

# Lost but not forgotten: patients lost to follow-up in a trauma database

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**Objectives:** To determine the characteristics of patients lost to follow-up and to identify if they are significantly different from those who are followed up in the context of a prospective randomized controlled trial. **Design:** A retrospective review of a prospectively acquired trauma database. **Setting:** A level 1 university-affiliated trauma hospital. **Patients:** Two hundred and thirty-six patients treated for displaced intra-articular calcaneal fractures between April 1991 and December 1996. Of these, 198 were categorized as “attenders” and the remaining 38 were deemed “nonattenders.” Demographics, severity of injury, intervention and post-treatment status of the 2 groups were compared. Demographic information, including age, gender, occupation workload, Workers’ Compensation Board involvement and other standard trauma information were compared and the differences analyzed. **Results:** The nonattenders were younger than the attenders, and there was a significantly increased proportion of Aboriginal Canadians in the nonattenders group. Attenders were more likely to be “skilled or semi-skilled clerical, sales, service or trades crafts” workers, and nonattenders were more likely to be “unskilled clerical, sales, service or labour” workers. Attenders were more likely to have a preoperative Bohler’s angle of  $< 0^\circ$ , compared with a preoperative Bohler’s angle of  $0^\circ$  to  $15^\circ$  for nonattenders. **Conclusions:** This trauma population is at higher risk of being marginalized by society and may not have the same accessibility to a study nurse or a hospital contact person. Patients lost to follow-up are a demographically and clinically different patient population from those who remain involved in a long-term prospective trauma study.

**Objectifs :** Déterminer les caractéristiques des patients perdus au suivi et voir s’ils sont très différents de ceux que l’on suit dans le contexte d’une étude contrôlée, randomisée et prospective. **Concept :** Étude rétrospective d’une base de données sur les traumatismes acquise de façon prospective. **Contexte :** Hôpital de traumatologie affilié à une université de niveau 1. **Patients :** Deux cent trente-six patients traités pour des fractures intra-articulaires déplacées du calcaneum entre avril 1991 et décembre 1996. Sur ce total, 198 ont été classés comme «participants» et les 38 autres, comme «non-participants». On a comparé les caractéristiques démographiques, la gravité de la blessure, l’intervention et l’état après le traitement des sujets des deux groupes. On a comparé les données démographiques, y compris l’âge, le sexe, la charge de travail, l’intervention de la Commission des accidents du travail et d’autres renseignements usuels sur les traumatismes et l’on a analysé les différences. **Résultats :** Les non-participants étaient plus jeunes que les participants et comptaient beaucoup plus d’Autochtones. Les participants étaient plus susceptibles d’être des «travailleurs qualifiés ou semi-qualifiés, employés de bureau, vendeurs, préposés au service ou gens de métier» et les non-participants, des «travailleurs non qualifiés, employés de bureau, vendeurs, préposés au service ou journaliers». Les participants étaient plus susceptibles d’avoir un angle de Bohler préopératoire de  $< 0^\circ$ , comparativement à un angle de  $0^\circ$  à  $15^\circ$  chez les non-participants. **Conclusions :** Cette population de traumatisés est plus exposée à être marginalisée par la société et peut ne pas avoir la même facilité d’accès à une infirmière ou à une personne-ressource dans un hôpital. Les patients perdus au suivi constituent une population différente sur les plans démographique et clinique de ceux qui continuent à participer à une étude prospective de longue durée portant sur un traumatisme.

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The loss of patients to follow-up is a concern to all clinical researchers, and little work has been published on this subject.<sup>1-3</sup> Much of the work that has been done has been in the field of substance abuse and psychiatry.<sup>4-6</sup> Recently, the issue has been acknowledged and investigated by a few researchers in the field of orthopedics.<sup>7-12</sup> A succinct description of patients lost to follow-up was published in 1995, when Wildner<sup>12</sup> described 5 possible hypotheses for patients who fail to attend for follow-up: Are they silent because they are dissatisfied? Are they so satisfied that they do not want to be bothered? Have they died? Have they just moved? Are they simply dissatisfied with follow-up studies and paperwork?

