Short-term Clinical Course of Knee Pain in Children and Adolescents: A Feasibility Study Using Electronic Methods of Data Collection

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Abstract

Background and Purpose. Musculoskeletal disorders, such as knee pain, are common in children and adolescents, but there is a lack of high quality research that evaluates the clinical course of these conditions. The objective of this study was to evaluate the feasibility of conducting a prospective study of children and adolescents with knee pain using electronic methods of data collection. Methods. Children and adolescents with knee pain that presented to primary care physiotherapy clinics were enrolled and followed-up on a weekly basis via short messaging service (SMS) until their knee pain had recovered (i.e. two consecutive weeks of no pain). Feasibility was assessed in terms of recruitment, retention and response rates to SMS and an online questionnaire. Baseline and 6-month follow-up measures included pain, disability, physical function, physical activity and health related quality of life. Kaplan-Meier survival analysis was used to estimate the median time to knee pain recovery. Results. Thirty participants (mean age 13.0 ± 2.2 years, 53% boys) were recruited over 26 months. The overall response rate to weekly SMS follow-up was 71.3% (809 received/1135 sent). One third of participants stopped responding to SMS prior to recovery, and these participants typically had a much lower response rate during the time they remained in the study. At 6-month follow-up, 80% of the cohort completed the final online questionnaire, and 29% of participants still reported current knee pain ($\geq 1/10$ VAS). The median time for knee pain recovery was 8 weeks (95%) CI: 5, 10). Conclusion. Electronic data collection alone seems insufficient to track pain recovery in young people and may need to be supplemented with more traditional data collection methods. Researchers should consider further measures to address slow recruitment rates and high attrition when designing large prospective studies of children and adolescents in the future. Copyright © 2016 John Wiley & Sons, Ltd.

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Keywords

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Introduction

Musculoskeletal (MSK) conditions are a major public health issue and the leading cause of disability globally (Vos et al., 2015). They pose a significant burden to primary health-care systems (Woolf and Pfleger, 2003), even during childhood and adolescence (Henschke et al., 2014). Studies suggest MSK conditions become common during adolescence, for example, back pain prevalence increases from 1% at age 7 years to 12-40% at 12 years and increases to 39-71% by 15 years (Hill and Keating, 2009). This is important given MSK pain in adolescence predicts pain and disability in adult life (Hestbaek et al., 2006; Kamaleri et al., 2009a, 2009b). Hence, better understanding of MSK pain in young people has considerable promise in reducing the individual and societal burden of these conditions.

There are few suitably designed longitudinal studies that investigate the clinical course of MSK conditions in children and adolescents (Artus et al., 2014). Prospective cohort studies to date have drawn upon population samples of school children, including those with, and without pain, and collected follow-up measures at wide time-intervals. (Jeffries et al., 2007; Hill and Keating, 2009; McBeth and Jones, 2007) These studies do not report on the correct variables at an appropriate frequency in well-defined clinical samples to accurately delineate prognosis. Several large cohort studies (El-Metwally et al., 2005; Hestbaek et al., 2006; Rathleff et al., 2013) only collect data at intervals of 1 year or more which means that variation in condition severity and impact that occurs within this time period is not captured. Furthermore, these studies capture information about how often a child experiences pain over a defined time period, this means that information about pain intensity, which is strongly related to the impact of the condition (Tiira et al., 2012), is not recorded. Investigation of clinical course requires a sample of clinical patients that are followed-up at frequent time intervals with patient-relevant measures such as pain intensity and disability (Hayden et al., 2010).

Large cohort studies are time-consuming, expensive, and it can be difficult to maintain good data quality because of attrition (Spector and Hochberg, 1994). The use of electronic data collection in health research is growing in popularity because it offers an efficient and flexible means of collecting information. Advantages over phone or in-person follow-up include reduced researcher and participant burden, which enables more frequent data collection from large samples. An example comes from a recent Danish study that collected data via short messaging service (SMS) to track individual patients' pain intensity every week in a large sample of adult participants with back pain, this enabled the identification of distinct patterns of back pain recovery over a 1-year follow-up period (Kongsted *et al.*, 2015). Another study followed MSK disorders in school children via weekly SMS answered by the parents (Wedderkopp *et al.*, 2012). It is not clear whether the follow-up rates reported by this study can be replicated when the child, rather than the parent, is asked to respond to SMSs about their symptoms.

