



Full Length Article

The journey for adolescents and young adults with chronic conditions transitioning to adult care with successful warfarin management[☆]



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ABSTRACT

Health transition of youth from a child-centered care model to the adult model has been recognized to be of critical importance due to the increasing numbers of children now surviving chronic conditions. A formalized transition process is required adequately assess the AYA's readiness for transition and to move towards adult care. Indefinite warfarin therapy poses challenges as warfarin is a narrow therapeutic index drug that requires frequent monitoring and attentiveness to warfarin interactions and affects.

Objective: The objective of this study was to evaluate transition to adult care for AYAs requiring indefinite warfarin therapy within a structured self-management program.

Outcome measures: Results were compared between Phase 1 (enrollment to patient self-management) and Phase 2 (independent warfarin management) 6 months following confirmation of transition to adult care. There was no statistical difference between outcome measures except INR testing frequency, and no adverse events.

Conclusions: This transition process resulted in successful transition as measured by TTR and other clinical endpoints from pediatric to adult care. Implementing a formal transition process for young adults with chronic health conditions that considers patient preferences motivates and empowers them over time to develop autonomy with warfarin self-management, results in successful transition and warfarin management.

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1. Introduction

Health transition of youth from a child-centered care model to the adult model has been recognized to be of critical importance due to the increasing numbers of children now surviving chronic conditions, and a lost to follow-up rate of approximately 50% [1–3]. The need for a transition processes is required because the transition of child-centered to adult healthcare is frequently associated with poor outcomes for young adults [4–6]. An adult-oriented health care model requires that the adolescent-young adult (AYA) become autonomous, self-manage their health care, and be knowledgeable of their health condition and the health care system. Current health systems impose artificial boundaries between child-centered and adult care; these include structural barriers such as funding streams and age limits, set by health systems, which are inconsistent with the adolescent's readiness for transition [7]. Every young person's development naturally includes a process towards independence. However, for adolescents with

chronic conditions, transitions are further challenged by their health situation. They often achieve fewer developmental milestones; experience more restrictions in social situations compared to their healthy peers, and may lag behind in education and work, independent living, and relationships [8].

The need for formalized transition processes prompted the American Academy of Pediatrics/American Academy of Family Physicians/American College of Physicians to publish a clinical report [9] on transition from adolescence to adulthood for children with chronic conditions. The report established an algorithm with six core principles to facilitate successful transition.

Adolescents requiring indefinite/long-term warfarin therapy are a group at particular risk given the complexity of warfarin management [10–13]. Successful warfarin management, determined by time-in-therapeutic-range, is multifaceted, requiring frequent international normalized ratio (INR) testing, knowledge and assessment of factors that may influence warfarin metabolism (diet, illness, medication, errors (i.e. missed doses)), and warfarin dose adjustments. This complexity results in increased burden for the adolescent (patient) and family unit [14,15]. Increased burden is associated with decreased health related quality of life, which affects adherence. Adherence is directly associated with safety and efficacy [16] of therapies and is as low as 50% in both

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children [10] and adults [17]. Home INR monitoring using a coagulometer is associated with improved TTR in both children and adults [10] with patient warfarin-self-management empowering AYAs to have control over the therapy and a further increase in TTR [18,19]. No study has evaluated the transition process using the American Academy of Pediatrics core principles in adolescents/young adults requiring indefinite warfarin therapy.

1.1. Objective

The objective of this study was to evaluate transition to adult care for AYAs requiring indefinite warfarin therapy within a structured self-management program.

The primary outcomes were sustainability of safe and effective warfarin management as measured by continued follow up in adult care, and time in therapeutic range 6 months post-transition confirmation. Further measures included warfarin knowledge scores, adherence to therapy, out of range INRs (≤ 1.6 and ≥ 5), and adverse events.

1.2. Outcome measures

Transition success was determined by the sustainability of effective warfarin management post-transition to adult care. Outcome measures to evaluate effective transition in warfarin management were compared between the first 6 months on warfarin-self-management (with parental support) (Phase 1) and 6 months post-transition confirmation (Phase 2) with confirmed continued follow up in adult care. Outcome measures that were compared included: patient time-in-therapeutic-range, frequency of INR testing, number of INRs < 1.6 or ≥ 5 , the number of calls to the anticoagulation team for support, warfarin knowledge scores, adherence to reporting INRs, and adverse events (bleeding and thrombotic). Major bleeding events were defined as those requiring an emergency visit or admission to hospital. A thrombotic event was defined as any objectively confirmed thrombosis. Upon the completion of transition, follow appointments occurred on a yearly basis with the adult anticoagulation team.