Populations at risk for trauma have many inherent ongoing difficulties.<sup>13,14</sup> Kawochi and associates<sup>13</sup> concluded that variations in health within a population are primarily related to social factors like income inequality, educational differences and racism.

Murray, Britton and Bulstrode<sup>8</sup> concluded that patients who are lost to follow-up have a worse outcome than those who continue to be assessed. They compared clinical information from the subjects' last clinic visit with control-matched subjects in the attendees group. Their finding that patients who are lost to follow-up were headed for a worse outcome than those who are not lost reinforces the importance of achieving a low attrition rate among study subjects. In their opinion, if patients who are lost are simply grouped with those who are not, a falsely optimistic conclusion will be reached concerning treatment outcome.

The purpose of this study is to determine if patients with a displaced intra-articular calcaneal fracture (DIACF) who are lost to follow-up (defined as an inability to achieve follow-up at 2 yr) are systematically different in terms of demographics and clinical condition from those not lost to follow-up. Our objectives were to determine if these patients form a distinct

demographic group, and if patients who are eventually lost to follow-up start with more serious injuries and suffer more postoperative problems and complications.

## Methods

The 236 patients in this study are a cohort from a larger multicentre randomized clinical trial comparing operative versus conservative management of DIACFs. This larger study had been reviewed previously by the ethics committee at the University of Calgary and granted approval. The inclusion criteria were those of the original study: (1) patients presenting or referred to the contributing institutions with displaced DIACFs; (2) displacement greater than 2 mm from the anatomic position as demonstrated by axial and coronal computed tomography of the injured calcaneus; (3) age between 16 and 50 years; and (4) informed consent obtained. The exclusion criteria included medical contraindications, a previous calcaneal condition or surgery, coexisting foot injury, open calcaneal fracture, injury more than 14 days old and head injury. In addition to these original criteria the following restrictions were added: (1) patients must have been treated by the senior author; and (2) patients whose injury predated Dec. 31, 1996. Limiting the patient set using these criteria afforded the authors first-hand knowledge of follow-up techniques as well as allowing sufficient time for follow-up without the need for censoring.

The authors and the study nurse reviewed 533 patient files. Using exclusion criteria, the number was reduced to 236. Of this group, 38 (16%) patients were lost to follow-up. Each patient's file was reviewed and discussed. In order for patients to be placed in the lost to follow-up (nonattenders) group, sufficient time must have been allowed for follow-up, adequate attempts to find them must have been made, with no

known reason for them to have failed to attend (e.g., died).

On entry into the study, patients were given standard information about the study, consent was obtained and they were introduced to the study requirements. All were informed that they would be followed up for 2 years or more.

Our study nurse used standard methods in an attempt to achieve follow-up with all study subjects (Fig. 1). Telephone and mailing address information provided by the patient on initial contact was used. Additional information from patient charts, such as next of kin and business numbers, was also used. Directory assistance was used for any patient who could not be contacted by the above-mentioned methods. These search methods were comparable to those recently described by Smith and Watts.<sup>11</sup>

In order to categorize and analyze the subjects' occupations, the Pineo-Porter-McRoberts socioeconomic classifications of occupations (Pineo codes) were used.<sup>15</sup> The original 16 Pineo codes were collapsed into 4 categories: managerial and professional;

