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# Total Hip Replacement for Coxarthrosis Secondary to Congenital Dysplasia and Dislocation of the Hip

LONG-TERM RESULTS\*

BY JAMES R. MACKENZIE, M.D., F.R.C.S.(C)†, SCOTT S. KELLEY, M.D.‡,  
AND RICHARD C. JOHNSTON, M.D.§, DES MOINES, IOWA

*Investigation performed at the Iowa Methodist Medical Center, Des Moines*

**ABSTRACT:** Between 1970 and 1982, sixty-six total hip replacements were performed with cement, without bone-grafting, in fifty-three patients who had congenital dysplasia and dislocation of the hip. Preoperatively, the patients had had Crowe type-II, III, or IV subluxation. Current information was available for fifty-nine hips in forty-six patients after an average duration of follow-up of sixteen years (range, ten to twenty-one years). The average age of the patients at the time of the operation was fifty-three years (range, twenty-three to seventy-three years). The average Harris hip score at the most recent examination was 92 points (range, 61 to 100 points). Eight hips were revised. The reason for the revision was infection in two hips, fracture of the femoral stem in two, and loosening of the acetabular component in four. The rate of revision for aseptic loosening, therefore, was 10 per cent (six hips). In the unrevised hips for which radiographs were available, the rate of radiographic loosening of the femoral component was 5 per cent (two hips) and that of the acetabular component was 32 per cent (twelve hips). We did not find a relationship between the amount of horizontal or vertical displacement of the center of the femoral head and the rate of loosening. Kaplan-Meier survivorship analysis with revision as the end point predicted a rate of survival of 85 per cent (95 per cent confidence interval, 75 to 95 per cent) at fifteen years. With radiographic loosening as the end point, the predicted rate of survival was 68 per cent (95 per cent confidence interval, 54 to 81 per cent) at fifteen years. We concluded

that, for patients who have Crowe type-II, III, or IV congenital dysplasia of the hip, good long-term results can be obtained with insertion of a femoral stem with cement. The high rate of loosening of cemented acetabular components is a concern.

McQueary and the senior one of us (R. C. J.), in 1988, reviewed the results of sixty-six total hip replacements that had been performed without bone-grafting in fifty-three patients who had had congenital dysplasia and dislocation of the hip<sup>20</sup>. After an average duration of follow-up of 8.5 years (range, two to fourteen years), none of the hips had been revised because of loosening, two had been revised because of a deep infection, and six had radiographic evidence of loosening.

The present study is a review of the same series. All of the patients had had Crowe type-II, III, or IV subluxation preoperatively. Type-II subluxation is characterized by 50 to 75 per cent subluxation of the femoral head and a deficient acetabular roof. In type-III subluxation, there is 75 to 100 per cent subluxation of the femoral head, the superior portion of the acetabular roof is completely absent, and the anterior and posterior columns are intact. In type-IV subluxation, the femoral head is completely dislocated and the superior lip of the true acetabulum is deficient, but otherwise the acetabular roof provides better coverage than it does in type-III subluxation. In type-IV subluxation, the true acetabulum, while incompletely formed, is recognizable.

The two methods of reconstructing the acetabulum in patients who have an inadequate amount of bone in the superior portion of the acetabulum secondary to congenital dysplasia of the hip are to accept a superior position for the acetabular component<sup>22</sup> or to move the acetabulum inferiorly and use a filler for the defect. The use of bone grafts in these situations has been evaluated in previous studies<sup>6,7,9,21,27</sup>. The present study describes a series of patients in whom the defect was filled with cement.

## Materials and Methods

Between 1970 and 1982, the senior one of us (R. C. J.) performed sixty-six total hip replacements with ce-

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†University of Calgary, 335-401 Ninth Avenue S.W., Calgary, Alberta T2P C35, Canada.

‡University of North Carolina, 242 Burnett-Womack Building, Box 7055, Chapel Hill, North Carolina 27599. Please address requests for reprints to Dr. Kelley.

