Providers' Ease of Transition to Adult Care for Youth with Varying Medical Needs

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Abbreviations: HCT, health care transition

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Abstract

This study assessed health care transition practices and compared healthy children, children with chronic medical conditions, care-dependent children, and medical technology-dependent children. Surveys were returned by 320 practicing pediatricians, internists, and family practitioners. One-third reported a standardized age for transition. Transition was more difficult for children with high needs, and transitions were more difficult for pediatricians than for internists or family practitioners. Three-quarters of the doctors reported they had no formal transition process, and 80% had no training on transitioning patients with chronic diseases suggesting that further training in health care transition is needed.

Introduction

The successful transition of youth to adult-oriented care has been long been a topic of national interest (Lotstein et al., 2005; Reiss, Gibson & Walker, 2005; Scal & Ireland, 2005; Burns, Sadof & Kamat, 2006; Young et al., 2006). Data suggest that the movement of adolescents into the adult health care system is often arbitrary and unsystematic, and patients may forsake the system entirely until medical crises impel them to seek care as adults (Blum et al., 1993; Rosen, 1994; Viner, 1999). Lapses in health care are undesirable for anyone, but adolescents with chronic medical conditions are especially likely to suffer adverse physical or psychological consequences if attempts to transition into adult health care are neglected or fail (Sawyer et al., 1997; Kipps et al., 2002; Baines, 2009; Chaturvedi et al., 2009). Currently in the United States, more than 500,000 youth with special health care needs age into adulthood every year (Hallum, 1995; Reiss & Gibson, 2002). About half of these patients have intellectual disability, significant mental health issues, or developmental disabilities (Blum et al., 1993; Suris, 1995; Vander Stoep et al., 2000). The other patients have chronic medical conditions such as cystic fibrosis, juvenile diabetes, congenital heart disease, sickle cell disease, or neuromuscular disease. At least one-third of these conditions are moderate or severe (Blum et al., 1993; Callahan, Winitzer & Keenan, 2001), including dependence on some form of medical technology (e.g., feeding tubes, mechanical ventilators).

In 2001, the American Academy of Pediatrics (AAP), the American Academy of Family Physicians, and American College of Physicians/American Society of Internal Medicine co-issued a consensus statement (2002) aimed at ensuring that by the year 2010, all physicians providing primary or subspecialty care to young people with special health care needs would: 1) understand the rationale for transition from child-oriented to adult-oriented health care; 2) have the knowledge and skills to facilitate that process; and 3) know if, how, and when transfer of care is indicated. Nevertheless, after nearly a decade of effort and a despite resolution by the 2007 AAP Annual Leadership Forum designating the transition of youth with special health care needs to adult health care as a top-10 priority (American Academy of Pediatrics et al., 2011), the implementation of structured health care transition (HCT) programs has not been realized.

Despite the universal recognition that a proactive HCT process is the best preparation for an uninterrupted transfer of medical care between pediatrics and adult care, current evidence suggests that many young patients with complex medical conditions continue to face challenges in their HCT (McPherson et al., 2004; Lotstein et al., 2005; Tuchman, Slap & Britto, 2008). A recent national survey revealed that pediatricians remain poorly informed about the conclusions of the AAP 2001 consensus statement on HCT (McManus et al., 2008). Only 47% of U.S. pediatricians who responded to the survey made specific referrals to adult primary and specialty physicians to assist most of their adolescent patients who have special health care needs. Similarly, a study of HCT in young adults with intellectual disabilities in Australia identified a lack of communication between different levels of health care as a detriment to the transition process, potentially resulting in a loss in continuity of care (O'Connell, Bailey & Pearce, 2003). The present survey was designed to assess HCT practices in the state of Connecticut and compare transitions of healthy children, children with chronic medical conditions, children with neurodevelopmental disabilities, and medical technology-dependent children.