2. Methods

The transition process includes six essential elements which were identified and adapted from the American Academy of Pediatrics core principles [9] and include the following essential elements: 1) AYA registry, 2) transition policy, 3) transition goals, 4) transition planning and developing readiness, 5) transition and transfer of care, and 6) transfer completion [9,20].

2.1. Inclusion and exclusion criteria

2.1.1. Adolescent/young adult database (essential element 1)

A database was maintained of all patients > 11 years of age on warfarin for ≥ 3 months, who were fluent in English, were eligible to participate in the study.

This prospective longitudinal cohort, nested within the EmPoWARed study [14], enrolled adolescents/young adults with underlying chronic conditions who were prescribed long term warfarin therapy and were followed by the KIDCLOT [21] program between May 2008–2012 with data collected until August 2014. All patients provided informed consent and assent consistent with the Health Research Ethics Board at the University of Alberta and then participated in the formalized transition process (described below). The patient group included patients 11–28 years with chronic health conditions who were followed by KIDCLOT. The KIDCLOT program is a dedicated anticoagulation program at Stollery Children's Hospital, Edmonton, Alberta, Canada. Within this program, home INR testing (patient tests INR at home and reports INR to KIDCLOT to make warfarin dose change) is the standard of care with coagulometers [22,23] on loan to patients. Adult care is provided

by an adult hematologist connected to the KIDCLOT© program with shared resources including website and patient education.

2.1.2. Transition policy & process (essential element 2)

The KIDCLOT program uses an evidenced based transition policy to guide transition that includes warfarin self-management. The health provider begins discussions with the adolescents/young adults and caregiver as early as age 11 years to develop a collaborative transition plan which includes identifying patient preferences for transition, developing patient knowledge and skill to successfully self-manage their warfarin.

Participants were enrolled in to the EmPoWARed study [14] at various ages. Warfarin self-management takes self-testing a step further and requires the AYA to learn to adjust their warfarin dose and determine their next INR test date in order to achieve and maintain a target INR. The AYA and family attend an age appropriate group anticoagulation clinic appointment where they participate in comprehensive warfarin education as the commencement of warfarin self-management. The interactive classroom session (approximately 1.5 h) is followed by a focused individual assessment to evaluate and promote transition readiness and address outstanding patient needs. Education is age appropriate and encourages participation of both the AYA and parent to develop warfarin knowledge over time.

The AYA and family then participate in a 3-month apprenticeship in warfarin management. During the apprenticeship, the AYA entered the INRs on-line into www.KIDCLOT.com with discussion with the health provider for out of range INRs. This reporting method is efficient, easily accessible, patient friendly, and engaging. The website alerts the AYA to consider any changes in diet, illness, medications, or errors such as missed doses that may influence their warfarin dose decision. In addition, the AYA receives an email reminder when INR testing is due.

This apprenticeship period was followed by independent warfarin self-management performed collaboratively by the AYA and family with the AYA progressing in independence. A detailed description of the EmPoWARed methods has previously been published [14].

2.1.3. Transition goals (essential element 3)

The goals of transition were to engage the AYA to develop knowledge and skill to motivate and empower each AYA to safely and effectively manage their warfarin therapy.

2.1.4. Transition planning and developing readiness for adolescents and young adults (essential element 4)

Adolescent/young adults are encouraged to participate in warfarin dose decisions and report INR with warfarin dose decision into the website via computer or smart-phone (mHealth) [24–26]. To further empower the AYA and increase their knowledge and competence, the AYA returns to KIDCLOT clinic with education sessions tailored for AYA every 12–18 months until transitioned to adult care. During the visits the knowledge and participation of the AYA in their warfarin management is evaluated using the validated warfarin questionnaire [27,28] with a score of $> 80\%$ considered acceptable. Any incorrect responses were reviewed with the AYA prior to leaving clinic to facilitate further development of warfarin knowledge. Adherence was evaluated through website entries of INRs, testing intervals, and confirming that the warfarin dose decision is consistent with the education provided and the dosing algorithm. A health provider independent of the study team carried out evaluation of adherence.

Adolescent/young adult preparedness for transition was assessed using an un-scored modified Transition Readiness Questionnaire [29] (Fig. 1) from 2012 to 2014, and competence in managing warfarin therapy was assessed over the study period with a decision for transfer made at a minimum age of 17–18 years, or after one year of successful warfarin-self-management. Early discussion about the need to purchase a coagulometer to continue warfarin self-management occurred at every appointment to facilitate family budgetary planning.