§Des Moines Orthopedic Surgeons, 6001 West Town Parkway, Des Moines, Iowa 50266.

ment in fifty-three patients who had severe congenital dysplasia and dislocation of the hip. Current information was available for forty-six patients (fifty-nine hips; 89 per cent) after an average duration of follow-up of sixteen years (range, ten to twenty-one years). Twenty-eight patients (thirty-seven hips) returned for physical and radiographic examination at an average of sixteen years (range, ten to twenty-one years) postoperatively. Fourteen patients (seventeen hips) were interviewed by telephone and, of these, eight patients (eight hips) sent radiographs that had been made at an average of eighteen years (range, twelve to twenty-one years) postoperatively. Four patients (five hips) had died, and a relative was interviewed by telephone. The remaining seven patients (seven hips) were lost to follow-up.

Fifty-eight procedures were performed in forty-seven women and eight were performed in six men. The average age of the patients at the time of the index operation was fifty-three years (range, twenty-three to seventy-three years).

The clinical information that was obtained was similar to that in a previous report<sup>13</sup>. Patients were questioned with regard to their activities of daily living, including the ability to put on shoes and socks, to climb stairs, to rise from a sitting position, to pick up objects from the floor, and to carry objects such as a suitcase; the distance that they were able to walk; and the use of walking aids. Pain in the hip was graded as mild, occasional pain that did not affect activities; moderate pain (the patient was active but had modified or given up activities); or severe pain that caused serious limitations. The patients were asked several questions regarding the level of satisfaction with the operation: Did your operation increase function? Did it decrease the pain in the hip? Did it decrease your need for medications? Are you satisfied with the result?

The indication for the operation was severe, disabling pain in the hip that was unresponsive to non-operative measures. All of the procedures were performed at the Iowa Methodist Medical Center by the senior one of us (R. C. J.). A Charnley prosthesis (Thackray, Leeds, England) with a twenty-two-millimeter head was used in sixty-four hips, and an Iowa femoral stem with a twenty-eight-millimeter head and a Tibac acetabular component (Zimmer, Warsaw, Indiana) were used in two.

The operative procedure was described previously<sup>20</sup>. It involved a transtrochanteric approach to the hip joint and a complete capsulectomy. The acetabulum was reamed until the reamed surface was flush with the floor of the acetabular fossa. An anchoring hole for cement was placed superiorly, but no such hole was placed medially. The acetabular component was placed medially and inferiorly.

Twenty-two hips had Crowe type-II subluxation, eighteen had type-III subluxation, and nineteen had type-IV subluxation. Previous operative treatment in-

cluded seven open reductions, six pelvic osteotomies, five femoral osteotomies, one hemi-arthroplasty with an Austin Moore prosthesis, one replacement with a Judet prosthesis, and fifteen previous cup arthroplasties.

Serial and current radiographs were available for forty-five hips, including the eight hips that were revised. We assessed the preoperative radiographs to determine the Crowe classification of subluxation and the horizontal and vertical displacement of the center of the femoral head. The immediate postoperative radiographs were used to determine the location of the center of the femoral head, the type and alignment of the prosthesis, the method of reattachment of the greater trochanter, and the adequacy of the cementing technique. The most recent radiographs were examined for evidence of loosening, polyethylene wear, heterotopic ossification, and osteolysis.

We referenced the location of the center of the femoral head to a line drawn through the teardrops<sup>22</sup>. The vertical height was measured perpendicular to this reference line. The horizontal displacement of the center of the femoral head was measured along this line as the distance from the teardrop.

Loosening of the acetabular component was defined according to the criteria described by Hodgkinson et al. Definite loosening was indicated by a complete radiolucent line (type-III demarcation), evidence of subsidence or migration of the implant, or a fracture of the implant or the cement mantle. Type-II demarcation was indicated by a radiolucent line in two of three zones. Cups with type-II demarcation were considered to be definitely loose if the radiolucent line was progressive and possibly loose if the radiolucent line showed no evidence of progression. Type-I demarcation was indicated by a radiolucent line in the outer zone only; cups with type-I demarcation were considered stable.