Method

Survey

The survey instrument was mailed to a list of 2,676 primary care physicians practicing in the state of Connecticut in 2010. The Authors obtained a list of physicians in the state through the

WebMD National Physicians Data Source. The source originated from *The Little Blue Book,* which is a published reference of licensed providers for a locality. The survey consisted of 33 questions asking characteristics of the doctor, types of patients served, and information on transitioning patients to adult care. The survey was developed by a focus group interested in health care transition practices. For pediatric providers, questions related to the transfer of care to adult providers; for adult providers, questions related to the assumption of care. Due to the absence of patient-specific information and the voluntary responses by practitioners, the requirement for informed consent was waived by the Institutional Review Board of the University of Connecticut Health Center.

Statistical Analysis

Data analysis was conducted using Statistical Package for the Social Sciences 19.0 (SPSS) software (SPSS Inc, Chicago, Ill). Data were analyzed to determine: 1) the impact of type of practitioner on ease of transition process by complexity of patients (one-way x 3 ANOVA between practitioner groups); and 2) the impact of who initiates transition process on ease of transition by complexity of patients (one-way x 4 ANOVA between groups of who initiated the transition: patient, doctor and staff, patient and doctor and staff, and combination with subspecialty). The dependent measure was ease of transition and was rated by the doctors on a five point scale ranging from very easy (1), easy (2), neither easy nor difficult (3), difficult (4), or very difficult (5). To control for type 1 error across multiple tests, an adjusted Bonferroni p value of 0.0125 was used to detect significance. Effect sizes for differences between the practitioners' ease of transition were determined by the eta-squared (η^2) statistic, which describes the ratio of variance explained in the dependent variable by a predictor while controlling for other predictors. An η^2 value of 0.0099 constituted a small effect, 0.0588 a medium effect, and 0.1379 a large effect (Cohen, 1988). Results were presented as mean ± standard deviation values (continuous variables) or as percentage responses (categorical variables).

Results

Response Rates

Surveys were returned by 137 practicing pediatricians, 118 internists, and 65 family practitioners in the state of Connecticut, representing a response rate (RR) of 12.0%. Response rates were similar amongst providers of adult care (10% RR), family (e.g., adult and pediatric) care (14% RR), and pediatric care (21% RR). Table 1 shows selected background characteristics of the survey respondents. Almost all the participating physicians had patients with no chronic diseases as part of their practice, patients with chronic diseases, and care-dependant patients. Only 25% of respondents cared for technology-dependent patients.

Transition Practices

Table 2 details the age of transition, how transition age was determined, who initiated the transition process, what formal processes were utilized, and where training on transitioning occurred. Almost half of the physicians answered that their patients were transitioned at 18 years of age, followed by transitioning patients when they were over 21 years old. Transition times varied significantly between provider groups, with pediatricians most likely to transition at college graduation or age 21 years, and internists most likely to accept patients in transition at age 18 years ($p < 0.0001$). In contrast, most family practitioners responded "other" to age of transition, possibly reflecting the lack of need to transition patients in a family practice setting. The transition age was primarily determined by the patient or family, sometimes by a standardized age, or rarely by a subspecialty provider. Only about half of responders strongly considered patient ability and readiness for self care in determining time of transition. The requirement of patient self-management in transition was not influenced by patient type (i.e., strongly considered in 49% of independent/well patients, 57% of independent patients with chronic disease, 53% of dependent patients, and 49% of technology-dependent patients; $p = 0.41$).