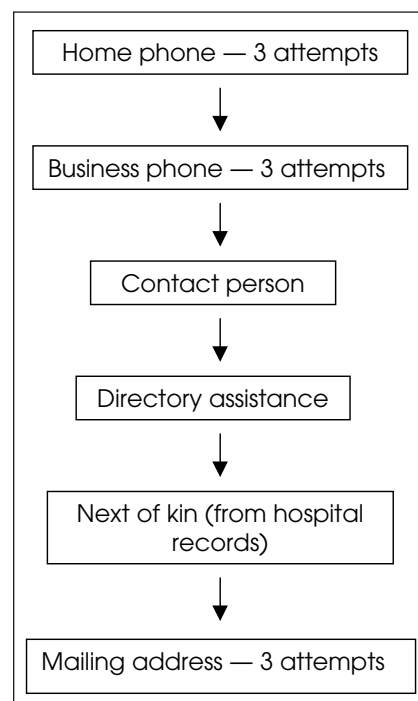


FIG. 1. Algorithm for follow-up strategy.

semiprofessional, technicians and middle management; skilled/semiskilled clerical–sales–service or trades–crafts; or unskilled clerical–sales–service or labour. Severity of injury was categorized by Bohler’s angle, measured with a hand-held goniometer placed over the lateral plain film.<sup>16</sup> Bohler’s angle is the complement of the angle formed by 2 lines: a line drawn between the highest part of the anterior process and the highest part of the posterior articular surface, and a line drawn between the same point on the posterior articular surface and the most superior point of the tuberosity. Normally, Bohler’s angle ranges from 25° to 40°, with a similar angle in the 2 calcanei of any one patient.<sup>16</sup> The measurements were grouped as follows: class A > 16°, class B 0° to 15° and class C < 0°.<sup>16</sup>

The results were analyzed using the  $\chi^2$  test for 2 independent proportions for binomial variables. Continuous variables were analyzed by Student’s *t*-test. A probability value of less than 0.05 was considered significant. All *p* values are 2-tailed.

**Results**

The majority of nonattenders simply could not be located. The remainder could be located but for various reasons refused to come to hospital for a follow-up visit. This second group was deemed uncooperative, and these patients were included in the group of nonattenders. Comparison of the 2 categories (attenders v. nonattenders) demonstrated several significant demographic differences (Table 1). Nonattenders were younger, with an average age of 36.1 years versus 40.1 years (*p* = 0.02). Aboriginal people were almost 16 times more likely to be nonattenders than attenders (*p* < 0.001). In terms of occupation, attenders were more likely to have an occupation in Pineo code category 3 (skilled/semiskilled clerical–sales–service or trades–crafts) (*p* = 0.015). Nonattenders were more likely to have an occupation in Pineo code category 4 (unskilled clerical–sales–service or

labour) (*p* = 0.019). There was no significant trend with regard to Pineo code category 1 or 2 because of small numbers in each group after stratification. There was no significant difference between the 2 groups in terms of Workers’ Compensation Board status.

Another category of comparison between the 2 groups was severity of injury. This was compared, using data available at the time of injury. There was no significant difference between attenders and nonattenders in terms of the presence of associated injuries or bilateralism. There was no

difference in the presence of bilateral versus unilateral calcaneal fractures when the 2 groups were compared. There were significant differences in the preoperative Bohler’s angles. Attenders are more likely to have a Bohler’s angle of < 0° (*p* < 0.001). Nonattenders are more likely to have a Bohler’s angle between 0° and 15° (*p* < 0.001). There was no significant difference for Bohler’s angles > 16°. Comparison of the 2 groups in terms of treatment method and post-treatment status did not demonstrate any significant differences.

**Table 1**

**Demographics, Severity of Injury, Treatment and Post-treatment Status for 236 Patients With Displaced Intra-articular Calcaneal Fracture**

