

PEER REVIEW HISTORY

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ARTICLE DETAILS

TITLE (PROVISIONAL)	Programs to support transitions in care for children and youth with complex care needs and their families: A scoping review protocol
AUTHORS	Doucet, Shelley; Curran, Janet; Breneol, Sydney; Luke, Alison; Dionne, Emilie; Azar, Rima; Reid, Amy; McKibbon, Shelley; Horsman, Amanda; Binns, Krystal

VERSION 1 – REVIEW

REVIEWER	Sue Lukersmith Australian National University, Australia
REVIEW RETURNED	14-Sep-2019

GENERAL COMMENTS	<p>There are significant conceptual issues with the protocol which needs to be clarified in the paper. Whilst the scoping review aims to better understand the “interventions and programs’ (page 5 line 13), I consider the review scopes transition programs and NOT interventions. The authors are confusing the two. Page 6 line 27 states the purpose is to map the range of interventions that support transitions. However the data extraction table (intervention design) does not extract details of the interventions rather the program ‘characteristics’ (it is not clear what characteristics other than the two examples provided on page 11 of objective, population of the Program) and a rather loose phrase ‘broad focus of transition’ (which may refer to one of the programs target). The protocol will be relevant if the paper is revised to focus on programs not intervention.</p> <p>Programs involve one or more interventions. The scoping review does not extract to the granularity level of interventions. An intervention is a service throughput – the act performed. The axis of interventions are the target (the entity on which the action is carried out), the action (what is done by the professional) and the means (the processes and methods by which the action is carried out) – refer to the WHO International Classification of Health Interventions https://www.who.int/classifications/ichi/en/.</p> <p>The phrase ‘discontinuity or gaps’ is used. It is not clear whether the question concerns the absence of services or a lack of coordination between services. Do these refer to the same problem or does the question concern the broader concept of care coordination programs an integrated care strategy. Case management in all its models and various titles, is a relational and individual care coordination strategy.</p> <p>there are weaknesses and limitations in the search strategy with #2. Whilst some of the concepts relate to the child e.g. medically fragile, and the AND relate to the program e.g. patient care</p>
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	<p>planning (which is a case management intervention), community integration (which is a target of case management or care coordination), models of care (which relates to the program), and yet others may relate to both e.g. Complex.</p> <p>the data extraction table does not extract details of the interventions (target, action and means) rather provides qualitative descriptors of the program.</p> <p>The authors state there is no limitation on geography, yet only Canadian websites are identified in the grey literature search, rather than an international focus, although there is hand searching of scoping reviews which may mean it is international. It appears the purpose of the paper is to scope transition programs in Canada. Clarity around the geography of the scoping review is needed.</p> <p>If the geography is International, then reviewing the literature to the point of saturation on particular program characteristics may be a pragmatic requirement.</p> <p>Include a diagram or brief description of the JBI scoping method to orient the reader and particularly to highlight the stepwise times of consultation with the team.</p>
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REVIEWER	Patience White Got Transition USA
REVIEW RETURNED	09-Oct-2019

GENERAL COMMENTS	<p>This is a proposal for a scoping review on interventions to support transition that is defined broadly including such transitions as health, school, living situations. The author proposes two research objectives of transition intervention for children with complex care needs:</p> <ol style="list-style-type: none"> 1. Map a range of interventions that are in the literature to support transitions from birth to age 19 in many areas (education, special education, health, etc.) before transitioning to adult care. 2. Map range of interventions to support complex needs between ages 14-25 as they transition from pediatric to adult care. Though not explicitly stated, this objective seems to be limited to health care transitions. <p>The author adopts a very broad definition of complex care needs (CCN) that is stated as needing health and social needs in the presence of a recognized medical condition or no unifying diagnosis. This is a very broad definition only excluding youth without a chronic condition, those who are over age 25 or institutionalized. This reviewer recommends that the author more clearly define and narrow the population to be studied. Perhaps reviewing other established definitions available such as the US Bureau of Maternal and Child Health definition for youth with special health care needs or a definition for medically complex youth as outlined by E. Cohen (Pediatrics, 2011). In addition, this reviewer recommends that the author review the literature on transitions to update her background information and references. The author stated "the literature on transitional care interventions for youth with CCN has not been systematically examined". There are systematic reviews of transitions, for example in health care transitions, in the literature (e.g. one example Gabriel 2017 J. of Pediatrics) and those papers and others in areas as behavioral</p>
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	<p>health should be part of the background research discussed in this article.</p> <p>This reviewer thinks that the two objectives are not distinct enough from each other to do a good scoping review. When looking at appendix II, the data extraction tool, there will be a lot of over lap between columns #1 and #2. In addition the intervention categories outlined in the Appendix II are very broad and need clarification through defining what is being looked for. This reviewer suggests that the author only address one of the objectives and probably look more closely at objective #1 as there are systematic reviews around objective #2.</p> <p>The search terms seem reasonable as a place to start as was the review process. In sum, this reviewer suggests that completing an updated back ground section with updated articles, narrowing and the objectives and clarifying the population and transitions to be studied would make this a better project.</p>
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VERSION 1 – AUTHOR RESPONSE