The transition process was initiated by the patient or family, the doctor or their staff, or rarely by the subspecialty doctor. Transition initiation was also dependent upon practice type. The majority (77%) of internal medicine providers responded that patients or families initiated the process, as compared to only 20% of pediatric providers ($p < 0.0001$). It is noted that internists may be unaware of what occurred in pediatric practices prior to patients transferring in to their adult practice; however, their response suggests that the initial contacts for these patients came from the transitioning youths and families themselves, rather than from the pediatric care providers. Most (60%) pediatric practices reported initiating the transition discussion 1 year prior to the transition, with only 8% providing 2 years and 3% providing 4 years of discussion. Three-quarters of the doctors answered that they had no formal transition process. Only 10% of respondents had written transition materials for the patient or family. Even fewer physicians reported alternating visits between pediatric and adult care providers to assist in transition, periodic evaluation of the process of transition, determination of self mastery skills, or a care/transition coordinator. Nearly 80% of physicians noted they never received any training on transitioning patients with chronic diseases. Of those who reported some training, 6% and 14% received it during medical school and residencies, 7% received training in post-residency CME programs, and 8% used their own independent resources to receive training.

Ease of Transition for Different Providers

Figure 1 displays mean scores on ease of transition process for type of practitioner and level of patient complexity. Independent of patient complexity, transition of youth with special health care needs (e.g., patients with chronic diseases, care-dependent patients, and technology-dependent patients) was more difficult for pediatricians (mean 2.79 ± SD 0.85) than for internists (2.20 ± 0.70; $p < 0.0001$). Family practitioners found it easier to transition such patients (2.06 ± 0.80) than either pediatricians ($p < 0.0001$) or internists ($p < 0.0001$). As shown in Figure 2, knowledge of adult providers (Fig. 2A) and financial issues (Fig. 2C) became more important as the complexity of the patient increased in HCT considerations by all three physician groups ($p < 0.0001$).

Independent, Well Patients. There was a statistically significant difference in mean score on ease of transition for type of practitioner for independent, well adolescents (F (2, 194) = 15.62; $p < 0.001$). The effect size was large ($\eta^2 = 0.14$). Post-hoc comparisons indicated that pediatricians rated transition significantly more difficult than internists (2.80 ± 0.85 vs. 2.25 ± 0.64; $p < 0.0001$) or family practitioners (2.06 ± 0.80; $p < 0.0001$). Family practice and internal medicine physicians did not differ in their assessment of ease of transition for these patients.

Patients with Chronic Diseases. There was a statistically significant difference in mean score on ease of transition for type of practitioner for adolescents with chronic diseases (F (2, 226) = 18.76; $p < 0.001$). The effect size was large ($\eta^2 = 0.14$). Pediatricians rated transition significantly more difficult than internists (3.27 ± 0.81 vs. 2.65 ± 0.77; $p < 0.001$) or family practitioners (2.57 ± 0.83; $p < 0.001$), with no difference between the other 2 groups of providers.

Care-Dependent Patients. There was a statistically significant difference in mean score on ease of transition for type of practitioner for care-dependent adolescents (F (2, 229) = 18.96; $p < 0.001$). The effect size was large ($\eta^2 = 0.14$). Pediatricians rated transition significantly more difficult than internists (3.70 ± 0.86 vs. 2.95 ± 0.96; $p < 0.001$) or family practitioners (3.03 ± 0.93; $p < 0.001$), with no difference between the other 2 groups of providers.

Technology-Dependent Patients. There were no significant differences for transitions in technology-dependent adolescents. However, the means indicated similar trends as the other three client groups, with pediatricians (3.69 ± 0.95) rating transition the most difficult followed by internists (3.43 ± 1.08) and family practitioners (3.30 ± 1.42).

Transition Considerations

The majority of providers cited patient and family concerns as a variable to be considered in planning and timing of transitions. Consideration of this factor did not change between providers (75% pediatricians, 71% internists, 77% family practitioners; $p = 0.67$) or between patient types (74% independent, 73% chronic disease, 73% dependent, 82% technology-dependent; $p = 0.21$). Other important considerations included knowledge of adult providers about the medical condition (43%, Fig. 2A), willingness of adult providers to accept the transfer (53%, Fig. 2B), and financial issues (19%, Fig. 2C). For children with special health care needs (e.g., those with chronic diseases, neurodevelopmental disability, or technology dependence), willingness of adult providers to accept the patient was a greater concern for pediatricians (70%) than for internists (57%) or family practitioners (43%) ($p = 0.002$).