Loosening of the femoral component was defined according to the criteria described by Harris et al.<sup>10</sup>. Subsidence of the implant or cement mantle, a fracture of the implant or cement, or the appearance of a new radiolucent line between the implant and the cement was considered a sign of definite loosening. Probable and possible loosening were not recorded because we think that the importance of radiolucent lines at the cement-bone interface of femoral components has not been clearly established.

Wear was measured with a technique similar to that described by Livermore et al. All radiographs were inspected for evidence of osteolysis (well circumscribed lytic defects at the cement-bone interface); if osteolysis was found, earlier radiographs were reviewed to determine if it was progressive. Acetabular osteolysis was recorded with use of the zones described by DeLee and Charnley and femoral osteolysis, with use of those described by Gruen et al. Heterotopic ossification was classified according to the system of Brooker et al.

The Kaplan-Meier method was used to calculate the probability of retention of the original prosthesis from the time of the initial arthroplasty to one of two end points: (1) revision of the original prosthesis and (2) radiographic evidence of loosening of one or both components. The Fisher exact test was used to compare rates of loosening among the four types of defects (type-II, III, and IV subluxation and revision of a cup arthroplasty). The Wilcoxon rank-sum test was used to compare the average vertical and horizontal displacements of the loose components with those of the well fixed components.

## Results

### *Clinical Results for the Unrevised Hips*

Clinical results were available for fifty-one unrevised hips in forty-one patients. Three patients, who had had a revision arthroplasty on one side and an unrevised arthroplasty on the contralateral side, were included in both groups. Clinical information was obtained with an interview in the office for twenty-three patients (thirty hips) and a telephone interview with the patient, family, or caregiver for eighteen patients (twenty-one hips). This telephone interview was with a living relative of the four patients (five hips) who had died. Incomplete information was obtained for two patients who had dementia; the data for these patients were partially included in the results.

The patients who had unrevised hips were functioning well at the time of the most recent examination. The patients who had one revised and one unrevised hip also were functioning well; the revisions did not affect the clinical results. Forty-eight hips (94 per cent) had slight or no pain. Thirty-seven hips (73 per cent) did not limit the distance that the patient could walk. Twenty-five (68 per cent) of the thirty-seven living patients for whom complete information was available could walk without assistance. All but one of the patients who needed assistance in order to walk had other musculoskeletal or neurological problems that contributed to the need for a cane or crutches. Most patients were able to perform their normal activities of daily living. Thirty-two of the thirty-seven patients were able to put on shoes and socks without difficulty. Twenty-four were able to go up and down stairs normally or with only the assistance of a banister. Twenty were able to rise from a sitting position without assistance. Twenty-six had no difficulty picking up objects from the floor.

Twenty-three patients (thirty hips) were able to return for full clinical and radiographic examination at an average of sixteen years (range, ten to twenty-one years) postoperatively. The average age of these patients at the time of the index operation was fifty-three years (range, twenty-seven to sixty-six years). The average Harris hip score was 50 points (range, 33 to 92 points) preoperatively and 92 points (range, 61 to 100 points) at

the time of the most recent follow-up examination.

### *Complications*

Current information regarding complications was available for forty-six patients (fifty-nine hips); seven other hips were lost to follow-up. Eight (14 per cent) of the fifty-nine hips were revised, six months to fifteen years after the index operation. The average age of the eight patients was fifty-four years (range, forty-two to sixty-three years) at the time of the index operation. The reason for the revision was infection in two hips, fracture of the femoral component in two, and loosening of the acetabular component in four. Two of the four hips that were revised because of loosening of the acetabular component had revision of that component only. In one of these hips, the original femoral component broke two years later and was revised. A total of three Charnley femoral components — including two extra-narrow components and one narrow component — were revised because of fracture. There were no other revisions of loose femoral components. Of the two hips that were revised because of infection, one had direct reimplantation of the prosthesis and the other had delayed reimplantation.