To facilitate collection of robust prognostic and clinical course information on children and adolescents with MSK pain, the feasibility of electronic data collection methods in this group needs to be established. The aim of this study was to determine the feasibility of recruiting, retaining and following up a prospective cohort of young people with knee pain presenting to primary care, using electronic data collection methods (SMS and online questionnaire).

Methods

Study design, setting and participants

Ethical approval for this study was granted by the Human Research Ethics Committee of The University of Sydney, Australia (Protocol No.: 14519). Data were collected from May 2012 to June 2014. Participants were recruited from private physiotherapy clinics in Sydney, Australia.

Physiotherapists were approached to recruit participants to the study, gain consent, administer a baseline questionnaire and complete a baseline assessment within 2 days of the initial consultation. Thereafter physiotherapists provided clinical care as they saw fit, participation in the study had no influence on clinical management. When participants were discharged, physiotherapists completed either a paper-based or online follow-up questionnaire. Physiotherapists were reimbursed \$AUD100 per enrolled participant to cover the time required to complete the study procedures (approximately 3 hours).

Children and adolescents (aged 8–18 years) were eligible to participate in this study if they presented with the primary complaint of pain or discomfort in the knee (region indicated on a body chart diagram). Referral of knee pain beyond the knee did not preclude inclusion. All participants (and their parents/guardians) had to be able to speak and read English and provide written informed consent.

Commencing the week after enrolment, children and adolescents participating in the study were sent two SMS messages each week that asked about their knee pain. SMS follow-up was stopped when the patient had recovered, defined as two consecutive weeks reporting no pain. Six months after recruitment, participants were contacted by email and/or phone and asked to complete a web-based follow-up questionnaire. Participants were reimbursed with a \$30 voucher recognizing the significant length of follow-up, the time taken to respond to the SMS and the mobile phone costs associated with participating in the trial.

Variables and measurements

Baseline

The baseline questionnaire completed by participants included socio-demographic characteristics such as age, gender and school year. Also included were a series of questionnaires consisting of measures of pain intensity (Quadruple Visual Analogue Scale — QVAS (Jensen *et al.*, 1996)), knee-specific (Lower Extremity Functional Scale — LEFS (Binkley *et al.*, 1999)) and general function (Functional Disability Index — FDI (Walker and Greene, 1991)), child health related quality of life (Child Health Questionnaire — CHQ-50 (Ruperto *et al.*, 2001)) and physical activity (Adolescent Physical Activity Recall Questionnaire — APARQ (Booth *et al.*, 2002; Gwynn *et al.*, 2010)).

At baseline, the Patient-Specific Functional Scale (PSFS) (Chatman *et al.*, 1997) was administered by physiotherapists. Physiotherapists and participants identified three important activities that the participants were unable to do, or had difficulty with as a result of their knee problem. The three activities were identified as relatively light, moderate and vigorous or sustained activities and recorded on a scale from zero (unable to perform activity) to 10 (able to perform activity at the same level as before this episode).

Follow-up

Participants were sent two SMS messages every week until their knee pain had resolved. One message contained two questions: "What is your knee pain RIGHT NOW?" and "Over the past week what was your AVERAGE knee pain?" The Numeric Pain Scale (Williamson and Hoggart, 2005) was used with 0 indicating no pain and 10 the worst possible pain. The other SMS question asked participants to rate their ability to complete the activities that they had nominated as having difficulty performing in the baseline PSFS questionnaire and read "How would you rate your ability to complete a) [activity 1], b) [activity 2], c) [activity 3]?" Response instructions were numeric on a scale from 0 (unable) to 10 (completely able). All SMS messages were sent and received via the SMSGlobal web messaging platform (https://www.smsglobal.com/). Incoming SMS responses were downloaded into a Microsoft Excel spreadsheet for analysis.

