiple studies. Where reported results related to specific studies, these are referenced. Where the interpretation is a synthesis that goes beyond this, we have not referenced original studies.

RESULTS

Search results

Figure 1 shows the screening outcomes. Initial database searches returned 424 journal articles. The manual reference list search revealed one additional article. After removal of 176 duplicates, title and abstracting screening excluded 185 articles. Of the 64 articles that were screened at full text, six met the inclusion criteria.

Study and participant characteristics

Characteristics, strengths and limitations of the included studies are detailed in Table 2. Included studies involved participants recruited from specialist burns centres or outpatient rehabilitation sites in Canada, Sweden and Australia (Johnson et al., 2016; Mansfield et al., 2014; Nguyen et al., 2016; Stergiou-Kita et al., 2014). Very specific patient populations limited the transferability of results to the wider burns population. A common strength among studies was relevant quotation usage to verify results.

Figure 1

Screening for Inclusion

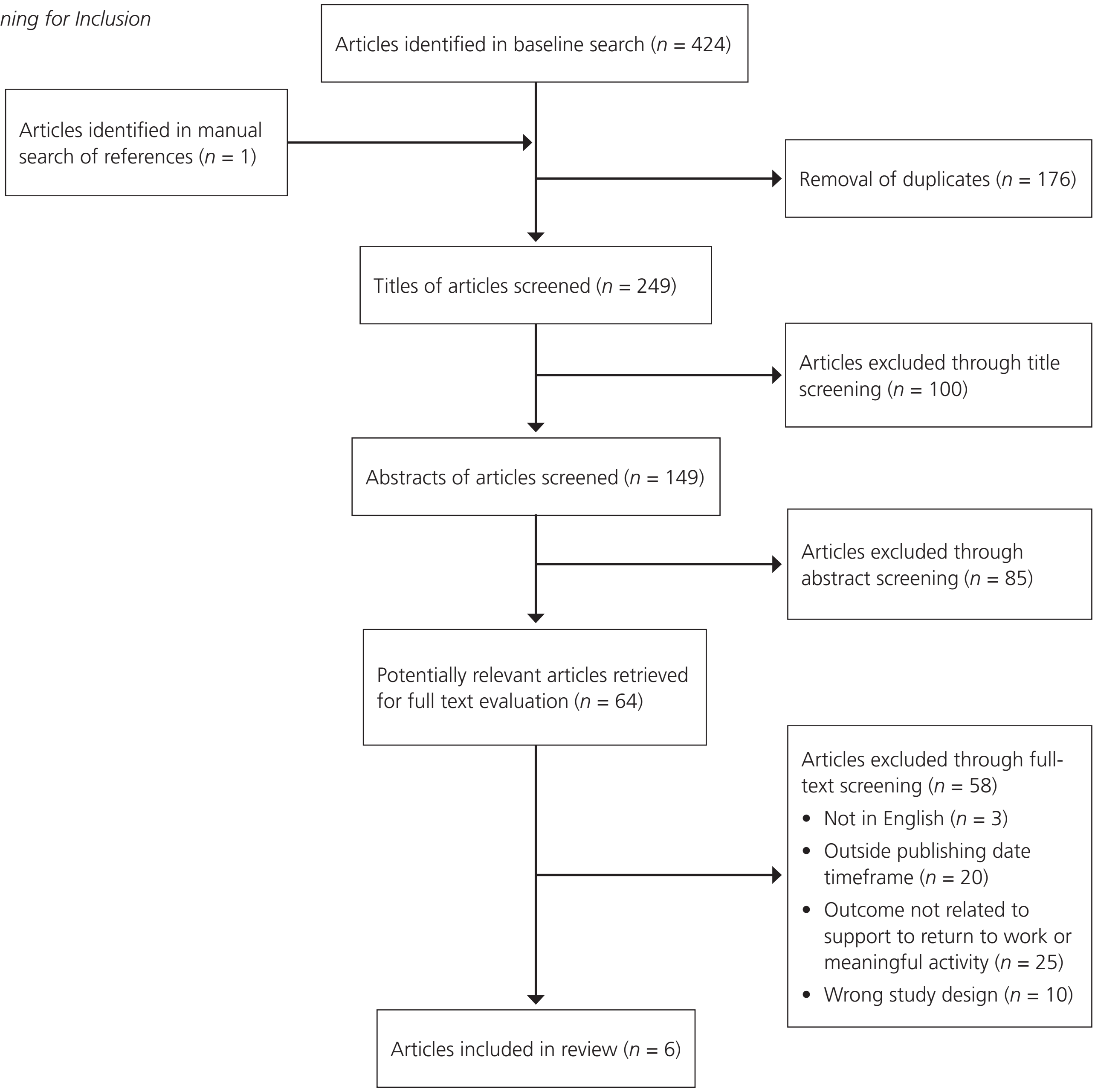


Table 2

Study Characteristics

Author	Methodology and country	Aims	Participants	Strengths/limitations
Öster et al. (2010)	Qualitative descriptive (content analysis) Sweden	Exploration of burn patients' perception of factors seen as facilitators or barriers in the process of returning to work after a severe burn injury	*n* = 39 Burn injury patients previously employed or studying	Strengths Participants chose interview location Neutral, experienced interviewer Moderate sample size Effective use of quotations to verify results Limitations Only included previously employed participants Participants interviewed up to six years after RTW Two participants interviewed together
Mansfield et al. (2014)	Qualitative descriptive (thematic analysis) Canada	Assessment of how worker, job, workplace, injury, compensation, and support elements interact and influence the RTW process	*n* = 13 Burn survivors who experienced a workplace electrical injury	Strengths Provides specialised insight into electrical injuries Detailed data analysis protocol Effective use of quotations to verify results Limitations Small sample size Specific type of burn injury Impairment information was self-reported Authors do not outline strengths and limitations of the study
Stergiou-Kita et al. (2014)	Qualitative descriptive (thematic analysis) Canada	Aimed at gaining an understanding of workers' RTW experiences including challenges and beneficial support	*n* = 13 Burn survivors who experienced a workplace electrical injury and attempted to RTW	Strengths Provides specialised insight into electrical injuries Detailed data analysis protocol Effective use of quotations to verify results Limitations Small sample size Specific type of burn injury Impairment information was self-reported
Johnson et al. (2016)	Heideggerian phenomenology Australia	Interprets information on the lived experience of hospitalisation and recovery following burn injury	*n* = 18 Burn patients and family members following hospital discharge	Strengths Perspectives from patients and carers Effective use of quotations to verify results Limitations Only recruited from one state in Australia Only included English speaking participants High proportion of industrial accidents
Lamble et al. (2019)	Cross-sectional study with a qualitative component Canada	Comparing RTW outcomes between the KT intervention group and a control group, describing the RTW and the KT intervention experience	*n* = 29 Burn survivors who participated in the KT intervention study (*n* = 15) Matched controls (*n* = 14)	Strengths Included participants from multiple employment fields Groups matched for age, sex and TBSA Both qualitative and quantitative information Clear validation process of questionnaires Limitations Groups not matched by job task, burn location or time since injury Excluded those who had not returned to work Interviewed up to two years following intervention

Author	Methodology and country	Aims	Participants	Strengths/limitations
Nguyen et al. (2016)	Qualitative descriptive (thematic analysis) Canada	Investigating burn survivors' and clinicians' perspectives on barriers and facilitators to work reintegration	*n* = 29 Burns unit MDT clinicians (*n* = 9) Burns survivors (*n* = 20)	Strengths Participants had various employment statuses, diverse workplaces and roles Perspectives from both patients and clinicians Effective use of quotations to verify results Limitations Focus groups had differing combinations of informants Small sample size Recruitment from only one burns unit

Note. KT = knowledge translation; MDT = multidisciplinary team; RTW = return to work; TBSA = total body surface area.