Only two patients were unsatisfied with the result of the operation. One of them, who had had a revision because of an infection, had no pain at the time of the latest follow-up examination but walked with a limp and had difficulty with activities of daily living. The second patient had no pain but had weakness in one lower limb. The reason for the weakness was not determined; the patient had a negative Trendelenburg sign and normal neurological findings (including normal muscle strength). All of the other patients thought that the operation had increased function and decreased pain and the need for pain medication.

### *Radiographic Results*

Current radiographs were available for thirty-seven (73 per cent) of the fifty-one unrevised hips. Thirty-five of the thirty-seven femoral components were intact and had no evidence of definite loosening; the other two femoral components had a radiolucent line at the cement-prosthesis interface in zone 1. By strict definition, these two femoral components were loose even though the radiolucent line was non-progressive and the patients were asymptomatic.

Twelve (32 per cent) of the thirty-seven unrevised acetabular components were radiographically loose. Ten acetabular components had evidence of definite loosening with a complete radiolucent line (type-III demarcation<sup>11</sup>) between the cement and the bone. Only one of the ten patients was symptomatic. Seven hips had type-II demarcation. In two of these hips, the radiolucent line was progressive and the cup was considered loose; in the other five, the line was non-progressive and the cup was considered possibly loose.

Table I Rates of Revision and Radiographic Failure Based on Preoperative Diagnosis*		
Group	Rate of Revision†	Rate of Loosening†‡
Subluxation <sup>4</sup>		
Type II	0/17	2/13
Type III	0/10	3/8
Type IV	2/16	4/14
Revision of cup arthroplasty	2/14	6/8
Total	4/57 (7%)	15/43 (35%)
*The data on the two hips that were revised because of an infection are not included.		

We evaluated the relationship between the type of defect and the rate of failure of the acetabular component (Table I). Because of the high rate of failure associated with a previous cup arthroplasty, we evaluated patients who had a previous cup arthroplasty as a separate group. The rate of revision was based on the status of all of the hips at the time of the most recent examination. The seven hips that had been lost to follow-up and the two hips that had been revised because of an infection were excluded, leaving fifty-seven hips. The five hips in patients who had died were included as they all were functioning well until the time of death. The rate of loosening was based on the forty-five hips for which current radiographs were available. The two hips that were revised because of an infection were excluded, leaving forty-three hips. The components that were considered loose included those that had been revised.

Among the hips that had not had a previous cup arthroplasty, those that had Crowe type-III subluxation had the highest rate of loosening (three of eight hips). With the numbers available, however, we could detect no significant differences in the rates of loosening

among hips that had Crowe type-II, III, and IV subluxation ( $p > 0.05$ ). When these three groups were combined, the rate of loosening was 26 per cent (nine of thirty-five hips). The hips that had had a previous cup arthroplasty had the highest rate of failure of the index acetabular component (six of eight hips); this rate was significantly higher than that for the combined group of hips that had Crowe type-II, III, or IV subluxation ( $p = 0.01$ ).

The center of the femoral head was moved inferiorly and medially at the time of the operation. The average horizontal displacement decreased from fifty-seven millimeters (range, thirty-six to seventy-nine millimeters) preoperatively to twenty-seven millimeters (range, twenty to thirty-four millimeters) postoperatively. The average height of the center of the femoral head decreased from forty-five millimeters (range, sixteen to 108 millimeters) preoperatively to twenty-three millimeters (range, eight to thirty-four millimeters) postoperatively.

With the numbers available, we could detect no significant difference between the hips in which the prosthesis had failed (had been revised or was radiographically loose) and those in which it was well fixed with regard to either horizontal or vertical displacement ( $p > 0.05$ ). The average horizontal displacement of the femoral head was twenty-seven millimeters (range, twenty-three to thirty-one millimeters) in the hips in which the prosthesis had failed and twenty-seven millimeters (range, twenty to thirty-four millimeters) in those in which it was well fixed. The average vertical displacement of the center of the femoral head was twenty-one millimeters (range, eight to thirty-two millimeters) in the hips in which the prosthesis had failed and twenty-two millimeters (range, fourteen to thirty-four millimeters) in those in which it was well fixed.