Initiation of Transition Effects on Ease of Transition

Figure 3 displays mean scores on ease of transition process for who initiated the transition and level of client complexity. There was a statistically significant difference in mean score on ease of transition for who initiated transition for independent clients (F (3, 185) = 6.44, $p < 0.001$). The effect size was medium ($\eta^2 = 0.09$). Practices that had patients initiate transition reported easier transitions (2.22 ± 0.72) than practices who initiated transition utilizing both the patient and the doctor/staff (2.69 ± 0.85; $p = 0.010$) or the doctor/staff only (2.78 ± 0.89; $p = 0.001$). There were no significant findings for those who initiated transition by the subspecialty providers. Similar findings were seen for patients with chronic diseases and for care-dependent patients. For patients with chronic diseases, transitions initiated by the patient (2.67 ± 0.84) were felt to be easier than transitions initiated by the doctor/staff (3.41 ± 0.78; F (3, 217) = 9.13, $p < 0.001$; $\eta^2 = 0.11$). For the care dependent patients, practices who initiated transition by the patient (3.02 ± 0.96) had an easier time with transitions compared to those who initiated by the patient and the doctor/staff (3.62 ± 0.88) or those who initiated by the doctor/staff (3.69 ± 0.88; F (3, 219) = 7.781, $p < 0.001$; $\eta^2 = 0.10$). There were no significant findings for the technology dependent client group.

Of interest, independent of patient groups, there were no statistical differences between ease of transition and any formal transition practice for any provider group, including written transition materials, alternating pediatric and adult visits, and a specific transition coordinator. Nor were there any differences between ease of transition and provider training in transition, including medical school/residency training, CME training, independent training, or no training at all. Even when focusing only on doctor/staff-initiated transitions, neither format transition practices nor provider training had any impact on ease of transition for any group of patients.

Discussion

Our low response rate and the possibility of response bias prevent us from making definitive statements; however, the results of the present study support national findings on HCT between pediatric and adult medical care. The pediatricians who responded to this survey typically transitioned patients by age 21 years or college graduation, and internal medicine physicians typically accepted patients aged 18 years or older. Only a third of practices had a standardized age of transition. Seventy-one percent of responding pediatricians reported initiating HCT discussions with patients, most within 1 year of transition. This percentage was identical to what was obtained in the 2008 national AAP survey of pediatricians, in which two-thirds of practicing pediatricians responded that transition planning should begin between ages 18 and 20 years (McManus et al., 2008). Such a short period may be appropriate for some healthy children; however, it is unlikely to meet the needs of medically complex patients, in whom it is recommended that a written HCT plan should be prepared by age 14 years and updated annually with the young person and family (American Academy of Pediatrics et al., 2002). This discrepancy suggested a lack of coordination and/or insufficient communication between the transferring pediatric and accepting adult service.

As anticipated, the HCT process was perceived as being more difficult for adolescents with increasing health care complexity (i.e., chronic disease to neurodevelopmental dependence to technology dependence) compared to independent, well youth. This trend was similar for all practitioners. These results suggested that our survey respondents may have the same difficulties implementing HCT as the respondents on other surveys, which have included inadequate training in the disease processes (Peter et al., 2009; Suris, Akré & Rutishauser, 2009), capitated reimbursement systems that discourage acceptance of young adults with severe disabilities as new patients (Hallum, 1995; Sawyer, Blair & Bowes, 1997; Earl & Blackwelder, 1998; Viner, 2000), and lack of support from adult hospital or clinics (Esmond, 2000). In the present study, we found that adult providers' knowledge of the patients' conditions and financial considerations had greater impact on HCT for patients with chronic diseases and for patients with neurodevelopmental disability and technology dependence than for independent, well adolescents.