Status	Nonattenders (n = 38)	Attenders (n = 198)	<i>p</i> value
<b>Demographics</b>			
Age, yr			0.02
Mean (SD)	36.1 (11.1)	40.1 (11.3)	
Range	18–58	15–65	
Gender, no. (and %)			0.194
Male	36 (94.7)	173 (87.4)	
Female	2 (5.3)	25 (12.6)	
Racial status, no. (and %)			< 0.001
Native	6 (15.8)	2 (1.0)	
Non-native	32 (84.2)	196 (99.0)	
Occupation category, no. (and %)			
1	3 (7.9)	4 (2.0)	0.05
2	2 (5.3)	22 (11.1)	0.280
3	9 (23.7)	89 (45.0)	0.015
4	24 (63.2)	83 (41.9)	0.019
Workers’ Compensation Board case			0.418
Yes	11 (28.9)	72 (36.4)	
No	27 (71.1)	126 (63.6)	
<b>Severity of injury</b>			
Associated injuries, no. (and %)			0.332
Yes	7 (18.4)	51 (25.8)	
No	31 (81.6)	147 (74.2)	
Bilateral v. unilateral, no. (and %)			> 0.05
Unilateral	35 (92.1)	186 (93.9)	
Bilateral	3 (7.9)	12 (6.1)	
Preoperative Bohler’s angle*			
Class A (> 16°)	6 (18.8)	32 (17.4)	> 0.05
Class B (0°–15°)	20 (62.4)	82 (44.6)	< 0.001
Class C (< 0°)	6 (18.8)	70 (38.0)	< 0.001
<b>Treatment</b>			
Study arm, no. (and %)			0.2186
Open reduction and internal fixation	22 (57.9)	93 (47)	
Conservative	16 (42.1)	105 (53)	
<b>Post-treatment status</b>			
Complications, no. (and %)			> 0.05
Complications present	6 (15.8)	27 (13.6)	
No complications present	32 (84.2)	171 (86.4)	

\*Values were missing for 6 nonattenders and 14 attenders. Reduced sample sizes of *n* = 32 for nonattenders and *n* = 184 for attenders were used.

A systematic chart review of all nonattenders is summarized in Table 2: 76% were smokers, 45% had a history of alcohol abuse and 32% had a history of substance abuse, 13% had been incarcerated and 32% had had a psychiatric admission.

**Discussion**

Follow-up rates in prospective trauma studies are often noted to be less than 100%. Trauma patient pop-

ulations are not merely a random sample from a general orthopedic practice. Patients are often nomadic construction workers and other labourers. A brief review of initial presentations reveals that many of them suffered their injury jumping off roofs and over fences while intoxicated or under the influence of drugs. Some patients were either in the process of committing a crime or attempting to evade law enforcement at the time of their injury. To follow

such a population requires careful prospective planning and diligent work from both the principal investigator and the study nurses. A study must be carried out with the philosophy and understanding that the greater the retrieval rate, the more reliable the study. Even with such efforts, patients are inevitably lost. Loss of patients can lead to changes in the strength and statistical conclusions drawn from a study. Nonrandomized studies particularly are at risk for "lost to follow-up" patients. Randomization should equalize the distribution of this group between control and treatment arms. This selection bias could prove harmful if it leads to the recommendation of one treatment method over another on the basis of incomplete or inaccurate data.<sup>6,11,17</sup>

Demographically there were 3 categories that proved to be significantly different between attenders and nonattenders: nonattenders were generally younger, Aboriginal and involved in more manual labour. These differences, though intuitive, demonstrate the attitudes of a younger population as less responsible for medical follow-up.<sup>13</sup> Before drawing any conclusions on the basis of the differences discovered, one must first look more closely at the method of follow-up. It is possible that strategies are biased to a certain population, leaving others at a disadvantage of being contacted.<sup>5,13</sup> Aboriginal status was the only cultural difference that we investigated, and without a more thorough analysis of other groups only limited conclusions can be drawn from this difference. It should also be noted that the number of Aboriginals in the study makes it difficult to draw any meaningful conclusions from this difference. Attenders were more likely to have higher skills (Pineo category 3) than nonattenders (Pineo category 4). In our opinion, this demonstrates a significant discrepancy between the groups in terms of socioeconomic status and education level. It is possible that patients were nonattenders