Heterotopic ossification was graded in forty-three hips and was found to be grade 1 in four hips (9 per cent), grade 2 in three (7 per cent), and grade 3 in one (2 per cent). No hip had grade-4 heterotopic ossification.

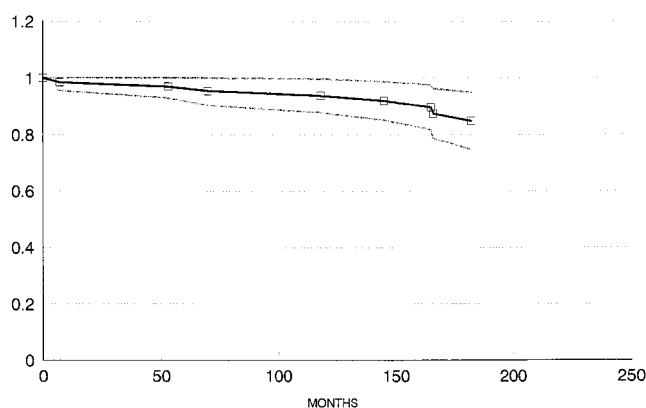


FIG. 1-A

Fig. 1-A: Survivorship curve with 95 per cent confidence limits, with revision as the end point.

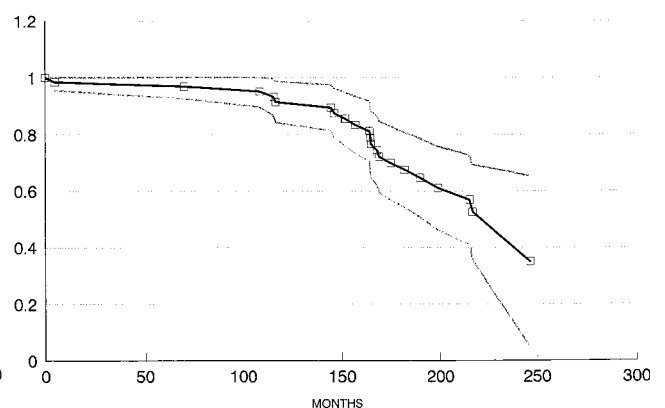


FIG. 1-B

Fig. 1-B: Survivorship curve with 95 per cent confidence limits, with radiographic loosening as the end point.

Osteolysis was graded in thirty-seven hips and was found around seven (19 per cent) of the acetabular components and three (8 per cent) of the femoral components. Four of the hips that had acetabular osteolysis had it in more than one zone. Two of the three hips with femoral osteolysis had measurable polyethylene wear (twelve millimeters in one hip and three millimeters in the other) as seen on plain radiographs. These two hips had progressive lytic changes surrounding the acetabular component as well. Both of the hips in which a twenty-eight-millimeter femoral head had been used had marked acetabular osteolysis, and one of these two hips had marked femoral osteolysis.

#### *Survivorship Analysis*

Kaplan-Meier survivorship analysis with revision as the end point predicted a rate of survival of the prosthesis of 85 per cent (95 per cent confidence interval, 75 to 95 per cent) at fifteen years (Fig. 1-A). With radiographic loosening as the end point, the fifteen-year rate of survival of the prosthesis was 68 per cent (95 per cent confidence interval, 54 to 81 per cent) (Fig. 1-B).

#### **Discussion**

The unresolved issue in total hip arthroplasty for congenital dysplasia and dislocation of the hip is how best to reconstruct the acetabulum. McQueary and the senior one of us (R. C. J.) previously reported the results of sixty-six total hip arthroplasties performed with cement and without bone-grafting in fifty-three patients who had congenital dysplasia of the hip and who were followed for an average of 8.5 years<sup>20</sup>. The purpose of the present study was to evaluate these same patients after a longer duration of follow-up.

The use of cement to fill the superior defect has been associated with excellent short-term results. In the study by McQueary and one of us (R. C. J.), the rate of radiographic loosening was 10 per cent (six of sixty-one hips) and no revisions were performed because of loosening. Linde et al. reviewed the results of 123 total hip replacements that had been performed without bone-grafting because of congenital dislocation of the hip and reported radiographic loosening in twenty-three hips (19 per cent) after an average duration of follow-up of nine years<sup>17,18</sup>.