Independent of patient complexity, transition of children with special health care needs was easier for family practitioners than for either pediatricians or internists. An analysis of the 2005-2006 National Survey of Children with Special Health Care Needs found that lifespan-oriented providers (i.e., family practitioners and pediatric/internal medicine dual certified practitioners) are more likely to facilitate HCT for youth with special health care needs than were child-only providers (Nishikawa, Daaleman & Nageswaran, 2011). The majority of our family practitioners noted no age of transition, indicating their potential continued care of well and medically complex young adults. Transition likely means something very different for family physicians than pediatrics or internists, related more to referring to adult subspecialists rather than transitioning primary care responsibilities.

There were several limitations to our study, the most significant of which was our low response rate. The low response rate may reflect the low priority given to this topic by primary care providers, or it could be due to our lack of incentives or reimbursement for completing the survey. It is possible that providers who were most likely to complete and return the survey were also the most involved in and/or concerned with HCT planning. Response rates were similar for the three groups of providers, but we cannot make any conclusive statements about providers not participating in the study. In addition, the surveys were limited to primary care physicians practicing in a single state. We chose to study only primary care practitioners because of the importance of the primary health care team in transition planning (Fiorentino et al., 1998; David, 2001; American Academy of Pediatrics et al., 2002), even though adolescents with chronic illnesses often may have less contact with their primary care providers than with their subspecialty teams (Pennell & David, 1999; Viner, 1999; Binks et al., 2007). We did not include nurses, advanced nurse practitioners, or physician assistants in the survey – individuals who may also play major roles in HCT in the primary care setting. Finally, it is important to emphasize that physician perceptions about the delivery, ease, and concerns related to HCT may have little or no correlation with the outcome of the HCT or with patient/family perceived ease and satisfaction with the transition.

Implications for Practice

With few model practices exemplifying high-quality transition programs in the primary care setting, training providers in the principles of health care transition remains challenging (McManus et al, 2008). The present study found that most of the responding primary care providers in Connecticut had no formal HCT process. They reported that HCT became progressively more difficult as the complexity of their adolescent patients' needs increased, but that in general, HCT was easier when initiated by the patient than by the physician. Physicians in pediatrics reported the most difficulty with adolescent HCT, while physicians in family practice reported the least. Physicians received little training in HCT and were uniformly interested in additional training. The ongoing challenges of providing safe and effective HCT to adolescents with special health care needs reinforce the life-course approach to primary care – whether it is provided in a family practice setting, in a combined pediatric-adult multispecialty group, or in innovative relationships between pediatric and adult primary and specialty care services. Such coordinated HCT programs are essential to maximizing medical homes which enhance quality of life and preservation of health for adolescents as they age into adulthood.

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Table 1

Background Characteristics of Respondents Completing the Study Survey (n=320)

Background Characteristics	Responders	Percentage
Primary client base		
Children	137	43%
Adults	118	37%
Family practice	65	20%
Practice Setting		
Solo	59	18%
Small group (less than 4 Drs)	114	36%
Large group (more than 4 Drs)	118	37%
Multispecialty group	29	9%
Complexity of Patients		
Patients with no chronic diseases	297	93%
Patients with chronic diseases	293	92%
Care-dependent patients	262	82%
Technology dependent patients	80	25%

Table 2

Transition Characteristics of Physicians

	All Physicians	Pediatrics	Internal Medicine	Family Practice
Transition Characteristics	Responders (Percentage)	Responders (Percentage)	Responders (Percentage)	Responders (Percentage)
Age of transition				
Under 18	26 (8%)	1 (1%)	18 (15%)	7 (11%)
18 years old	129 (41%)	19 (14%)	92 (78%)	18 (27%)
21 years old	33 (10%)	30 (22%)	2 (2%)	1 (2%)
Between 18-21	28 (9%)	24(18%)	3 (3%)	1(2%)
Over 21	62 (20%)	58 (43%)	1 (1%)	3 (5%)
Transition age determined by				
Patient/family	187 (60%)	93 (68%)	60 (52%)	34 (57%)
Standardized age	117 (37%)	50 (37%)	56 (48%)	11 (18%)
Subspecialty	22 (7%)	15 (11%)	5 (4%)	2 (3%)
Initiation of transition process by				
Patient/family	149 (50%)	28 (20%)	85 (77%)	36 (75%)
Dr./staff	64 (22%)	52 (38%)	6 (5%)	6 (13%)
Patient and Dr./staff	60 (20%)	48 (35%)	7 (6%)	5 (10%)
Subspecialty	23 (8%)	9 (7%)	13 (12%)	1 (2%)
Process for transition				
No formal transition process	228 (76%)	97 (73%)	84 (76%)	47 (89%)