The six qualitative studies reported on 141 participants, with sample sizes ranging from 13 to 39 (Johnson et al., 2016; Lamble et al., 2019; Mansfield et al., 2014; Nguyen et al., 2016; Öster et al., 2010; Stergiou-Kita et al., 2014). All studies included adults between the ages of 20 and 59 years and the majority (80%) of participants were male. Between 24% and 100% of burn injuries were work-related. The mean percentage total burn surface area (TBSA) of burn injuries was recorded by Johnson and colleagues (2016), Lamble and colleagues (2019), and Öster and colleagues (2010) and ranged from 14.3% to 29%. Five studies reported time since injury, which ranged from two months to over 10 years (Lamble et al., 2019; Mansfield et al., 2014; Nguyen et al., 2016; Öster et al., 2010; Stergiou-Kita et al., 2014). These studies also reported the percentage of participants who returned to work as ranging from 65% to 85%. Participants returned to various employment fields in differing capacities as outlined in Table 3.

Study quality

All six studies were considered high quality and were included (Public Health Resource Unit, 2002). In Section A, five studies scored 'Yes' for five of the six questions corresponding to high validity of results (Johnson et al., 2016; Lamble et al., 2019; Mansfield et al., 2014; Nguyen et al., 2016; Stergiou-Kita et al., 2014). The only weakness was lack of consideration of the researcher–participant relationship. The exception was Öster et al. (2011), who employed a neutral interviewer to minimise the influence of pre-existing assumptions during interviews, therefore scoring 'Yes' for all six questions. All six studies scored 'Yes' to all six questions in Section B, corresponding to appropriate reporting of results. In Section C, all included studies were determined to be valuable, therefore having high external validity.

Thematic synthesis

Five analytic themes were identified through thematic synthesis: 1) Addressing the complex impact of burn injury; 2) personal connections as vital support; 3) skilled and specialised healthcare as central to RTW; 4) value of knowledge; and 5) considering the work environment. Each theme contained several sub-themes, which are outlined in Figure 2. While Figure 2 displays all synthesised data, the following results outline key information relevant to burn injury support only. Excluded data did not describe factors specific to support to RTW, such as barriers to RTW or encompassed information less relevant to burns support clinicians such as union or financial supports. Note that the themes described below are analytic themes that were developed as the next step on from descriptive themes, in order to specifically address the need for key clinical information. We have comprehensively referenced the original studies that contributed data to each aspect, but have not included specific quotes. The themes are constructed across multiple studies, and multiple points of references within those studies, and the nature of analytic themes is that they aim to "go beyond" (Thomas & Harden, 2008, p. 7) the findings of the primary studies – key to the original contribution of a synthesis such as this.

Theme 1: Addressing the complex impact of burn injury

1.1. Potential for complex impairments. Burn injuries resulted in various physical, cognitive and psychosocial impairments leading to functional limitations and difficulty performing work tasks (Lamble et al., 2019; Mansfield et al., 2014; Nguyen et al., 2016). Recovery timeframes, and therefore RTW, varied depending on the nature and degree of the injury and resulting impairments. Some physical impairments may be short-term, such as muscle weakness, while others, like muscle contractures, remained long after discharge, significantly inhibiting RTW for study participants (Mansfield et al., 2014; Öster et al., 2010; Stergiou-Kita et al., 2014). Recovery from less-visible psychological challenges, such as post-traumatic stress disorder (PTSD), was reported to take longer than recovery from physical impairments (Johnson et al., 2016).

The impact of different types of burn injuries also varied. Electrical burn injuries may cause invisible, severe, persistent impairments with additional cognitive challenges such concentration and memory issues that further complicate recovery (Mansfield et al., 2014; Stergiou-Kita et al., 2014). Impairments needed to be considered at an individual level, which meant that RTW could not be a standardised process or timeframe.

Table 3

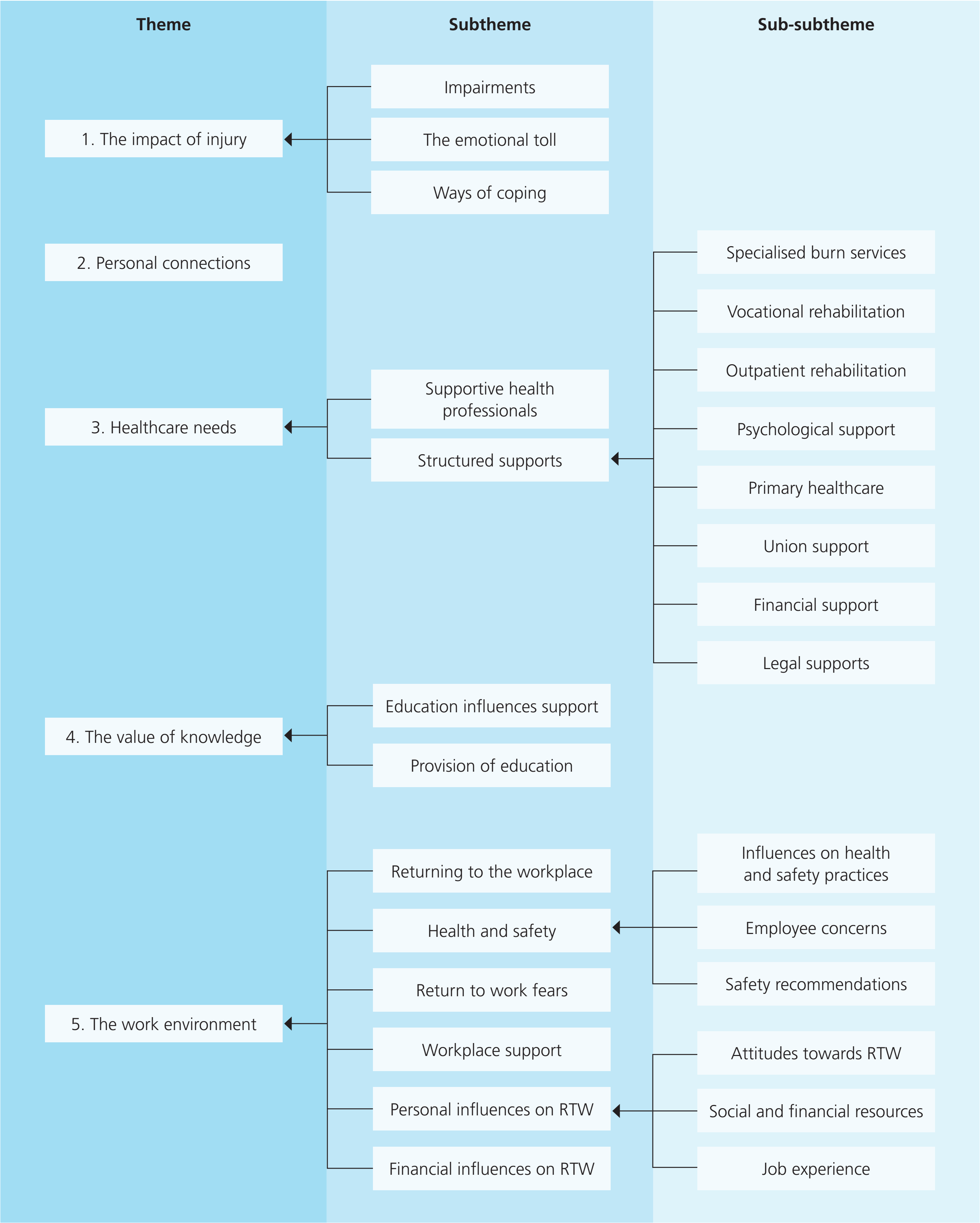
Participant Characteristics from Included Studies

Characteristic	Study					
	Öster et al. (2010)	Johnson et al. (2016)	Mansfield et al. (2014)	Stergiou-Kita et al. (2014)	Lamble et al. (2019)	Nguyen et al. (2016)
Age (years)	Mean, 39.7	Mean, 37.4	Range, 20–59	Range, 20–59	Mean, 42.5	Mean, 44.5
Mean TBSA (%)	29	25	Not reported	Not reported	14.3	Not reported
Sex (% male)	74	73	92	92	83	65
Work-related injuries	41	64	100	100	24	25
Time post injury (years)	Mean, 4.6 years	Not reported	Range, 1–9 years	Range, 1–9 years	< 1 year, 10% 1–3 years, 52% 3–5 years, 10% 5–7 years, 21% 7–10 years, 3% > 10 years, 3%	Range, 2 months–5 years < 1 year, 15% 1–2 years, 40% 2–3 years, 25% > 3 years, 20%
Employment field	Not reported	Skilled trade, 27% Manual labour, 18% Administration, 9% Disability pension, 18% Agriculture, 9% Hospitality, 9% Truck driver, 9%	Skilled trade, 62% Survey technician, 8% Information technology, 8% Laundry, 8% Engineer, 15%	Skilled trade, 62% Survey technician, 8% Information technology, 8% Laundry, 8% Engineer, 15%	Not reported	Skilled trade, 25% Manual labour, 15% Administration, 15% Education, 5% Service/marketing and sales, 20% Mining, 5% Healthcare and social services, 15%
Employment status post injury	Employed, 77% Student, 3% Sick leave, 15% Disability pension, 8%	Not reported	Employed, 85%	Employed, 85%	Employed, 99%	Employed, 65%

Note. TBSA = total body surface area.