Reviewer 1 Comments	Author Response	Page #
<p>(1) There are significant conceptual issues with the protocol which needs to be clarified in the paper. Whilst the scoping review aims to better understand the “interventions and programs’ (page 5 line 13), I consider the review scopes transition programs and NOT interventions. The authors are confusing the two. Page 6 line 27 states the purpose is to map the range of interventions that support transitions. However the data extraction table (intervention design) does not extract details of the interventions rather the program ‘characteristics’ (it is not clear what characteristics other than the two examples provided on page 11 of objective, population of the Program) and a rather loose phrase ‘broad focus of transition’ (which may refer to one of the programs target). The protocol will be relevant if the paper is revised to focus on programs not intervention.</p>	<p>The authors agree with this suggestion to remove the term intervention as it is currently used and focus on programs instead. This will remedy the issue regarding not specifically extracting the intervention characteristics as you noted here. Rather, we are focusing on the broad characteristics of programs to create a description of existing transitional care programs.</p>	<p>Throughout manuscript in blue font.</p>
<p>(2) The phrase ‘discontinuity or gaps’ is used. It is not clear whether the question concerns the absence of services or a lack of coordination between services. Do these refer to the same problem or does the question concern the broader concept of care coordination programs an integrated care strategy. Case management in all its models and various titles, is a relational and individual care coordination strategy.</p>	<p>We note the confusion here, and have changed the wording to “lack of coordination between services or gaps in care that can occur...”</p>	<p>p.4 (Introduction)</p>

<p>(3) There are weaknesses and limitations in the search strategy with #2. Whilst some of the concepts relate to the child e.g. medically fragile, and the AND relate to the program e.g. patient care planning (which is a case management intervention), community integration (which is a target of case management or care coordination), models of care (which relates to the program), and yet others may relate to both e.g. Complex.</p>	<p>The authors note that some concepts in strategy #2 may relate to both as you say. This was intentionally done. For example, “intervention” was used as a synonymous term to “program” within this strategy. Through consultation with one of our librarian authors (ARH), it was found that when "intervention" was left out of the search strategy, many articles that talk about programs were lost due to indexing issues with the term "programs". Thus, both of these terms are used in this strategy. Similar results follow suit with other terms that may overlap.</p>	<p>N/A</p>
<p>(4) The data extraction table does not extract details of the interventions (target, action and means) rather provides qualitative descriptors of the program.</p>	<p>As noted in the response above, the protocol will focus on programs rather than specific interventions.</p>	<p>N/A</p>
<p>(5) The authors state there is no limitation on geography, yet only Canadian websites are identified in the grey literature search, rather than an international focus, although there is hand searching of scoping reviews which may mean it is international. It appears the purpose of the paper is to scope transition programs in Canada. Clarity around the geography of the scoping review is needed.</p>	<p>We apologize for the confusion. authors have added more detail to make it clearer that we will be using the CADTH tool as a <i>guide</i> for searching the grey literature. While this is a Canadian tool, it includes multiple international sources of literature that will be searched to ensure the search is not limited to Canada. There are no geographic limitations applied to any databases or grey literature searches.</p>	<p>p.6, information sources</p>
<p>(6) Include a diagram or brief description of the JBI scoping method to orient the reader and particularly to highlight the stepwise times of consultation with the team.</p>	<p>For further clarification on this methodology, we have added the “steps” of the JBI framework which outlines the information presented in the manuscript.</p>	<p>p.5-6, methods</p>
<p>Reviewer 2 Comments</p>	<p>Author Response</p>	<p>Page #</p>
<p>(1) This is a proposal for a scoping review on interventions to support transition that is defined broadly including such transitions as health, school, living situations. The author proposes two research objectives of transition intervention for children with complex care needs:</p> <ol style="list-style-type: none"> 1. Map a range of interventions that are in the literature to support transitions from birth to age 19 in many areas (education, special education, health, etc.) before transitioning to adult care. 2. Map range of interventions to support complex needs between ages 14-25 as they transition from pediatric to adult care. Though not explicitly stated, this objective seems to be limited to health care transitions. 	<p>Thank you for your comments. We have slightly altered the second objective to note “...as they transition from pediatric to adult health care”.</p> <p>As noted in a previous comment, we have also changed the wording around “interventions” to now say “programs” where applicable.</p>	<p>p.5, review objectives</p>