Directions to Youth and Young Adults: Please V the box that best describes your skill level in the following areas that are important for transition to adult health care. There is no right or wrong answer and your answers are kept confidential and private.

Directions to Caregivers/Parents: if your youth or young adult is unable to complete the tasks below on their own, please check the box that best describes **your** skill level
 Check here if you are a parent/caregiver completing this form.

<i>Adapted from TRAQ; Wood et al; April 2015</i>	No, I do not know how	No, but I want to learn	No, but I am learning to do this	Yes, I have started doing this	Yes, I always do this when I need to
Managing Medications					
1. Do you know why you are taking warfarin?					
2. Do you reorder and fill your warfarin prescription if you need to?					
3. Do you know what your dose of warfarin is?					
4. Do you take your warfarin correctly on your own?					
5. Do you write down your warfarin doses each time you check your INR?					
INR testing					
6. Do you know what your target INR is?			No	Yes	
7. Do you know how often you usually check your INR?					
8. Do you test your INR yourself?					
9. Do you keep track and a record of when to check your INR?					
10. Do you know what to do if your INR is high or low?					
11. Do you report your INR to KIDCLOT on your own?					
Appointment Keeping					
12. Do you contact KIDCLOT if you have any questions about your warfarin or need a clinic appointment?					
13. Do you contact KIDCLOT if there are any changes in your health?					
Tracking Health Services					
14. Do you fill out the medical history form, including a list of your allergies and medications?					
15. Do you keep a calendar or list of medical appointments?					
16. Do you make a list of questions before your doctor's visit?					
Talking with Providers					
17. Do you tell the doctor or nurse what you are feeling?					
18. Do you answer questions that are asked by the doctor, nurse or clinic staff?					
Managing Daily Activities					
19. Do you keep your home/room clean or clean up after meals?					
20. Do you use neighborhood stores and services (For example; grocery or pharmacy stores or laboratory services)?					

Fig. 1. KIDCLOT anticoagulation transition readiness assessment questionnaire.

Within this study KIDCLOT identified options for transition, with the AYA making the choice for adult care. Three options were presented to the AYA for INR/warfarin management. One option provided seamless INR reporting for warfarin-self-patients and other alternatives included transition to local anticoagulation clinic or family physician. Second option was to perform patient self-testing and report their INR's for dose adjustment with an adult healthcare provider. The final option was to attend a laboratory for venous INR's and transition with an adult healthcare provider.

2.1.5. Transition and transfer of care (essential element 5)

Each AYA participated in the decision about readiness for transfer of care. AYAs who needed additional support continued to be mentored by KIDCLOT for an additional year. This provided a definite endpoint to further prepare the AYA for successful transition.

Joint AYA clinics with pediatric and adult health providers were held to allow the AYA to familiarize themselves with the adult provider. KIDCLOT was available as resource for the adult provider. The kidclot.com website provided a portable anticoagulation summary that was accessible by the adult anticoagulation team or was printable by the patient. In addition to the anticoagulation summary, a letter of transfer was prepared for the adult provider summarizing, indication for anticoagulation, INR target range, warfarin dose, and any patient related challenges from the AYA and/or KIDCLOT perspective.

2.1.6. Transfer completion (essential element 6)

KIDCLOT continued to follow AYA until confirmation was received that the adult care provider had seen the AYA with care assumed. The last six months of data occurred after of confirmation of transition of care. Documentation of transfer was entered into the electronic medical

record system. Clinic attendance, continuation of warfarin therapy and INR testing an additional year post-transition was evaluated.

2.2. Statistical analysis

The AYA's baseline characteristics are reported descriptively. The TTR for each group and study phase was estimated using linear interpolation [30] between INR values. Outcomes were compared using paired *t*-test, Wilcoxon signed-rank test, or Kruskal-Wallis test as appropriate. A *P* value < 0.05 was considered statistically significant. Stata/SE 13 (Stata Corp, College Station, TX) was used for the statistical analysis.