Figure 2

Themes from Thematic Synthesis



Note. RTW = return to work.

1.2. Emotional toll. Emotional trauma experienced by some people with burn injury worsened RTW stress (Johnson et al., 2016; Lamble et al., 2019). Emotional challenges included feelings of dejection, fear, frustration and appearance-related self-consciousness (Johnson et al., 2016; Lamble et al., 2019). Questions about the injury or changes in appearance reminded people of their accident, causing added discomfort (Lamble et al., 2019). It was important that others supporting people who had experienced burn injury considered the added emotional impact of injury. Burn injury may cause identity challenges as people lose a degree of control over their lives after injury (Johnson et al., 2016). Specifically, job changes could elicit occupational grieving due to the relationship between career and identity (Nguyen et al., 2016). Identity challenges linked to career changes add to the emotional toll of injury, inhibiting RTW (Nguyen et al., 2016)

1.3. Supporting coping. Support to facilitate RTW often involved more wide-ranging support for people to cope with emotional trauma, fears and identity concerns. People with burn injury experiencing emotional trauma appreciated psychological assistance and additional time to reflect and process injury events (Johnson et al., 2016; Lamble et al., 2019; Stergiou-Kita et al., 2014). Practical solutions like involvement in self-care and finding novel ways of completing tasks were experienced to further enhance recovery through facilitation of independence (Johnson et al., 2016; Öster et al., 2010).

People with burn injury needed to confront re-injury fears as a way of coping with lasting emotional trauma, especially following workplace accidents (Öster et al., 2010). Returning to the injury-site was one way of confronting and overcoming one's fears (Nguyen et al., 2016). Effective coping strategies can help people with burn injury to manage emotional stressors throughout the RTW journey.

Theme 2: Personal connections as vital support

Relationships with compassionate and understanding family members, friends, employers, colleagues and other people with burn injury were reported to provide crucial informal support (Johnson et al., 2016; Lamble et al., 2019; Mansfield et al., 2014; Nguyen et al., 2016; Öster et al., 2010; Stergiou-Kita et al., 2014). Informal support networks provided comfort, distraction, motivation and practical assistance, which facilitated RTW (Johnson et al., 2016; Lamble et al., 2019; Mansfield et al., 2014; Öster et al., 2010).

Theme 3: Skilled and specialised healthcare as central to RTW

3.1. Supportive, skilled health professionals. Supportive, motivating and emotionally invested health professionals were experienced as facilitators of RTW (Lamble et al., 2019; Mansfield et al., 2014; Öster et al., 2010). There were multiple elements to this experience: healthcare providers needed to recognise each person's unique injury and refer those experiencing ongoing symptoms for further treatment (Stergiou-Kita et al., 2014). Studies also indicated that health professionals should advocate for their patients while also providing self-advocacy strategies (Mansfield et al., 2014; Stergiou-Kita et al., 2014). Self-advocacy skills could empower people with burn injury to take greater control of their rehabilitation and have the confidence to request further support if required (Stergiou-Kita et al., 2014). This facilitates people to take charge of their recovery journey, working towards RTW.

3.2. Structured supports that recognise vocational needs

Specialised burn services. Specialised services with expert healthcare professionals were seen to provide the most appropriate care following burn injury, improving RTW outcomes (Mansfield et al., 2014; Stergiou-Kita et al., 2014).

Deliberate, structured vocational rehabilitation. Structured VR facilitated RTW through job-task analysis, expert work-adaptation recommendations and work-readiness assessments (Lamble et al., 2019; Öster et al., 2010; Stergiou-Kita et al., 2014). Establishing work-readiness was considered an essential part of VR and the RTW process, indicating that comprehensive, burn-injury-specific resources for assessing and addressing work-readiness are needed to enable successful RTW (Öster et al., 2010).

VR that was reported to be successful facilitated effective communication between the person with burn injury, their family, workplace and healthcare team (Lamble et al., 2019; Mansfield et al., 2014; Nguyen et al., 2016; Öster et al., 2010; Stergiou-Kita et al., 2014). A comprehensive VR MDT was considered vital, including VR coordinators who can problem-solve VR issues from the initial injury to RTW (Öster et al., 2010). Co-ordinated VR can enable a smoother RTW transition. Synthesised, the qualitative evidence indicated that early engagement in vocational conversations is beneficial, which can begin with the acute MDT and carry on into the community setting.

Participation-focused outpatient rehabilitation. Early rehabilitation was considered necessary to help people with burn injury regain adequate function required for activities of both daily living and work tasks. Helpful post-discharge physiotherapy rehabilitation involved task-related strength and endurance training (Lamble et al., 2019; Öster et al., 2010). Individualised training and goal setting was reported to elicit functional improvements, which facilitated RTW (Lamble et al., 2019; Öster et al., 2010). Shifting the focus from impairments to activities and participation during rehabilitation optimised subjective quality of life in the longer term (Lamble et al., 2019).

Psychological support. Formal psychological support was recommended, with studies indicating it should be offered to all people with burn injury through routine, early initiation of psychological screening and referrals (Johnson et al., 2016; Lamble et al., 2019; Öster et al., 2010; Stergiou-Kita et al., 2014). As illustrated in prior themes, people with burn injury often experience psychological challenges; therefore, appropriate psychological support is necessary to facilitate recovery and RTW.

Theme 4: The value of knowledge

4.1. Education influences support. People with burn injury were reported to feel better supported by those with burn injury knowledge (Lamble et al., 2019; Nguyen et al., 2016; Öster et al., 2010; Stergiou-Kita et al., 2014). People with burn injury could more effectively communicate their needs when others understood their injury experience (Lamble et al., 2019; Nguyen et al., 2016). Appropriate education enabled people with burn injury to RTW with reduced anxiety about workplace interactions (Lamble et al., 2019). Examples of beneficial education included describing a major burn injury, the pressure garments and adaptive equipment used to treat scars, and the rehabilitation process (Lamble et al., 2019). Uninformed employers were felt to be more likely to pressure people to prematurely return to previous tasks (Lamble et al., 2019; Nguyen et al., 2016; Öster et al., 2010; Stergiou-Kita et al., 2014). In particular, electrical injuries are often misunderstood and not legitimised by employers, work colleagues and insurance providers due to the invisible sequalae of injury (Mansfield et al., 2014; Stergiou-Kita et al., 2014). Therefore, specific information should be provided to improve support received.

4.2. Provision of education. Studies supported the provision of education to the person with burn injury, their workplace and family and friends using a flexible, personalised and accessible information tool (Lamble et al., 2019; Nguyen et al., 2016). Education about the roles of various health professionals helped people with burn injury to better direct their RTW queries (Lamble et al., 2019). Explaining the healing and rehabilitation process provided people with burn injury with the knowledge and terminology to discuss their condition (Lamble et al., 2019). Provision of additional social interaction strategies assists with workplace reintegration (Nguyen et al., 2016).

Workplace education about possible physical impairments should include solutions to overcome these barriers (Mansfield et al., 2014; Nguyen et al., 2016). Inclusion of testimonies of previous burn injury RTW successes may be useful (Mansfield et al., 2014; Nguyen et al., 2016). Informative workplace conversations facilitate increased understanding of the worker's journey and their needs, and help to justify required accommodations (Mansfield et al., 2014; Nguyen et al., 2016).