<p>(2) The author adopts a very broad definition of complex care needs (CCN) that is stated as needing health and social needs in the presence of a recognized medical condition or no unifying diagnosis. This is a very broad definition only excluding youth without a chronic condition, those who are over age 25 or institutionalized. This reviewer recommends that the author more clearly define and narrow the population to be studied. Perhaps reviewing other established definitions available such as the US Bureau of Maternal and Child Health definition for youth with special health care needs or a definition for medically complex youth as outlined by E. Cohen (Pediatrics, 2011).</p>	<p>This broad definition was chosen intentionally. We did not want to say “medically complex” or children with “special health care needs” as not all complex care needs are necessarily medical in nature. Rather, they may be social or educational needs. Thus, the term “CCNs” reflects this range of individuals who would benefit from transitional care programs and will improve the range of programs that will be reported on through this scoping review.</p>	<p>N/A</p>
<p>(3) In addition, this reviewer recommends that the author review the literature on transitions to update her background information and references. The author stated "the literature on transitional care interventions for youth with CCN has not been systematically examined". There are systematic reviews of transitions, for example in health care transitions, in the literature (e.g. one example Gabriel 2017 J. of Pediatrics) and those papers and others in areas as behavioral health should be part of the background research discussed in this article.</p>	<p>The background section of this manuscript has been revised that gives more details on existing reviews, and where they fall short of the objectives of this review which are broader and will encompass more and newer sources of literature on the topic.</p>	<p>p.4-5, Background</p>
<p>(4) This reviewer thinks that the two objectives are not distinct enough from each other to do a good scoping review. When looking at appendix II, the data extraction tool, there will be a lot of overlap between columns #1 and #2. In addition, the intervention categories outlined in the Appendix II are very broad and need clarification through defining what is being looked for. This reviewer suggests that the author only address one of the objectives and probably look more closely at objective #1 as there are systematic reviews around objective #2.</p>	<p>We have taken note of your suggestion but feel that the revisions made to the manuscript will be sufficient to provide more clarity surrounding these points that you have addressed.</p>	<p>Throughout manuscript</p>
<p>(5) The search terms seem reasonable as a place to start as was the review process. In sum, this reviewer suggests that completing an updated background section with updated articles, narrowing and the objectives and clarifying the population and transitions to be studied would make this a better project.</p>	<p>Thank you for your comments. We hope the revised version will provide more clarity for the reviewers, and for future readers of your journal.</p>	<p>N/A</p>

VERSION 2 – REVIEW

REVIEWER	Dr Sue Lukersmith Australian National University, Canberra Australia
REVIEW RETURNED	06-Jan-2020

GENERAL COMMENTS	<p>please revise page 3 when again you refer to interventions rather than programs</p> <p>"that have been measured and described as a result.(suggest remove transitional interventions) of transitional interventions" and add transitional to the programs in the beginning of the sentence. same sentence is on page 6 second last sentence in paragraph.</p> <p>I suggest you remain cautious in using the term international scoping in terms of the grey literature. Whilst there are some international websites mentioned it is not exhaustive, and so not considered comprehensive as is your peer reviewed literature search strategy.</p>
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REVIEWER	Patience White Got Transition National Center Professor Of Medicine and Pediatrics George Washington University School of Medicine and Health Sciences
REVIEW RETURNED	20-Dec-2019