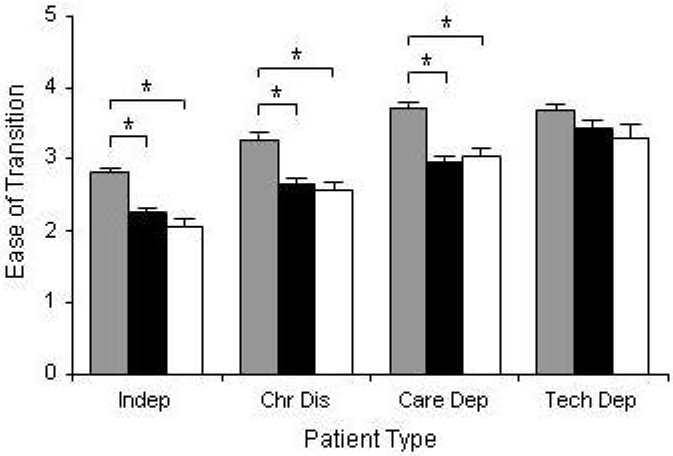
Standardized process	40 (13%)	20 (15%)	17 (16%)	3 (6%)
Written materials for patient/family	29 (10%)	19 (14%)	8 (7%)	2 (4%)
Alternating visits between pediatric and adult care providers	7 (2%)	3 (2%)	2 (2%)	2 (4%)
Periodic evaluation of the process	7 (2%)	4 (3%)	2 (2%)	1 (2%)
Determination of self mastery skills	6 (2%)	4 (3%)	1 (1%)	1 (2%)
Care/transition coordinator	6 (2%)	5 (4%)	1 (1%)	0 (0%)
Training on transitioning patients with no chronic diseases				
Never received any training	235 (78%)	108 (%)	90 (78%)	37 (66%)
Residency	41 (14%)	11 (8%)	13 (11%)	17 (30%)
Independent resources	24 (8%)	15 (11%)	5 (4%)	4 (7%)
Post-residency CME	21 (7%)	7 (5%)	9 (8%)	5 (9%)
Medical School	18 (6%)	1 (1%)	9 (8%)	8 (14%)

Figure Captions

Figure 1. Mean ease of transition process indicator scores for type of practitioner and level of client complexity. Gray = pediatricians; black = internists; white = family practitioners. Data represent mean + SE values. * indicates $p < 0.05$ between bracketed groups.

Figure 2. Transition concerns for practitioner type and level of client complexity. Gray = pediatricians; black = internists; white = family practitioners. Data represent mean + SE percent of responders citing the specific concern. * indicates $p < 0.05$ between bracketed groups.

Figure 3. Mean ease of transition scores for who initiates transition and level of client complexity. Solid = patient/family; striped = Family and MD; stippled = MD/staff; crossed = subspecialist. Data represent mean + SE values. * indicates $p < 0.05$ between bracketed groups.