Theme 5: Considering the work environment

5.1. Benefits of returning to the workplace. As well as practical issues such as financial needs, is important to consider the therapeutic benefits of returning to work (Johnson et al., 2016; Lamble et al., 2019; Nguyen et al., 2016). Working was reported to elicit improvements in both function and self-esteem while providing structure and routine (Lamble et al., 2019; Nguyen et al., 2016; Öster et al., 2010).

5.2. RTW Fears. The RTW process may create fear and anxiety among people with burn injury, where they experience an enduring sense of vulnerability due to re-injury or unemployment fears (Johnson et al., 2016; Lamble et al., 2019; Mansfield et al., 2014; Stergiou-Kita et al., 2014). This could further impede RTW. Work-related injuries have been correlated with increased RTW stress; therefore, people returning to work after burn injury may require increased emotional support (Johnson et al., 2016; Stergiou-Kita et al., 2014). Furthermore, while initiating VR was considered appropriate quite early in the rehabilitation process, the timing of RTW was discussed as an important issue to be carefully considered. Sometimes the timing of RTW could create added stress, as people with burn injury experienced pressure to RTW before they were ready (Lamble et al., 2019; Stergiou-Kita et al., 2014). Premature RTW can cause added job-performance anxiety and fear of losing one's professional reputation, while also triggering symptoms of PTSD (Lamble et al., 2019; Stergiou-Kita et al., 2014).

5.3. Workplace support. RTW was facilitated when people with burn injury returned to supportive work environments with task modifications and assistance from colleagues (Lamble et al., 2019; Mansfield et al., 2014; Nguyen et al., 2016; Öster et al., 2010). Flexible, progressive RTW enabled people with burn injury to engage in rehabilitation while maintaining employment, further facilitating work reintegration (Johnson et al., 2016; Lamble et al., 2019; Mansfield et al., 2014; Nguyen et al., 2016; Öster et al., 2010).

DISCUSSION

Theme one in this review has highlighted the emotional impact of burn injury and its effect on RTW. Perceived outcome following burn injury comprises both physical impairments and the psychosocial impact of injury (Kildal et al., 2005). Fear of re-injury was highlighted in the present review as a catalyst for anxiety and the potential to delay RTW. This fear has been reported to be one of the strongest predictors of delayed RTW (Bunzli et al., 2017). Emotional support has been highlighted within burns literature as an effective coping strategy (Kildal et al., 2005). Furthermore, the psychosocial benefits of RTW in itself are well described in VR literature (Bunzli et al., 2017). The present review supports informal support from family, friends, employers, colleagues and other people with burn injury who likely provide this crucial emotional support. The therapeutic benefits of returning to work were also highlighted in the present review.

Theme three identified a need for formal psychological intervention following burn injury due to the psychological and emotional impact of injury. Literature has shown the benefits of psychological treatment on symptoms, clinical outcomes and quality of life (Waddell et al., 2008). Finnes and colleagues (2019) evaluated the effect of psychological treatment on sickness absence among individuals with common mental or musculoskeletal disorders. The authors identified a reduction in sickness absence; however, specific effective treatment modalities were not identified (Finnes et al., 2019). As stress disorders and depression are prevalent following burn injury, formal psychological support for people with burn injury could be equally successful in reducing RTW time (Dalal et al., 2010).

This review outlined the importance of specialised, structured VR that includes work environment and/or job accommodation and effective communication between the workplace, the injured person and healthcare providers. Research with musculoskeletal and chronic condition populations supports structured VR programmes, improved communication and work adaptations (Franche et al., 2005; Waddell et al., 2008; Welsh Assembly Government, 2006). Temporary work accommodations facilitate early return to appropriate tasks, allowing for a gradual transition to previous work demands (Waddell et al., 2008)**.** Additionally, as no single service can deliver effective VR alone, increased communication between RTW parties provides workers with more successful, coordinated care (Waddell et al., 2008).

VR components are discussed extensively in literature, particularly within chronic condition populations (de Buck et al., 2002; Waddell et al., 2008; Welsh Assembly Government, 2006). Effective components include physical training, skills training, employment placement, personalised education and action plans, counselling, guidance and group meetings involving education, exercise and peer support (de Buck et al., 2002; Waddell et al., 2008; Welsh Assembly Government, 2006). Outpatient follow-up was highlighted in this review as an appropriate setting to deliver these key components. In the New Zealand setting, specialist VR providers may also be involved. RTW support for people with burn injury should consider inclusion of these elements, and clear communication between the various rehabilitation providers even when there is specialist VR provision, as research has highlighted the importance of coordinated care.

The value of knowledge and therefore the importance of appropriate education was another prevalent finding identified in theme four. Lamble and colleagues (2019) offered a possible method of delivering education. In this study, participants viewed six videos addressing various aspects of burn injuries, the recovery process and RTW. The participants then had the opportunity to show these videos to family, friends, employers and colleagues. An occupational therapist was also available to answer questions and discuss appropriate work tasks and potential adaptations (Lamble et al., 2019). While Lamble and colleagues' (2019) quantitative results were not significant, participants in this study identified the need for workplace education to enable progressive, safe RTW. Education remains a key component of successful VR among a variety of non-burn injury populations (Waddell et al., 2008). As public knowledge of burn injury rehabilitation is limited, workplaces are often not prepared for workers' specific needs in regard to job-task modifications, rehabilitation engagement and progressive RTW. Our review findings confirm that educated workplaces are experienced as more supportive during RTW. Additionally, people with burn injury who are educated are more likely to self-advocate (Lamble et al., 2019; Mansfield et al., 2014). Therefore, comprehensive education should be provided to all stakeholders.

This review identified that people with burn injury require a wealth of formal and informal support that facilitate RTW, outlined in themes two and four. Similarities can be seen in RTW literature in other injury populations. For example, Murphy and O'Hare (2011) found workplace-based social support as key in facilitating RTW after spinal cord injury. Workplace social support provides a welcoming environment, enhancing comfort and motivation (Murphy & O'Hare, 2011). Health professionals should ensure people with burn injury receive adequate social support, either within or outside the workplace, and consider facilitating peer-support groups as part of VR (Grieve et al., 2020).

Review strengths and limitations

A key strength of this review was the rigour of the process, including independent screening and critique of all articles. Other strengths included following a pre-established process that outlined inclusion and exclusion criteria and analysis approach, and that we included recently published studies, ensuring relevance to the current system and climate.

The review was limited by lack of available research within the burn injury population. Authors were unable to address the return to meaningful activity aspect of the research question, due to absence of literature. The findings could also be limited by the search parameters. A limited number of databases were searched, and it is possible some key studies were not indexed in the selected databases. Finally, because we elected to resolve differences in reviewer decisions by discussion processes and all differences were quickly resolved in this way, we do not have data on initial inter-rater agreement.

A major limitation in application of the review findings to the local context was that no New Zealand burn injury studies were identified for inclusion. Furthermore, most participants were Caucasian, with very few Indigenous participants. As Māori are overrepresented in New Zealand burn statistics, it is important to examine the specific considerations required when supporting this population to RTW following burn injury (Tracy et al., 2019). Lack of Indigenous participants and methodologies makes it even more important to have further development in partnership with Māori as part of implementation of the recommendations from overseas research within an Aotearoa New Zealand context.

Clinical implications

Physiotherapists involved with burn injury rehabilitation should consider all aspects of this review to better understand the experiences and specialised needs of people who have experienced burn injury. Key clinical implications include referrals from the acute hospital setting to ensure early outpatient follow-up and provision of specialised VR and comprehensive education. Physiotherapists should consider referrals to ACC VR programmes alongside providing outpatient follow-up. Additionally, physiotherapists need to be aware of the importance of psychology input, ensuring appropriate referrals are made and psychology input is provided. Outpatient rehabilitation should include personalised, task-specific training. As part of the VR MDT, specialist physiotherapists must provide work adaptation recommendations and contribute to work-readiness training and assessment. Physiotherapists should provide detailed burn injury and RTW education to patients as well as workplace education as a part of VR. Physiotherapists as part of the VR MDT need to provide co-ordinated VR including effective communication between VR clinicians and the workplace.