GENERAL COMMENTS	<p>This reviewer still finds this scoping review to broad to be helpful to the literature and for informing future research questions. Including all transitions of care from any aspect of life is too all encompassing to learn the nuances that would be more helpful in informing research, policy and practice or promoting action in the future. Similarly, as most interventions are geared for the level of complexity of the youth being served, looking at all youth that have “ a medical condition” without a clear definition will only end up with broad generalizations that may or may not apply to many/most components of the populations. In addition, does the authors definition include those youth with behavioral health conditions or those with substance use disorders? In the inclusion criteria the authors define the population as those who have complex care needs (CCN) except those in long term care settings. Better definitions are needed to allow for any substantive observations.</p> <p>Other areas that still are confusing: the objectives are not consistently described through the paper. In the abstract objective #1 is looking at transfers of youth with CCN up to age 19 and the objective #2 is for pediatric to adult care. Later in the paper the second objective has an age from 14-25 and the age overlaps with objective one up to age 19. The authors should be more explicit as to what is different about objective one from two. For example, in objective two, is it only including those over age 20 following transfer to adult care? Does objective two include more than health care? More clarity about the objectives is needed and they should be described the same way throughout the project. In the background, the 15% quoted is old data and is referring to youth with cc with limitations which not the group of youth this paper is studying. There is more up to date data from National Survey of Children’s Health for the US. Also, in the background they mention that findings around transitional care programs have been difficult</p>
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	<p>to extract due to narrow focus, heterogeneity of interventions and outcomes and limited descriptions. They imply this has changed due to new evidence thus necessitating this scoping review. What is the data for this statement? Given to the broadness of this scoping review, the same challenges are likely. How do they know that their review will be different other than their statement that more papers have been published? Also, what will they add around objective two since there was a 2019 review in the journal of nursing?</p> <p>In the search strategy, the authors should identify the period that was covered in the search done in December 2018.</p> <p>In the data presentation again there needs to be clearer descriptions. For example, the author is describing the program design referencing outcome-do the authors mean measures or what type of study? When referencing focus of transition, do they mean the actual HCT intervention and does this reference objective 1 or 2?</p> <p>This reviewer suggests that the authors should consider a framework or organizing principles to organize the HCT programs and outcomes for the discussion. These have not been described. Also, how will they choose “key authors from included articles” to comment on the preliminary findings. This list is likely to be many given the broad nature of this scoping review. How will they narrow the number?</p> <p>This reviewer also asks the authors to look more carefully at the details of the paper-for example, what happened to reference #29? It is not listed.</p> <p>In sum, this reviewer did not think the authors adequately answered the questions posed in the original review.</p>
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VERSION 2 – AUTHOR RESPONSE

Reviewer Comments and Author Responses

Reviewer 2 comments	Author response	Section / Page #
This reviewer still finds this scoping review too broad to be helpful to the literature and for informing future research questions. Including all transitions of care from any aspect of life is too all encompassing to learn the nuances that would be more helpful in informing research, policy and practice or promoting action in the future.	We have included further description regarding the need for a broad level scoping review.	Background Page 5
Similarly, as most interventions are geared for the level of complexity of the youth being served, looking at all youth that have “ a medical condition” without a clear definition will only end up with broad generalizations that may or may not apply to many/most	We are sensitive to the fact that there is wide variation related to definition of this population in the literature. Our definition of this population is intentionally broad and aligned with a recent concept analysis focused on children with complex care, and would include behavioral and substance	Background Page 4