The six-month follow-up questionnaire was completed online by participants and included the following items: Pain intensity (QVAS), patient-specific, knee-specific and general function (PSFS, LEFS and FDI) and physical activity (APARQ).

Statistical methods

Descriptive statistics were used to characterize the cohort. Continuous outcome measures recorded at baseline and follow-up were summarized with means and standard deviations (SD); or medians and interquartile ranges when not normally distributed.

Response rate to SMS tracking was calculated by dividing the actual number of responses received by the total number of responses expected for each participant. Participants were censored if they still had pain the week before but stopped responding to the weekly SMS tracking for four consecutive weeks, time of censorship was listed as first week of non-response. SMS response rates were then calculated separately for participants who were uncensored and censored; the response rate of censored participants was calculated up to the week of censoring.

Using weekly pain intensity data Kaplan–Meier survival analysis was used to calculate median time to recovery from knee pain. Time of recovery was defined as the second consecutive week that a participant reported 0 out of 10, to the SMS question "What is your knee pain (intensity) RIGHT NOW". A survival plot was constructed to estimate the probability of recovery over the course of the study.

Descriptive statistics were generated using IBM SPSS (Chicago, IL, USA) version 22 and survival analysis was conducted in SAS (Cary, NC, USA) version 9.4.

Table 1.	Baseline	characteristics	of	participants	(n :	= 30)
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Year at school ^{\dagger} mean (SD)	8 (2)	
Duration of knee pain		
0–7 days	23.3%	
1-4 weeks	30.0%	
1-3 months	16.7%	
>3 months	30.0%	
Knee Pain (QVAS) mean (SD)		
Now	3.8 (2.5)	
Average	4.2 (2.1)	
Best	1.3 (1.6)	
Worst	8.0 (1.4)	
Knee Disability (PSFS) mean (SD)		
Light	4.6 (2.4)	
Moderate	4.1 (2.4)	
Vigorous/Sustained	4.3 (2.3)	
FDI (scale 0-60) mean (SD)	15.2 (9.7)	
LEFS (scale 0-80) mean (SD)	54.9 (14.7)	
APARQ (min/week) median (IQR)		
Moderate Physical Activity	90 (4, 360)	
Vigorous Physical Activity	364 (220, 668)	
Moderate-Vigorous Physical Activity	563 (459, 990)	

QVAS = Quadruple Visual Analogue Scale; PSFS = Patient Specific Functional Scale; FDI = Functional Disability Index; LEFS = Lower Extremity Functional Scale; APARQ = Adolescent Physical Activity Recall Questionnaire.

[†]In Sydney, Australia, school education is 13 years and divided into: Primary school, which runs from age 5–6 years to age 11–12 years (i.e. Kindergarten to Year 6) and Secondary school, which runs from age 12–13 years to age 17–18 years (i.e. Year 7 to 12).

Results

Thirty participants (53.3% boys) with a mean age $(\pm SD)$ of 13.0 (± 2.2) years were recruited over a period of 26 months. Forty-four physiotherapy clinics (including 108 physiotherapists) were contacted to recruit participants for this study; of these, only seven clinics (8 physiotherapists) actually recruited participants to

the study. Baseline characteristics of participants are presented in Table 1.

Overall response rate to SMS tracking was 71.3%, rates were significantly lower in participants who were censored than those that were not (Table 2). During the SMS tracking period, 10 of the 30 participants (33.3%) stopped responding to the weekly SMS before meeting the recovery criterion (zero pain score for two consecutive weeks) and were therefore censored. There was no significant difference between the baseline pain and disability scores for censored versus uncensored participants. At six-month follow-up, 24 out of 30 participants (80%) completed all or part of the online questionnaire (Table 3). There was no consistent pattern of difference on the baseline scores between participants that completed the six-month follow-up and participants lost to follow-up (Additional Material: Table S1).