Recommendations for future research

This review highlighted the lack of research addressing RTW support within the burn injury population. The importance of education was evident; however, an effective, standardised delivery tool still requires development. Building upon the findings of Lamble and colleagues (2019), future research should look to develop this tool with appropriate burn injury and RTW content discussed in the present review, considering video as an effective modality. Future research could assess current support provided by New Zealand burns units by gaining the perspectives of specialised health professionals and ACC representatives. This research should address considerations for Māori with burn injury.

CONCLUSION

The present review has highlighted the complex nature of burn injury recovery with impairments that are not only physical but also psychological and emotional. Despite common RTW fears, RTW should be encouraged due to clear therapeutic benefits. Successful RTW should involve support from specialised, supportive health professionals through facilitation of structured VR, communication and collaboration between all involved parties, outpatient rehabilitation, workplace support, psychological support, comprehensive education and informal social support. Support that facilitates return to meaningful activity following burn injury remains unclear.

KEY POINTS

1. Both physical impairment and emotional trauma affect work-ability and return to work (RTW) after burn injury.
2. Knowledge of common experiences regarding impact of injury can assist clinicians, employers and people experiencing injury to facilitate a successful RTW.
3. Vocational rehabilitation after burn injury needs to be specialised to the burn injury experience while acknowledging core principles of vocational rehabilitation more generally.
4. Vocational rehabilitation intervention should span burn care settings from acute to community, making physiotherapists vital personnel when it comes to both support and education.

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PERMISSIONS

No permissions were required.

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Experiences and Perceived Effectiveness of Carbon-fibre Triplanar Orthotics for People Affected by Polio: A Qualitative Descriptive Study

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ABSTRACT

A new type of carbon-fibre triplanar orthotic (CTO) was recently introduced to New Zealanders affected by polio. This study aimed to assess CTO recipients' experiences and perceptions of these orthotics. A qualitative descriptive study based on semi-structured interviews was conducted to explore experiences of people who have had polio regarding the impact of CTOs on health and wellbeing, the process of training and adjustment, and how benefits from the CTOs were or were not achieved. Participants described substantial investments of time, energy and money needed to acquire and adapt to CTOs (Theme 1). They expected the CTOs to improve their posture, mobility, relieve pain and prevent deterioration in functioning. However, frequently there was a mismatch between reality and expectations (Theme 2). Ongoing orthotic and rehabilitation support plus sustained commitment and effort by CTO recipients contributed to benefits gained from these orthotics (Theme 3). When considering purchase of a CTO, people who have had polio should be aware of the time, energy, effort and personal cost required to fully benefit from the new orthotic. They should also be aware that individual responses to orthotics, including subjective reports of success, can be highly variable.

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Key Words: Orthotics, Poliomyelitis, Post-polio syndrome, Qualitative Research, Rehabilitation

INTRODUCTION

There is currently an estimated 9,750 people in New Zealand living with the effects of polio (Jones et al., 2016; Jones et al., 2017). Polio (also called poliomyelitis) is a highly infectious viral disease that devastated communities worldwide in the first half of the 1900s (Smallman-Raynor & Cliff, 2006). New Zealand was no exception to this pandemic, with polio resulting in hundreds of deaths and long-term neuromuscular disabilities in the many thousands of people who survived the initial infection (Butterworth & Ross, 1994; Ross, 1993; Wilson & Baker, 2012). In addition, approximately 40% of those initially infected with polio went on to develop post-polio syndrome (Lin & Lim, 2005). Post-polio syndrome is characterised by the onset of new or worsening muscle weakness 30–40 years after the original polio attack, resulting in new or exacerbated disabilities. Currently, many thousands of New Zealanders experience mobility restrictions, joint contracture, shortness of breath and problems with sleep, fatigue and pain due to both the original impairments sustained during polio in their youth and/or as a consequence of post-polio syndrome, or as a result of living with a long-term disability (Chetwynd et al., 1993; McNalley et al., 2015).

It is difficult to establish the exact number of polio survivors in New Zealand because there is no formal record for this. Many people who survived polio just returned to their prior lives after recovering from the initial infection, managing their muscle impairments, joint problems and breathing difficulties independently, and "rarely spoke again of those polio years" (Morris, 2013, p. 1). Polio survivors became increasingly forgotten by the New Zealand health system after the successful introduction of a vaccine in the 1950s (Stewart, 2015).

One of the key needs in New Zealand's polio community today is for specialist orthotic services (Jackman, 2016, 2017). People who have had polio may have idiosyncratic muscle impairments in their lower limbs, contributing to a variety of problems with mobility-related activities such as walking short and long distances, climbing stairs and performing various activities of daily living (Farbu, 2010). Musculoskeletal changes following polio and post-polio syndrome are different than those experienced by people with other types of neurological conditions, such as stroke or multiple sclerosis, so require different solutions to optimise physical functioning (Genêt et al., 2010; Portnoy & Schwartz, 2013).

The standard type of orthotic for people who have had polio in New Zealand is made of metal or solid plastic, can be ill-fitting and uncomfortable, and is limited in the assistance it provides during walking (Jackman, 2016). These types of orthotics are primarily designed to help prevent hyper-extension during the stance phase of gait and foot drop during the swing phase. However, they do not correct the many other problems with joint alignment experienced by people who have had polio – particularly issues of inversion and eversion at the ankle or internal rotation at the knee – and can be uncomfortable for some to wear. In 2018, in response to these challenges, people who have had polio in New Zealand began exploring options for accessing a new type of carbon-fibre triplanar orthotic (CTO) provided by orthotists outside of New Zealand. These new orthotics used carbon-fibre materials to provide lightweight, dynamic support in three dimensions of movement (flexion/extension; inversion/eversion; internal/external rotation) and were promoted as having the potential to dramatically improve a person's functional abilities, reduce falls, reduce pain and discomfort, and reduce energy consumption during movement. The Duncan Foundation (a New Zealand registered charity for people living with neuromuscular conditions) began supporting individuals with polio to consider use of these new types of orthotics. They also began providing funding to support the physiotherapy required after people were fitted with a CTO. However, these CTOs still required a significant financial investment for people who have had polio, since funding for the orthotics was not (and still is not) available through New Zealand's health system, nor could they be funded by private insurance companies. Therefore, there was a need to gather information on the effectiveness of these new orthotics to inform decisions about whether to invest in them.

There are several challenges with undertaking research in this area of clinical practice. First, the population of people who might benefit from these CTOs is relatively small, with a high degree of heterogeneity in their presenting impairments, making it difficult to standardise interventions for research purposes and making randomised controlled trial methods unsuitable. Second, because little research has previously been conducted in this area of clinical practice, there is very little information about what types of standardised outcomes measures would best detect improvements that might be meaningful to the people receiving the orthotics. Third, there is little information beyond anecdotal reports on optimal preparatory and follow-up physiotherapy that is required for people to benefit fully from these CTOs. As such, we conducted an initial qualitative study to explore the experiences and perceptions of people affected by polio and who had received CTOs, regarding: 1) the impact of CTOs on their health and wellbeing; 2) the process of adjustment when learning to live with CTOs, including reflections on both the formal (e.g., provided by health professionals) and informal (e.g., learning from experience) aspects of the adjustment process; and 3) the possible mechanisms of effect regarding how CTOs achieved or did not achieve positive health effects.

METHODS

Research design

We conducted a qualitative descriptive study, influenced by grounded theory methods (Charmaz, 2014), to gather data from people affected by polio who had been recently fitted with a CTO. Ethical approval for this study was granted by the University of Otago Human Ethics Committee (Health) (reference number H19/021). The research team comprised one person with lived experience of paralytic polio and post-polio syndrome in New Zealand (AF, female, Pākehā) and two research physiotherapists with extensive experience of qualitative methods (WL, male, Pākehā and RM, female, Pākehā).

Participant recruitment

To be included in this study, participants needed to be adults diagnosed with polio, who had been fitted with a CTO within the past two years. The Duncan Foundation contacted recipients of the CTOs to elicit their willingness to participate in the study. At the time of the study (May 2019 to January 2020) only 10 people who have had polio in New Zealand had received a CTO. This study collected data from people who had already received their CTO and did not influence the way that CTOs were assessed or provided or how ongoing follow-up was delivered.