3. Results

There were a total of 19 AYAs were enrolled in the study (95% of the KIDCLOT AYA population) from June 2008 to August 2014 with follow confirmation of warfarin management and follow up in adult care until February 2016. Clinical characteristics of study sample are presented in Table 1. Median age at study enrollment was 17 years (range: 11.8–28.5). Adolescents/young adults performed warfarin self-management for a median of 3.8 years (range: 1.4–5.3) over the entire study period. There was no statistically significant difference in median knowledge scores between Phase 1 (parental support) and Phase 2 (independent management) at 94 (range: 88–100) and 96 (range: 84–100), respectively. Median time-in-therapeutic-range between Phase 1 when parents were participating in care (78.6%, range: 69.5–100) and Phase 2 (76.6%, range: 35.5–100) was not statistically significantly different (*P* = 0.81). There was a statistically significant decrease in the median number of INR tests performed between Phases 1 and 2; from 23 (frequency every week) to 9 (frequency 2 weeks) (*P* = 0.0006), respectively. Warfarin dose decisions resulted in a median of 0 INRs ≥ 5 in both phases (range: 0–1 and 0–2, respectively) (*P* = 0.30); and a median of 0 INRs ≤ 1.6 (range: 0–5 and 0–1, respectively) (*P* = 0.08) per patient in Phases 1 and 2, respectively. Frequency of INR test errors was a median of 0 (range: 0–2) per patient per 6 months in both phases (*P* = 0.94). Calls for support were a median of 0 (range: 0–4 and 0–1, respectively) per patient per 6 months in Phases 1 and 2 (*P* = 0.28), respectively. There were no clinically relevant adverse hemorrhagic or thrombotic events.

Two year post-transition clinic attendance demonstrated that all 19 patients continue to attend appointments with adult providers, 17/19 patients continued warfarin therapy and INR testing. Two patients had their warfarin therapy discontinued by healthcare providers. The remaining patients continue PSM.

4. Discussion

This study evaluated a formalized transition process for AYA prescribed indefinite warfarin therapy during a critical developmental period. What happens during this developmental period has a profound impact on the AYA's future [31–33] and in this study AYAs were prepared for successful in their transition to adult care. Although uninterrupted, preemptive care throughout a lifetime results in the best health outcomes, lower health costs, and improved quality of life; the

transition from pediatric to adult care is frequently associated with poor outcomes and loss of follow up for AYA's with medical conditions [4,32]. Discontinuities of care result from organizational barriers such as funding streams, program accessibility, and age restrictions set by the health system. These impose artificial boundaries between the pediatric and adult health systems. Furthermore, many adult providers lack familiarity with congenital disease processes, pediatric conditions, and developmental needs amongst AYAs [34]. Insufficient patient and family preparation, cognitive or psychosocial impairment, patient-provider attachment, inadequate program integration, and poor access to adult specialty care further impedes the effective transition of AYA from pediatric to adult providers [3,32,33]. As a result, widely within the literature, the AYA age range expands from 10 to 39 years of age. Within, Stollery Children's Hospital, KIDCLOT and the department of cardiology, cardiac young adults were historically (2012) followed by the pediatric program until discipline specific AYA programs were developed. Within this cohort, three cardiac patients continued to be followed by the pediatric program after 17 years of age. Developing programs partnerships that facilitates discussion between pediatrics, adult care and the AYA/family is essential to facilitating an effective transition from pediatric to adult care while minimizing the large numbers of AYAs that are lost to follow-up [1,3,7,33].

PSM and PST in adults are demonstrated to be safer than conventional management and are associated with consistently lower rates of thromboembolism [24,19] [35]. PSM further equips adolescents for transition to adult care. Self-management of chronic conditions requires executive functioning (problem solving, planning and organizational skills) [36]. The brain develops from infancy through to young adulthood with executive functioning being the last to mature [37]. Better executive functioning is associated with better adherence behaviours [38]. PSM facilitates the early development of executive functioning skills related to warfarin therapy. Health team/parental mentoring, repetitive practice, problem solving, planning, organizational skills, and consequences of behaviours (missed doses) is practiced such that it becomes second nature; almost like the activities of daily living [39–41].

A structured policy and plan for transition is essential with shared and agreed upon goals. Within this study, the defined transition policy incorporated six essential elements consistent with the core principles described in the American Academy of Pediatrics guidelines [9]. The KIDCLOT policy based on 6 essential elements provides structure for effective transition from pediatric to adult care. Implementation of the policy requires collaboration between the family, AYA, pediatric and adult care providers. Measuring skills required in AYA to successfully transition from pediatric to adult care was carried out using the modified Transition Readiness (mTRAQ) Questionnaire [29]. This tool [29] is a validated reliable questionnaire that guides the health provider in moving the AYA with chronic conditions towards transition to adult care in a systematic way. The TRAQ [29] measures skills in the domains of self-management and self-advocacy including education, work and activities of daily living in addition to medication management including prescription refills, and medical appointments. Transition Readiness Questionnaire [29] was modified (mTRAQ) to capture the concepts specific to anticoagulation and warfarin management. In fact, these skills were demonstrated to be essential to successful transfer of AYAs with congenital heart disease [1,32]. A formalized transition tool facilitates early discussions to identify patient preferences and transfer related challenges and then to collaboratively develop solutions [42,43].