The median time for knee pain recovery was 8 weeks (95%CI: 5 to 10 weeks) (Figure 1) with 30% of participants having knee pain for longer than 3 months. At six-month follow-up, the percentage of participants who reported knee pain (\geq 1 on the QVAS-Now) at the time of response was 29.2%.

Discussion

This study explored the feasibility of conducting a longitudinal cohort study on the clinical course of knee pain in children and adolescents presenting to physiotherapy. We identified three major threats to study feasibility: (1) the slow rate of recruitment; (2) the high percentage of participants that stopped responding to SMS tracking prior to recovery (33.3%); and (3) high loss to follow-up at 6 months (20%).

Table 2. Mean response rate to SMS tracking from the total number of messages sent

	SMS I	1. Pain	SMS 2. Disability (PSFS)			
	Now	Average	Activity 1	Activity 2	Activity 3	All items
All participants $(n = 30)$	74% (168/227)	71.8% (163/227)	75.8% (172/227)	67.8% (154/227)	67% (152/227)	71.3% (809/1135)
Uncensored participants $(n = 20)$	77.5% (117/151)	75.5% (114/151)	82.8% (125/151)	70.9% (107/151)	70.2% (106/151)	75.4% (569/755)
Censored participants $(n = 10)$	67.1% (51/76)	64.5% (49/76)	61.8% (47/76)	61.8% (47/76)	60.5% (46/76)	63.2% (240/380)

Response rate: %. In parenthesis: (total number of SMS received / total number of SMS sent).

PSFS = Patient Specific Functional Scale; SMS = short messaging service.

Childhood Knee Pain in Primary Care

 Table 3. Response rates and mean values at 6-month follow-up

Questionnaire	Ν	Response rate	Mean score
		(%)	(SD)
Pain (QVAS)			
Now	24	80	0.7 (1.4)
Average	24	80	1.4 (1.3)
Best	24	80	0.2 (0.4)
Worst	24	80	4.0 (3.3)
Disability (PSFS)			
Light	23	76.7	8.4 (3.0)
Moderate	23	76.7	8.1 (2.9)
Vigorous/Sustained	12	40	8.3 (3.9)
FDI (scale 0-60)	23	76.7	3.4 (5.9)
LEFS (scale 0-80)	22	73.3	72.9 (12.3)
APARQ (min/week)			
Moderate Physical Activity	21	70	15 (0, 83) [†] *
Vigorous Physical Activity	21	70	323 (240, 573) ^{†*}
Moderate-Vigorous Physical		70	435 (304, 743) [†] *
Activity			

*median, (IQR).

QVAS = Quadruple Visual Analogue Scale; PSFS = Patient Specific Functional Scale; FDI = Functional Disability Index; LEFS = Lower Extremity Functional Scale; APARQ = Adolescent Physical Activity Recall Questionnaire; SD = standard deviation.

Poor patient recruitment and retention are two wellknown threats to feasibility in clinical studies. In this study, recruitment relied on clinicians to screen and enrol young people. The length of time it took to recruit 30 participants (26 months) was a major challenge and represents a serious threat to the feasibility of conducting a large study on this population. Forty-four private physiotherapy clinics were approached to participate in this study; four of these declined on the basis that their patient base consisted of too few young people, and eight clinics did not respond to our requests for assistance. Of the remaining 32 clinics with which contact was made, only eight enrolled participants into the study. In order to be able to provide robust estimates of clinical course and identify prognostic factors with sufficient power, future studies on adolescent MSK pain would need to include approximately 10 times the number of participants as this pilot study. Fletcher et al., (Fletcher et al., 2012) found that the recruitment activity of clinicians in clinical studies can be improved by implementing qualitative methods at the study design phases to what are likely barriers to recruitment activity and how these may be overcome. This may be an important factor to consider in future studies to maximize clinician involvement.