Data collection

Semi-structured interviews were conducted by one researcher (AF) via videoconference. The initial interview questions were developed by two researchers (AF and WL) based on issues raised in a prior survey on orthotic experiences of Polio NZ members (Jackman, 2016) and on the lived experience of one of the researchers (AF) (see Appendix A). We sent questions to the participants in advance so they could prepare for the interview. Interviews lasted between 60 and 90 min, with one participant electing to provide written answers only. All interviews were digitally recorded and transcribed verbatim. We also collected demographic data including gender, age, ethnicity, age of onset of polio, limbs affected by polio, and orthotic and mobility aids used prior to the new CTO. We sought quantitative data on mobility before and after fitting of the orthotics (e.g., walking speed, endurance, balance) but this had not been routinely collected for all participants using standardised measurement methods so was not available for reporting.

Data analysis

We used NVivo 12 (QSR International) software to facilitate analysis and management of qualitative data. We used constant comparative methods to analyse the data (Charmaz, 2014). We read and reread each transcript, incorporating findings from additional data as the study progressed. We conducted initial data coding (open coding) on a line-by-line basis with subsequent analysis exploring relationships between codes to develop higher-order concepts. We did not have enough eligible participants to permit theoretical sampling or to test assumptions about reaching data saturation, so a full grounded theory study was not possible.

One researcher (AF) undertook initial analysis of all data, discussing and peer reviewing the data with a second researcher (WL) as the study progressed. A third researcher (RM) independently read and coded all data to further enrich the range of interpretations of the dataset. The whole research team was involved in the development of the final analysis, which was reached by consensus. To further strengthen the credibility and trustworthiness of this analysis, we provided participants with a summary of findings and presented preliminary (anonymised) findings as a presentation at a national polio conference in New Zealand on 18 October 2019. Feedback during and following this conference supported the direction of the analysis and the conclusions we had reached.

RESULTS

Participants

Eight out of 10 people (six men, two women; age range 55 to 77 years) who had received CTOs agreed to be interviewed. One declined because he was unable to use the CTO for health reasons unrelated to the orthotic. The other person declining did not provide a reason. Five participants had single CTOs and three participants had bilateral CTOs. We interviewed the participants 2 to 20 months following their CTO being fitted. Seven participants used orthotics (callipers or standard-issue ankle-foot orthosis) prior to CTO provision. Three participants lived in a city, three lived in a provincial town and two participants lived rurally (Table 1).

Table 1

*Participant Characteristics (*N *= 8)*

Age	Mean: 67.9 (range 55–77) years
Gender	Male: *n* = 6 Female: *n* = 2
Ethnicity	New Zealand European: *n* = 6 Māori: *n* = 2
Type of CTO	Single ankle-foot orthosis: *n* = 4 Bilateral ankle-foot orthoses: *n* = 2 Single knee-ankle-foot orthosis: *n* = 1 Bilateral knee-ankle-foot orthoses: *n* = 1
Time since CTO fitted	Mean: 13 (range 2–20) months

Note. CTO = carbon-fibre triplanar orthotic.

Overview of findings

The impact of CTOs on participants' health and wellbeing varied greatly, with some participants describing the impact as being positively "life changing" (Participant [P]3), while others described the CTOs as being "ill advised, [a] waste of time and an expensive nonsense" (P2). For those participants who had experienced improvements in their functioning, the CTO allowed them to participate more fully in valued activities and life roles and had a positive impact on their wellbeing: "The period of time I can stand for in the brace is pretty much limitless … it gives you a level of comfort and confidence that I never used to have" (P7).

However, of the eight participants, only one was using his CTO for most of his daily functioning, five were using their CTOs for part of their daily functioning and two were not using their CTOs at all. All participants described the process of adjustment as being both lengthy and energy intensive. At the time of the interview, none of the participants felt they had completed their journey to full use of their new orthotic. Some felt they had made no progress; others that they were about halfway to full adjustment to the orthotic; while most indicated that they were less than halfway. There were a variety of views as to whether CTOs were worth the investment, with several saying it was too early to tell.

Three key themes have been identified from participants' experiences and perceptions of CTO use. The first theme *(Substantial investments)* relates to the investment of time, energy, money and support that was needed to acquire and adapt to the new orthotics. The second theme *(Expectations and reality)* examines the range of expectations that participants had of the difference CTOs would make to their lives and how closely the reality matched their expectations. The third theme *(Contributors to success)* explores factors that appeared to contribute to recipients perceiving that the CTO optimised their health and wellbeing and therefore that their investment had been worthwhile.

Theme 1: Substantial investments

Overall, participants talked about the significant investment of time, energy and money required to purchase and train to use the CTOs, with no guarantee of success. Financially, CTOs were a significant investment with the cost of CTOs varying between NZ$10,000 to NZD$54,000 per person (mean NZD$19,250). Participants funded their CTOs from a variety of sources, including loans from Polio NZ and other philanthropic organisations, via crowdfunding or at personal cost.

> My total investment … [is] in the vicinity of $20,000 is expensive but I look at it from the point of view that if I want to retain my freedom, that's the price. That's what I am going to have to do. (P7)

Additional, usually unforeseen, costs were also incurred. These included costs associated with travel and accommodation for CTO assessments and follow-up appointments, treatment costs to attend physiotherapy sessions, vehicle modifications in response to altered posture or movement patterns, and purchase costs of parallel bars and other mobility equipment such as walking poles to allow the participant to practise using their CTOs. Participants often needed to purchase different footwear because the CTO would not fit in their existing shoes. Different size shoes were often required for each foot.

> We had to buy shoes about five sizes too big because to get the width you have to go up in shoe size … and it's compounded because you only need it on one leg and not on the other. (P8)

If the CTO was worn underneath participants' clothing, trousers also needed to be replaced to accommodate the CTO.

Physically preparing to get the CTOs and then learning to use them required a considerable investment of time and effort. Participants needed to undertake a daily stretching regime to improve their range of movement. They also needed to learn to stand and walk with new postures and movement patterns before they could use the CTOs functionally: "You've got to basically change your whole way of walking which you've been doing all your life, and you've got to change that, and it's a pretty difficult task" (P8).

Many began by putting their new orthotics on for just an hour every second day, increasing their duration and frequency of practice over time. Some participants ended up training several times each day: "When I got home, about four times a day I would get into my braces and just stand there between the parallel bars, initially just standing there and then starting to move my hips" (P3).

Donning and doffing the CTOs also took more time than previous orthotics, although participants reported that this became quicker with practice. Some participants reported that regular daily practice with the orthotic was not possible due to the time required to put on the CTO.

> I should be spending more time but when I put them on I usually have them on for about an hour and I have tried to put them on the weekend because that's the only time when I've really got time to focus on them. (P1)

A particularly vexing issue for participants was the need to slowly adapt to using the CTO while also needing to continue to use their previous orthotics to participate in daily tasks. When they reverted to using their old orthotics, it was challenging to return to the movement patterns they used to function at previous levels.

The extensive practice and associated concentration required to learn to use the CTO also involved a considerable investment of mental and emotional energy. Many participants reported that the demands of adjusting to the new orthotics could lead them to feeling exhausted, discouraged and even despairing: "Coping with that feeling of despair is the thing I would say everyone is going through and I certainly had to deal with" (P3).

Theme 2: Expectations and reality

In this second theme, we explore the impact of CTOs on participants' ability to undertake a range of functions and how closely reality matched their expectations. Participants had a variety of expectations of the difference CTOs would make to their lives. Reasons given for wanting to change to CTOs included factors related to improved postural alignment (i.e., standing straighter, preventing further deformation), improved mobility (i.e., improved walking, reduced falling), improved functioning (i.e., looking after self, having the opportunity to do things not previously able to do), relieving pain (i.e., by reducing the load on specific joints or surfaces) and preventing deterioration in functioning (i.e., being able to stay out of a wheelchair, retaining ability to mobilise independently and keeping active in the community for longer). Other reasons for transitioning to CTOs included getting an orthotic that was stronger and less likely to break.