Ease of Transition
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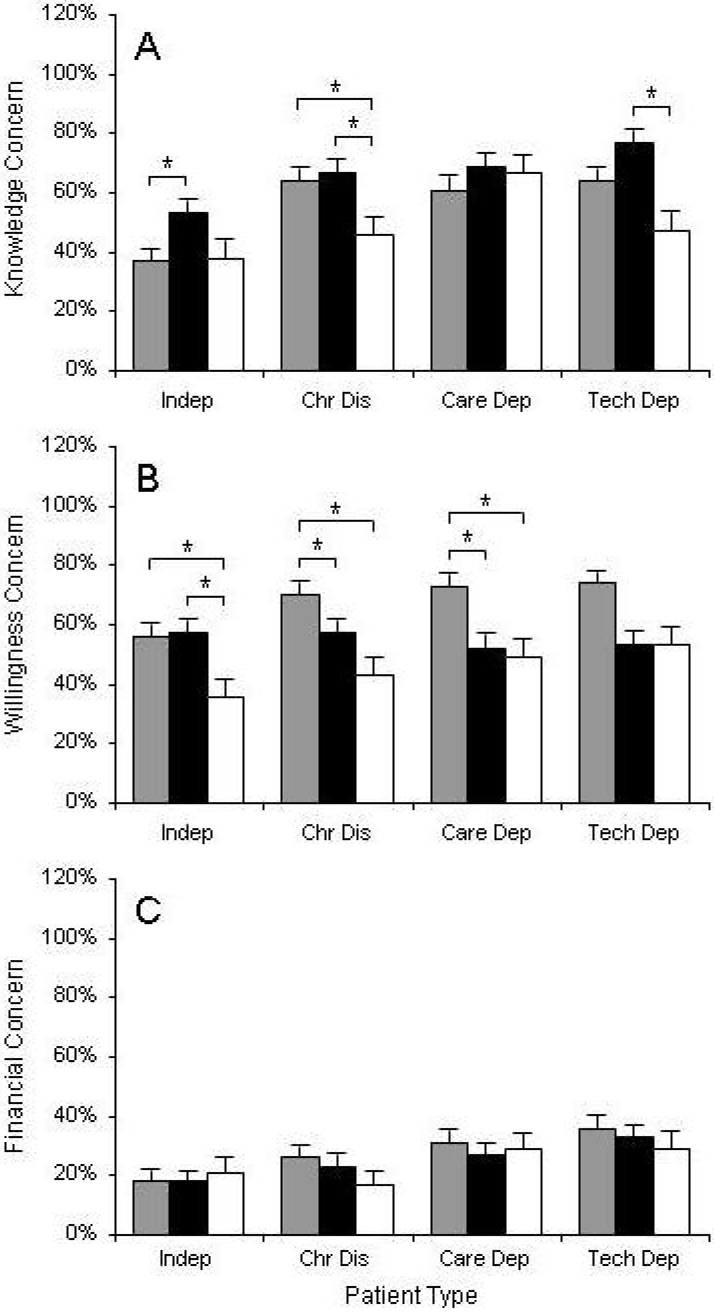
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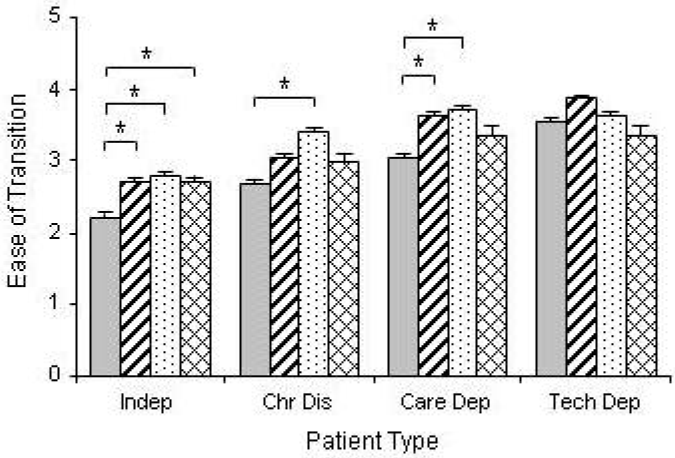
Tech Dep
Patient Type


5
4
3
2
1
0
Ease of Transition
*
*
*
*
*
*
Indep
Chr Dis
Care Dep
Tech Dep
Patient Type