The rate of revision in the present study was 14 per cent (eight hips) after an average duration of follow-up of sixteen years. The results on the femoral side were excellent, but those on the acetabular side were not. Since the time of the previous report<sup>20</sup>, four acetabular components were revised because of loosening. In addition, twelve (32 per cent) of the thirty-seven unrevised hips for which radiographs were available had radiographic evidence of loosening of the acetabular component.

The rate of radiographic loosening of the femoral component was 5 per cent (three hips) in the previous

study<sup>20</sup>, and it remained low after the longer period of follow-up described in the present study. In the present study, the rate of failure of the femoral component was 8 per cent (five hips); this includes the three fractured stems and the two stems with radiographic evidence of debonding but with no progression of radiolucent lines and no symptoms of loosening. Previous investigators have questioned whether such debonding truly indicates loosening. As discussed by Schulte et al., the polished surface of the Charnley stem is not likely to bond to cement. In the present study, no stem was revised because of loosening except for those that broke.

The extent of the acetabular defect, and how it is treated, are related to the degree of subluxation. It is difficult to quantitate the amount of cement needed to fill the defect in each of these situations, but on the basis of our experience at the time of the operation, hips with Crowe type-II subluxation needed the least amount of cement, followed by those with Crowe type-IV subluxation; hips with Crowe type-III subluxation and those in which a previous cup arthroplasty had been performed needed the most cement. In Crowe type-II subluxation, the superior portion of the acetabular roof, while deficient, is still present; hips with such a defect needed the least amount of bulk cement. We agree with Garvin et al. that 75 per cent coverage of the component with bone often can be obtained in hips with Crowe type-IV subluxation. In the present study, a small acetabular cup was placed in the true acetabulum and the pseudo-acetabulum was filled with cement. For patients who had Crowe type-III subluxation or who had a revision of a previous cup arthroplasty, the bulk cement provided 100 per cent coverage of the superior portion of the acetabular roof, with a thickness of more than one centimeter throughout. There was a trend toward increased loosening with larger amounts of bulk cement (Table I); revision of a cup arthroplasty and Crowe type-III subluxation were associated with the highest rates of loosening (six of eight hips and three of eight hips, respectively). This difference was significant only for the hips in which a previous cup arthroplasty had been performed ( $p = 0.01$ ). It may be that the previous operation was more detrimental than was the actual amount of bulk cement.

A common alternative technique for the treatment of the superior defect is to use an autogenous graft from the femoral head<sup>7,9,21,27</sup>. Short-term results of bone grafts generally have been favorable, but long-term results have been less impressive. Wolfgang studied forty-two hips (thirty-seven patients) in which an autogenous graft had been used and reported a 5 per cent rate of loosening of the acetabular component (two hips) after an average duration of follow-up of 5.7 years. Harris et al.<sup>9</sup> described a technique in which an autogenous graft was used in combination with insertion of an acetabular component with cement. Gerber and Harris used that technique in forty-seven hips (forty-one of which had

congenital dislocation or dysplasia) and reported that 21 per cent (ten) of the acetabular components had failed at seven years postoperatively. Mulroy and Harris assessed the same group of patients at an average of twelve years postoperatively and reported a rate of revision of the acetabular component of 20 per cent (nine of forty-six hips) and a total rate of failure of the acetabular component of 46 per cent (twenty-one of forty-six hips).

Garvin et al. followed twenty-three of the twenty-nine hips that originally had been described by Crowe et al. and reported that 17 per cent (four) of the acetabular components had failed after an average of fourteen years. Only six hips had been treated with structural bone grafts, none of which showed signs of loosening. In the rest of the hips, the components had been inserted with cement without bone-grafting. Unlike Harris et al.<sup>9</sup>, Garvin et al. thought that bone-grafting is necessary in only 20 per cent of patients. This difference in philosophy and the difference in the numbers of hips (six compared with forty-six) make it difficult to compare the study of Garvin et al. with that of Mulroy and Harris. Of the forty-one hips with congenital dislocation or dysplasia reported on by Mulroy and Harris, 61 per cent (twenty-five) had Crowe type-IV subluxation, compared with 57 per cent (thirteen) of the twenty-three hips in the study by Garvin et al.