> It was all about keeping me active and able to look after myself as I get older and also of course if I could walk better, you know that was the biggie. I mean you know if I could improve my walking and which of course I was limping more and more heavily as my legs deteriorated. (P6)

Postural alignment and standing

While not identified as being a key reason for wanting to transition to CTO use, improved postural alignment and endurance while standing emerged as one area in which participants noticed improvements. The CTOs appeared to contribute to the participants feeling they were able to stand with less effort for more extended periods, with improved postural alignment and with greater stability. This allowed participants to stand and converse with people more easily, which many participants reported was a significant benefit: "Before when I was talking with people I was looking around after about 5 minutes for someone to hang on to, but now I can just stand there for like half an hour and it's perfect" (P4).

Partners and other family members commented on how much straighter and/or taller the participant was standing. This ability to stand for more extended periods with less effort allowed participants to participate in activities and roles that were meaningful for them and had a positive impact on their wellbeing.

Mobility

Improved walking was a fundamental expectation held by many participants. One participant (P4) reported that he could now walk double the distance that he had been able to before transitioning to the CTO. Another recipient described the positive difference in his walking and that moving had become "amazingly different and wonderful" (P3). However, many of the participants reported that while they had mastered walking on the flat or uphill without too much difficulty, they struggled with downhill, cambers and uneven ground.

> It's fine going up a rise but going down a rise is dreadful. So, when I go to town, I've [still] got a crutch in the car and if I'm going to town to shop, I take the crutch with me. (P6)

Pain

Relieving pain was another key expectation that participants had of transitioning to using a CTO. Again, there were mixed responses as to whether CTO use impacted on participants' experience of pain. For some CTO wearers, their pain levels were reduced when wearing the CTO. For one participant (P3), the CTO had provided relief from the pain he had suffered for most of his life. Another (P1) commented that the pain in his knee and ankle joints had reduced because his ankles were held in fixed positions by the orthotics. However, for some participants, the changed movement patterns required to function while using the CTOs had contributed to the development of new pains in other joints. The participant who had reduced pain in his knees and ankle joints (P1) experienced new discomfort in his hips, for instance. Another reported having problems with his back as a result of wearing the CTO. He explained: "You can't limp with it; you have to walk properly and if I try and walk properly that's when it really hurts" (P2). As such, an increase in pain was an unanticipated reality for some participants, contrary to their expectations.

Functional activities

Another unanticipated reality for some participants was the negative impact that CTO use had on their ability to function within some of their daily activities. While one recipient found that performing activities such as "lifting, reaching up to heights, playing music, painting [were] just a million times better" (P3), many other participants found that the CTOs constrained their ability to undertake activities. While they were able to walk, they felt that the CTO was limiting their ability to undertake activities they had been previously able to do with their old orthotics, such as driving and gardening: "I quite quickly realised that even if I got walking properly on it, it was going to be a way big step down from what I had in terms of function" (P2).

Some mentioned finding it hard to bend down or kneel with the CTO on. Another observed that "as for twisting and turning and climbing ladders and walking on uneven ground, it was impossible" (P2). For other participants, substantial effort and time were needed to get to the point where the CTO did not constrain them. One participant (P6) reported that it had taken nine months of regular practice to get to the point where they could drive with their CTOs and walk around the supermarket without holding on to the trolley.

Theme 3: Contributors to success

Two key factors appeared critical to a successful transition to CTO use for participants: 1) access to ongoing orthotic support to adjust or modify the CTO and 2) access to rehabilitation support to facilitate and receive feedback on their movement retraining. The chances of success were also improved by sustained effort on the part of the recipient – to complete the required stretching exercises and to practise using the CTOs during mobilisation tasks and functional activities.

Ongoing orthotic and rehabilitation support

The importance of being able to access appropriate orthotic and rehabilitation support before and after the provision of the CTO was evident across all respondents, especially when this support was offered collaboratively and the clinicians worked together to solve problems.

> [The local orthotist] has been with [CTO provider], he's been making them over here for [the CTO provider]; we've seen him a couple of times. [The physiotherapist] would bring [the local orthotist] across to assess me to see if she was doing [it] right you know. The whole thing's a big learning curve even for the hospital as well. (P4)

Equity of access was related to the physical location of the recipient in relation to services, access to orthotic expertise and access to a physiotherapist with neurological rehabilitation expertise on an ongoing basis.

For participants in this study, the CTOs were provided by a supplier who was based outside of New Zealand. Therefore, CTO recipients required support from a New Zealand-based orthotic provider for adjusting the CTOs in response to emerging issues related to fit, comfort, amount of movement and evolving postural changes over time. Publicly funded orthotic services in New Zealand varied in their willingness to assist CTO recipients. This meant there was considerable variation between participants in their ability to access this required ongoing support. One recipient felt that her foot was rolling within her new CTO and her local orthotic service identified a possible cause so could make adjustments. A small number of recipients were able to adjust their own orthotics. Some participants had follow-up video conversations with the US-based CTO provider and, in a few cases, videos of standing and walking were sent for gait retraining feedback.

However, participants felt that more support was required than could be provided via online videoconferencing with the CTO provider. Participants required a qualified person such as a physiotherapist with neurological rehabilitation expertise to train them both before and after the CTO had been provided. Those who did access rehabilitative support before the provision of the CTO frequently reported improvements in postural alignment and strength separate to that provided by the orthotic, with one participant speculating that "now I have strengthened the leg, maybe we could have done away with these dynamic braces" (P4).

Participants also felt that, after the CTO had been provided, regular reviews over time were needed for a successful transition to CTO use. As one participant observed: "there should be someone [who] assesses you every three months to make sure [you're] doing it right" (P1). A small number of recipients were able to access physiotherapy services in their local publicly funded health services. The Duncan Foundation provided limited physiotherapy support to participants who were able to travel to the physiotherapist before and after fitting of the CTO. Others, however, did not have this opportunity and either had to pay for private physiotherapy or manage without any rehabilitative support: "They sort of gave you some suggestions and gave you a bit of assistance … it's very much relying on the individual to actually do the work" (P8).

Participants who did not receive this support were often unsure whether their gait technique was correct and were fearful that they would have to start over again if they made mistakes in their retraining: "What bugs me the most is that there is so much uncertainty. I don't know if I am doing things right" (P5).

One participant (P3) reported having to start again with learning correct movement patterns when the CTO provider gave him feedback that his new walking technique was suboptimal.

Sustained commitment and effort

All participants stressed the need for sustained attention to motor relearning over an extended period.

> The first six months of it is just all about retraining your mind, retraining how you stand, retraining the basic movements and once you've got those down, then I think the development after that comes a lot quicker. (P8)

Participants described that a great deal of self-discipline, perseverance and tenacity was required, stating that "you've really just got to drive yourself to stick with it and do the exercises" (P6). Participants talked about the importance of being "of a mindset to put in that work" (P6) to ensure a successful transition to CTO use. One participant noted that he had underestimated the need to do preparation exercises: "If you do a lot of work training yourself to stand properly before you get this thing, it would be a lot more effective and a lot easier, I think, to adapt to it" (P8).

For some participants, other daily responsibilities and activities made this sustained commitment difficult and, in some cases, unachievable. Some were unable to do the training needed because of their other health conditions. Participants who were in full-time paid employment reported that it was challenging to find the time and energy to practise wearing the new CTO, with one participant (P6) taking a month off work to concentrate on adjusting to the orthotic and another stating that "I put them on [at] the weekend because it is the only time when I really have time to focus on them" (P1).

DISCUSSION

The accounts of participants in this study demonstrate the variability in outcomes that can occur when people who have had polio receive new CTOs. Participants were more likely to find the experience of receiving a CTO worthwhile when they were able to access ongoing orthotic support to adjust or modify the CTO, when they received rehabilitation support to facilitate gait retraining and when they had the time and resources required to access and then learn to use their new orthotics. The chances of success were also improved by sustained effort on the part of CTO recipients.