Additionally the nature of the question used for SMS tracking might have adversely influenced the response rate in our study. The feasibility of SMS was recently assessed in a study of Australian children with haemophilia (Broderick *et al.*, 2012). The authors of this study used a yes/no response option and reported a follow-up rate of 86.8% to document bleeding episodes. In contrast, another study used SMS to collect data on eating and exercise behaviour in overweight children using response rate of 67% (Bauer *et al.*, 2010). The response rates to the SMS questions in our study were quite low. A mean response rate of 71% represents a substantial threat



Figure 1. Kaplan–Meier survival plot for knee pain recovery in children and adolescents

to study validity, as it is likely that this amount of missing data would introduce bias into estimates of prognosis calculated from a larger study. These response rates to follow-up were lower than in a study of Danish children with musculoskeletal pain (Jespersen *et al.*, 2015), which can be most likely explained by the fact that data in the Danish study were provided by parents, not children themselves. Differences in nature of the question, population (clinical versus population) and cultural attitudes to medical research may also help explain this discrepancy (Kelly *et al.*, 2002).

Our rationale to explore the feasibility of electronic data collection methods was, in part, motivated by the desire to minimize both researcher and participant burden and project expense. SMS reminders were used in studies by Moller et al. and Jespersen et al. (Moller et al., 2012; Jespersen et al., 2015) to improve data capture rates and also to flag where additional participant support was needed. In these studies, SMS reports of pain or injury would prompt a follow-up telephone call from researchers to further investigate the nature of the problem. Thus, participants reporting pain would receive feedback, adding to the significance of their response. Participants in the study of Jespersen et al. also received a clinical examination following the telephone call, if indicated. The response rates to SMS tracking in these two studies was much higher than ours ranging from 85% to 96% suggesting that children and their families respond better when there is greater contact with study staff. The additional burden for researchers and greater project cost may be necessary if optimal response rates are to be obtained.

The third major threat to feasibility in this study was participant retention. Over 30% of participants stopped answering SMS questions prior to recovery, and 20% of participants did not complete the 6 months follow-up questionnaire. A comparable loss to followup rate is likely to introduce bias into estimates of prognosis calculated from a larger study in the same population. In our study, we reimbursed participants for their time and the cost of their mobile phone use only. Future research may be guided by literature that suggests an actual financial incentive (monetary) might boost retention rates; notwithstanding, there are complex ethical issues with incentivizing young people to participate in research that must be considered. A definite reward (as opposed to lotteries) has been demonstrated to improve retention in young people (Henderson *et al.*, 2010) and this appears to increase in proportion to the incentive value (Booker *et al.*, 2011). Alternate methods such as reminder telephone calls also appear to have a greater effect in younger aged cohorts. In this study we did not employ reminder correspondence during the final follow-up period, and ongoing SMS messages or mixed follow-up methods (such as telephone calls) could have helped improve the follow-up rate (Booker *et al.*, 2011).

A limitation of our study is that we did not capture information on the reason for participant attrition (at both SMS and six-month follow-up). While the potential for electronic methods of data collection is clear, the follow-up rates in our study were quite low. It is possible that the density of information we sought, or regularity of contact, was too onerous for some participants and negatively influenced response rates.

Conclusion

Musculoskeletal conditions commonly affect young people and can prompt them to seek help from primary care clinicians. Larger studies are needed to help clinicians identify children at risk of poor recovery and to also better inform management strategies. Finding physiotherapists that were willing and able to identify, and recruit, participants to the study was challenging. While the use of electronic data collection methods is potentially useful in clinical research that follows young people over time, the methods used in our study led to unacceptably high levels of missing data. Researchers embarking on research in the area should seek solutions to the problems of low recruitment rates and high loss to follow up when planning large prospective studies in the future.

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Supporting information

Additional supporting information may be found in the online version of this paper at publisher's web site:

Table S1. Differences in baseline measures for children and adolescents based on follow-up attrition.