**Table 2**

**Results of Chart Review of the Nonattenders Group**

Patient no.	Smoker	History of			
		Alcohol abuse	Substance abuse	Incarceration	Psychiatric admission
1	Yes				Yes
2	Yes	Yes	Yes	Yes	
3	Yes	Yes	Yes		
4	Yes				Yes
5					Yes
6					
7	Yes	Yes	Yes		
8	Yes	Yes	Yes	Yes	
9	Yes	Yes			
10					Yes
11	Yes	Yes	Yes		
12	Yes				
13	Yes	Yes			
14					Yes
15	Yes				
16	Yes	Yes			Yes
17	Yes	Yes	Yes	Yes	Yes
18	Yes				
19	Yes	Yes			
20	Yes				
21					
22	Yes	Yes	Yes		Yes
23	Yes				
24	Yes	Yes			Yes
25					
26	Yes				
27	Yes	Yes	Yes	Yes	
28					
29	Yes				
30	Yes	Yes	Yes		Yes
31	Yes				
32					
33	Yes	Yes	Yes	Yes	
34	Yes	Yes	Yes		
35	Yes				Yes
36					Yes
37	Yes	Yes	Yes		
38	Yes				
Total, no. (and %)	29 (76.3)	17 (44.7)	12 (31.6)	5 (13.2)	12 (31.6)

owing to decreased flexibility in missing work and level of understanding of the need for follow-up.

With respect to injury severity, there was a significant difference between the groups. Attenders were more likely to have a more serious injury (Bohler's angle  $< 0^\circ$  or class C). Loucks and Buckley<sup>16</sup> concluded that extreme diminution of Bohler's angle at the time of presentation (i.e., class C) represented a significantly diminished outcome at 2 years as measured by the Visual Analog Scale and SF-36 scoring systems. Perhaps patients who are doing less well clinically are more likely to require and desire close follow-up with their surgeon. Nonattenders were more likely to have a less serious injury (Bohler's angle  $0^\circ$  to  $15^\circ$  or class B). Fewer patients in this group had extreme diminution of Bohler's angle, and therefore were less likely to have such a diminished clinical outcome. It is possible that these patients did not feel the same need to follow-up with their surgeon. More direct analysis and interpretation of outcome measures would prove superior to this indirect method of comparison. Unfortunately, since nonattenders are lost soon after their treatment, this outcome information cannot be obtained. It must also be considered that the reason why many of the categories did not demonstrate a statistically significant difference may have been the small sample size of the nonattenders.

In addition to the statistical differences already discussed, a review of the hospital charts of the nonattenders led to some interesting findings. As this was a retrospective study, limited conclusions can be drawn, but it is interesting to note that almost half (44.7%) the nonattenders had a history of alcohol abuse. Indeed, this percentage may be an underestimate as it was drawn only from a review of hospital charts. It is not unreasonable to assume that patients whose addiction, by definition, interferes with work and family would also be unable

to follow-up with their physician as part of a study. In addition, the percentage of patients with a history of psychiatric admission (31.6%) further describes this unique patient profile. We believe that this population is at higher risk of being marginalized by society and may not be as easy to contact. Within our population of nonattenders, 13.2% had a history of incarceration. Smith and Watts<sup>11</sup> discussed the issue of criminal activity in their paper mentioning, "Some patients will not be found despite an investigators best efforts.... Criminals ... may go to great extremes in order to hide their location."

In the past, trauma populations have not traditionally been thought of as a separate epidemiologic group. A new philosophy, which treats trauma like a disease process with its own patient population and comorbidities, is slowly gaining credibility. Populations at risk for trauma have many inherent ongoing difficulties.<sup>13,14</sup> Income inequality, educational differences, race, psychiatric problems and substance abuse often interfere with a patient's ability to follow-up (as part of a study). A population at higher risk of being marginalized by society may not have the same accessibility to a study nurse or a hospital contact person.

The greater the retrieval rate, the more reliable a prospective study becomes. It behooves investigators in prospective studies to use regimented and strict protocols to maintain patients in a study and to locate those who do become "lost." We feel this study demonstrates that patients lost to follow-up are a demographically and clinically different from patients who remain involved in a long-term prospective trauma study.

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