The use of the mTRAQ guides the healthcare provider in a structured approach to goal setting with the patient, which was a contributing factor to the positive outcomes including continued follow up in adult care. In general, the preparation process for transition, including setting of achievable goals, occurred during yearly clinic follow up appointments over 2–3 years until all steps of the mTRAQ were performed by the AYA being transitioned. Indefinite anticoagulation with warfarin is a substantial challenge in patients with the most significant challenge being adherence to taking warfarin every day, and INR testing, both of

Table 1
Clinical characteristics of study sample.

Median age (range) at study entry [years]	17.0 (11.8–28.5)		
Median number of years on study	3.8 (1.4–5.3)		
Indication for anticoagulation	N=	%	Target INR range
Mechanical valve-mitral	5	26	2.5–3.5
Mechanical valve-aortic	4	21	2–3
Fontan	6	36	2–3
Thrombophilia	2	10.5	2–3
Kawasaki's	2	10.5	2–3

which are directly associated with safety and efficacy of anticoagulant therapy. The goal of warfarin self-management is to build capacity in AYA by increasing knowledge and facilitating active participation in their health management. Giving control to AYA early facilitates development of autonomy through internalization of knowledge and important health concepts resulting in their ability to meaningfully participate in their health management. Brain development, specifically executive functioning is not complete until the mid-20's, which results in impulsive, irrational, disorganized, and risk taking behaviours, which compounds the underlying risk of anticoagulant therapy in adolescents [37]. The importance of engaging these patients in developing and internalizing knowledge during adolescence and young adulthood cannot be underestimated.

Within this nested study, adolescents and young adults were equipped with sufficient knowledge and skill to safely handle their warfarin therapy through implementation of the KIDCLOT transition policy, which incorporated warfarin self-management. The outcome scores following transition to adult care was completed were exceptional with knowledge scores of 95%, time-in-therapeutic range of approximately 80% and INR testing frequency and reporting every two weeks. International Normalized Ratio testing every 2 weeks in AYA is superior to time-in-therapeutic-range reported for children or adults [17,19,22,44]. Although, participants began the process of building capacity through warfarin self-management at different ages, 11 to 28 years, there is insufficient patient numbers to determine if there was any statistical difference between those AYA who participated in warfarin self-management at an earlier age, compared with those who started later. Importantly, all AYA maintained excellent warfarin control with routine follow up subsequent to transition. Previous studies report AYAs scored 27–62% [32,45] prior to transition and reports with of a lost to follow-up rate of approximately up to 50% [1–3].

Although this study demonstrated successful transition of AYAs requiring indefinite warfarin management from pediatric to adult care, there were specific limitations. Firstly, the results of this study are only generalizable to programs to that have capacity to incorporate warfarin self-management for chronic warfarin therapy. In addition, within this study all AYAs purchased a coagulometer, which may be a barrier for some patients. Finally, the small sample size could account for the lack of statistical significance in the TTR before and after the transition. It is important to acknowledge that parents of AYAs with chronic conditions may continue to provide support after transition is completed and this study did not examine parental support that may have been provided. Finally, one patient had reported time-in-therapeutic-range of 35% due to lack of reporting. However, on viewing the meter memory, INRs had been performed and were appropriately in the target range although this was not captured in the analysis.

5. Conclusions

The transition process within this study using patient warfarin self-management in combination with formal assessment using the six essential elements resulted in successful transition of AYAs from pediatric to adult care. Warfarin is a high-risk medication that adds further challenges that are compounded by transition to adult care. The adult anticoagulation programs/system(s) rely on an autonomous patient. Successful transition for patients who require warfarin is supported by implementing a formal transition process. This process must take into account adolescent brain development [37], chronic health conditions, and patient preferences, while empowering the AYA over time to develop autonomy through warfarin self-management. Although all transitioned AYA in this study chose to continue using an identical model for warfarin management, this program may be implemented with transition to either a dedicated anticoagulation clinic or family doctor. Further studies are recommended to evaluate long-term sustainability following transition to adult care.

Author roles

Mary Bauman: Concept/design, drafting article, critical revision of article, and approval of article; Stefan Kuhle: Design, data analysis/interpretation, statistic, and approval of article; Aisha Bruce: Data collection, critical revision of article, and approval of article; Lauren Bolster: Data collection, critical revision of article, and approval of article; Patti Massicotte: Design, data collection, drafting article, critical revision of article, and approval of article.

Conflict of interest

The authors have no relevant disclosures.

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