<p>components of the populations. In addition, does the authors definition include those youth with behavioral health conditions or those with substance use disorders? In the inclusion criteria the authors define the population as those who have complex care needs (CCN) except those in long term care settings. Better definitions are needed to allow for any substantive observations.</p>	<p>use disorders. We contend that our scoping review will help to identify definitional variation and provide direction for future work.</p>	
<p>Other areas that still are confusing: the objectives are not consistently described through the paper. In the abstract objective #1 is looking at transfers of youth with CCN up to age 19 and the objective #2 is for pediatric to adult care. Later in the paper the second objective has an age from 14-25 and the age overlaps with objective one up to age 19. The authors should be more explicit as to what is different about objective one from two. For example, in objective two, is it only including those over age 20 following transfer to adult care? Does objective two include more than health care? More clarity about the objectives is needed throughout the project.</p>	<p>We have made a clearer distinction between the two objectives and also made edits to more consistently describe each objective throughout the paper.</p>	<p>Throughout</p>
<p>In the background, the 15% quoted is old data and is referring to youth with cc with limitations which not the group of youth this paper is studying. There is more up to date data from National Survey of Children's Health for the US.</p>	<p>Thank you for your suggestions, which have been addressed in the manuscript. We added a more current reference and also changed the statistic to represent children with special health care needs and not chronic conditions.</p>	<p>Background Page 4 Reference Page 10</p>
<p>Also, in the background they mention that findings around transitional care programs have been difficult to extract due to narrow focus, heterogeneity of interventions and outcomes and limited descriptions. They imply this has changed due to new evidence thus necessitating this scoping review. What is the data for this statement? Given to the broadness of this scoping review, the same challenges are likely. How do they know that their review will be different other than their statement that more papers have been published? Also, what will they add around objective two since there was a 2019 review in</p>	<p>A broad level scoping review is required to begin to make sense of this heterogeneous body of literature. Mapping the current evidence regarding transitional care programs for children and youth with CCNs and their families will assist with identifying gaps and create direction for future systematic reviews and research.</p> <p>Regarding objective two and the 2019 article in the Journal of Nursing, their inclusion criteria was looking specifically at <i>evaluation</i> of transition interventions. They wanted to create an evidence map, where our focus is to include descriptions of</p>	

<p>the journal of nursing? In the search strategy, the authors should identify the period that was covered in the search done in December 2018.</p>	<p>existing programs, versus only looking at programs that have been evaluated. The 2019 article also only included other systematic reviews as it is a systematic review of systematic reviews. Ours differs as we excluded reviews.</p>	
<p>In the data presentation again there needs to be clearer descriptions. For example, the author is describing the program design <u>referencing outcome-do the authors mean measures or what type of study?</u></p> <p>When referencing focus of transition, do they mean the actual HCT intervention and does this reference objective 1 or 2?</p>	<p>Our definition of outcome includes: primary or secondary outcomes (if available) as described by authors in their methods section.</p> <p>Yes, focus of transition refers to the actual HCT intervention/program. This will be extracted whether it falls under objective 1 or 2.</p>	
<p>This reviewer suggests that the authors should consider a framework or organizing principles to organize the HCT programs and outcomes for the discussion. These have not been described. Also, how will they choose “key authors from included articles” to comment on the preliminary findings. This list is likely to be many given the broad nature of this scoping review. How will they narrow the number?</p>	<p>We will use the Theory, Model and Framework Comparison and Selection Tool to identify appropriate framework(s) to organize and categorize extracted intervention and program descriptions.</p> <p>Given the size of our team, we are not concerned that it will be too time consuming to contact key authors.</p>	<p>Data presentation Page 8</p>
<p>This reviewer also asks the authors to look more carefully at the details of the paper-for example, what happened to reference #29? It is not listed.</p>	<p>We have carefully reviewed the details of the paper. We thank you for catching the reference omission, which has been fixed.</p>	

Reviewer 1 comments	Author Response	Section / Page #
<p>“please revise page 3 when again you refer to interventions rather than programs”</p>	<p>This has been addressed where needed. See track changes in the paper on pages 2 and 7.</p>	<p>Pages 2 and 7</p>
<p>... "that have been measured and described as a result. (<i>suggest remove transitional interventions</i>) of transitional interventions" and add transitional to the programs in the</p>	<p>This has been addressed. See track changes in the paper on pages 3 and 5-6.</p>	<p>Pages 3, 5-6</p>

beginning of the sentence. same sentence is on page 6 second last sentence in paragraph		
I suggest you remain cautious in using the term international scoping in terms of the grey literature. Whilst there are some international websites mentioned it is not exhaustive, and so not considered comprehensive as is your peer reviewed literature search strategy.	We completely agree with the reviewer that this is an issue and have decided to remove the grey literature search from the protocol, given the broad scope of the review. This will be the focus of a future study.	Information sources Page 6