Another method of treating the acetabular defect is to accept a superior position for the center of the femoral head. Russotti and Harris reviewed the results of this technique in thirty-seven hips (thirty-four patients), twenty-eight of which had an acetabular defect that was secondary to congenital dysplasia. Those authors found that the center of most of the hips was located superiorly but no more laterally than normal. They reported a rate of failure of the acetabular component of 16 per cent (six hips) at eleven years. Radiographic loosening of the femoral component was noted in eight hips (22 per cent), four of which were revised. Other authors have described higher rates of loosening of the femoral component in association with a superior hip center<sup>15,28</sup>. Yoder et al. reported that patients in whom the center of the femoral head was in an almost anatomical position had a lower rate of loosening of the femoral component than did patients in whom the center of the femoral head was placed in a lateral or superior position.

The original study by McQueary and one of us (R. C. J.) described a significant ( $p < 0.04$ ) relationship between horizontal displacement of the femoral head and radiographic loosening of the acetabular component. After a longer duration of follow-up, we found no relationship between the location of the center of the femoral head and radiographic loosening; however, the hip center in the present study consistently was placed in an inferior-medial position.

The long-term results of total hip replacements performed with cement because of osteoarthritis have revealed an increasing prevalence of loosening of the

acetabular component with longer durations of follow-up<sup>24,26</sup>. Schulte et al. reviewed the twenty-year results of 330 Charnley hip replacements that were performed by the senior one of us (R. C. J.). The procedures were similar to those in the present study, but most of the hips did not have dysplasia; only seven of those hips are included in the present study. The rate of failure (revision or radiographic loosening) was 13 per cent (forty-three hips) for the acetabular components, compared with 6 per cent (twenty hips) for the femoral components. The average age of the patients was sixty-five years in the study by Schulte et al., compared with fifty-three years in the present study.

Age is one of the major factors determining the outcome of total hip replacement. Patients who are less than fifty years old have an increased risk of failure. In the present study, seven (35 per cent) of the twenty hips in the patients who were less than fifty years old at the time of the operation had evidence of loosening; at the time of the most recent examination, four had been revised and three had a radiographically loose component. Of the forty-six hips in the patients who were at least fifty years old, four had been revised (two because of infection) and ten (30 per cent) of the thirty-three unrevised hips for which current radiographs were available had a radiographically loose component. The rate of revision for loosening thus was 20 per cent in the patients who were less than fifty years old and 4 per cent in those who were more than fifty years old. Sullivan et al. reported on a group of sixty-three patients (eighty-four hips) who were less than fifty years old and who were followed for an average of eighteen years; nineteen of those patients were included in the present study. On the acetabular side, the rate of revision was 13 per cent (eleven hips) and the rate of revision or radiographic failure was 50 per cent (forty-two hips). On the femoral side, the rate of revision was 2 per cent (two hips) and the rate of revision or radiographic failure was 8 per cent (seven hips). Despite the overlap between the two studies, a comparison of the results suggests that patients who have congenital dysplasia of the hip do not have an increased risk of failure compared with patients of a similar age who have osteoarthritis.

In the present study, three femora (8 per cent) had radiographic evidence of osteolysis. There was a greater prevalence of osteolysis on the acetabular side. Osteolysis, originally referred to as so-called cement disease, is believed to be due to a reaction to wear debris<sup>12,23</sup>. The wear particles may arise from polyethylene or broken cement. Some authors have suggested that the reason for late failure of the acetabular component is the increased access of debris to the cement-bone interface on the acetabular side compared with that on the femoral side<sup>16,23</sup>.

NOTE: The authors thank Patricia Katz, who contacted the patients and families in this study, and Ralph Demasi for his help with the statistical analysis.

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