One prior qualitative study of orthotic use by people with neuromuscular conditions (including some people with experiences of polio) has also highlighted the variability in outcome experiences from new orthotics – ranging from very positive to very negative (McCaughan et al., 2019). This prior study identified that any transition from an old to new orthotic could be challenging, making people reluctant to move to a new orthotic. The new information that our study adds is the extent of structured therapeutic exercise that might be required before any new orthotic is useable – particularly when the new orthotic requires people to relearn movement patterns. For some participants in our study, this additional therapeutic exercise amounted to several hours of self-directed training each week over a period of many months.

These findings highlight the importance of comprehensive assessment and establishing clear expectations when prescribing costly interventions such as CTOs. Assessments before fitting of an orthotic need to focus on more than just the biomechanical aspect of movement but also should consider when and how people will be able to complete all of the movement retraining required to fully benefit from their new orthotics – within the context of their individual supports, resources and daily lives. Exploring people's goals, priorities and anticipated outcomes, while also providing information about potential challenges, is likely to facilitate a more successful transition to CTO use. Potential recipients may benefit from talking to peers who have already had a CTO fitted, as discussion with experienced peers is known to aid informed decision making (Hammell, 2007; O'Neill et al., 2007).

The experiences of participants in this study also indicated how challenging it is for people with long-term health conditions to find and access the health services they need over their lifespan. Some participants in this study reported that the intensive physical training they completed resolved some of the problems with pain and functioning they had been experiencing before even being fitted with the CTO. However, the participants in this study reported that this type of rehabilitation support to meet their ongoing and changing health needs was often not easy for them to access in their usual healthcare services.

We initially started this study as a result of a call from the polio community in New Zealand for more research to be conducted on the cost-effectiveness of orthotics. This study however illustrates several reasons why establishing a strong evidence base in this area is difficult. The population of people who might benefit from CTOs is relatively small for research purposes. Recruitment in clinical trials is notoriously difficult. For instance, almost half of all publicly funded clinical trials in the UK fail to meet their target sample size due to problems with participant recruitment (Walters et al., 2017). Recruitment rates are not just based on the number of people with a condition in a population but also on the eligibility of people to participate when considering exclusion criteria, the willingness of people to enrol in a randomised controlled trial – considering for instance that they may not receive the treatment they are hoping for – the ability of people to get to a clinical centre where a study is being conducted, the timing of the trial for when a person is ready for a particular intervention and so forth. Participant recruitment also must account for dropout rates. For comparison, only one third of stroke survivors who are screened to join clinical trials of stroke rehabilitation are actually recruited, with a median dropout rate of 6% (interquartile range 13%) of the people randomised to treatment groups (McGill et al., 2020). People who have had polio in New Zealand are highly diverse from a clinical perspective, relatively few in number in comparison to other conditions and geographically dispersed, making fully powered clinical trials very difficult to conduct.

As suggested by our study there is a high degree of variability in presentation, both biomedically (e.g., the nature and range of impairments) and psychosocially (e.g., social support, economic wealth, competing priorities, personal goals, attitude and resilience), which impact on an individual's response to CTOs. The orthotic itself is highly unlikely to influence changes in health and wellbeing without extensive additional therapy. The comprehensive additional therapy could itself have a large effect on the health and wellbeing of people who have had polio so would also need to be studied separately. This makes it difficult for the polio community to conduct the kinds of studies that are typically required for a strong economic argument to support new health funding from the public health sector or insurance providers. There is, therefore, a need to embrace 'practice-based evidence pathways' rather than solely 'evidence-based practice pathways' to gather meaningful evidence to support personal decision making and public health policy in this area of clinical practice, as recently advocated by Ogilvie et al. (2020).

Alternative research designs are needed to provide quantitative evidence supporting clinical and policy decision making around the funding of orthotics for people who have had polio. For example, single-case experimental designs (SCEDs) can rigorously demonstrate whether a treatment effect is evident for individual participants, while also exploring the range of responses to interventions (Kratochwill et al., 2013). Synthesised findings from a number of SCEDs can support the development of evidence-based practice by contributing knowledge not only about whether an intervention works in controlled and ideal circumstances but also on how it may work, for the range of people who access it (Shadish et al., 2014). This study suggests that future SCEDs on the topic of new orthotics for people with experience of polio could usefully focus on outcomes related to individually meaningful occupational performance, duration of time in standing per day and health-related quality of life.

Although we invited all potential participants in New Zealand to participate in this study (with only two declining), this study was limited by its small sample size, which reduced the range of experiences and opinions that we could draw on to develop these results. Furthermore, we did not have access to quantitative clinical data on the participants' impairments and functioning before and after receiving their orthotics, making it more difficult to consider the transferability of these findings to other people in other settings.

When considering the data from this study, it is important to be aware of the context in which they were collected. The participants in this study were the first people in New Zealand with polio to receive CTOs. The knowledge gained from these first cases and this study is likely to change the experiences of any people who have had polio who might decide to be fitted with CTOs in the future as they will be better prepared for the experience. Likewise, the experience of people receiving CTOs in other countries may differ depending on the supports and services that they have available to them. These findings will help guide the development of protocols and selection of outcome measures in future research on orthotics for people who have had polio.

CONCLUSION

When considering the purchase of a CTO, people who have had polio need to be aware of the time, energy, effort and personal cost that may be required to fully benefit from the new orthotic. They should also be aware that individual responses to orthotics, including subjective reports of success, can be highly variable. Research questions about the cost-effectiveness of these types of orthotics for people who have had polio are not suitable for randomised controlled trial designs, and other types of research approach, such as SCEDs, may be more useful to guide public policy and personal choice in this area of healthcare.

KEY POINTS

1. There is a high degree of variability among people affected by polio in terms of clinical presentation and responses to new orthotics.
2. When deciding to be fitted with a new, complex orthotic, people affected by polio need to have a thorough understanding of the commitment required in terms of money, time and effort to benefit from that orthotic fully.
3. Learning to use and fully benefit from a new carbon-fibre triplanar orthotic can take years, with ongoing input from orthotists and physiotherapists, so should be planned for when a new orthotic is being considered and fitted.

DISCLOSURES

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PERMISSIONS

Ethical approval was obtained from the University of Otago Human Ethics Committee (Health) (reference number H19/021). All participants provided informed consent.

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Appendix A

INTERVIEW QUESTIONS

1. **Could you please briefly tell me about your experiences of polio to date?**

   Prompts

   When did you get polio; where were you; what happened?

   What parts of your body were affected and in what way?

   How did having polio influence your life?

2. **Could you please tell me about your past experience of orthotic services?**

   Prompts

   What's it been like?

   What kind of orthotics have you worn? For how long?

   How did that make you feel? What do you think about that?

   What operations, if any, have you had to assist you with your mobility?

   What other health services have you used to assist you with your mobility?

   What relationship did you have with your orthotist?

3. **What has been your experience of getting dynamic braces?**

   Prompts

   What led you to decide to get dynamic braces?

   What did you expect it might be like to get dynamic braces?

   What were your expectations for the braces?

   What problems were you having that you hoped the dynamic braces would address?

   What was it like to be assessed for the dynamic braces?

   What was it like to be cast for the dynamic braces?

   What was it like to be fitted for the dynamic braces?

   What preparation did you do prior to receiving the braces? Any exercises?

4. **What has been your experience of adjusting to the braces?**

   Prompts

   What have you had to do to adjust to wearing the braces?

   What have you had to do to learn to use the braces effectively?

   What has that involved?

   What support have you had in learning to adjust to the braces?

   Do you have any comments on the cost of the dynamic braces and funding them?

   What resources were you supplied to guide your training?

   How well did you understand the information you were given?

   How well do you understand gait functions?

   What problems have you experienced since fitting (e.g. range of motion, muscular control, pain, body image etc.)?

5. **What has been the impact on you of having the braces on your health and wellbeing?**

   Prompts

   Physically

   Socially

   Emotionally

   Psychologically

   Financially

   Pain levels

   Fatigue levels

   Clothing and footwear

   How the orthotic looks and how it affects how you look

   How you function day to day

   Your work

   On your family

6. **Overall, how worthwhile have the orthotics been for you?**

   Other prompts

   Consider mechanism of effect:

   How did the braces lead to that effect?

   What other factors were involved in leading to that effect?

   Why or how did that happen?

   What did you do in order to gain/alleviate this effect?