Author's response to reviews

Title: Chronic kidney disease and support provided by home care services: a systematic review

Authors:

Sema K Aydede (sema.aydede@ubc.ca)
Paul Komenda (pkomenda@sbg.h.m.b.ca)
Ognjenka Djurdjev (ODjurdjev@phsa.ca)
Adeera Levin (ALEvin@providencehealth.bc.ca)

Version: 2 Date: 25 April 2014

Author's response to reviews: see over
April 24, 2014

Dear Dr Giorgina Barbara Piccoli:

Thank you for the opportunity to revise our manuscript entitled “Home care utilization in chronic kidney disease: a systematic review” (MS: 1800236237120229).

Below we have addressed each reviewer comment and have indicated where additions and changes to the manuscript have been made. We hope that our responses have adequately addressed reviewers’ comments. If you have any further questions related to this manuscript, please do not hesitate to contact me.

Sincerely,

Sema K. Aydede, PhD
Clinical Associate Professor
School of Population and Public Health
University of British Columbia
Health Economist Researcher
Provincial Health Services Authority
Suite 700, 1380 Burrard Street
Vancouver, BC V6Z 2H3 CANADA
(604) 875-7351 (Phone)
(604) 875-7365 (Fax)
sema.aydede@ubc.ca
saydede@phsa.ca

Reviewer's report
Title: Home care utilization in chronic kidney disease: a systematic review
Version: 1 Date: 12 February 2014

Reviewer: Donal O'Donoghue

Reviewer's report:

This is a timely and helpful SR. It highlights the need for more structured research addressing topics of CKD community, healthcare/social care system and patient/carer relevance in these populations receiving supported home care in advanced CKD. I support publication with minor changes;
1. I would ask the authors to consider alteration of the title – to most in the kidney home care includes self care. Maybe the tile should be assisted or supported home care?

Thanks for the helpful comments.

Revised title as “Chronic kidney disease and support provided by home care services: a systematic review”. Also changed “home care” to “home care services” in as many places as possible including the abstract and as a keyword to emphasize that the manuscript focuses on the services home care programs provide and is not about self care.

2. In the definition – does home mean usual place of residence or own home? Please clarify. The EoLC literature uses the term usual place of care and includes hospice and care home – I think these are excluded in this study (which is fine) but could it be more explicit

Specified that the focus is on services received in patients’ own home as indicated in the underlined section below (lines 117-118):

“Studies about adult patients with any CKD severity level and a HC intervention regarding services provided in patients’ homes were eligible.”

3. Could the search strategy be available as a wen appendix or eg on BC Renal Agency website

Included MEDLINE search strategy as an Appendix and revised the manuscript as indicated in the underlined section below (lines 177-178):

“Electronic databases included MEDLINE, EMBASE, CINAHL, PsycINFO, EconLit, Cochrane CENTRAL, Cochrane Methodology Register, Cochrane Database of Systematic Reviews, Centre for Reviews and Dissemination (DARE, HTA and NHS EED), ACP Journal Club and Web of Science (final search for MEDLINE is incorporated in the Appendix; final searches for other databases are available from the corresponding author).”

4. The term CKD modality leads me to think it is RRT modality – one doesn’t usually refer to non esrd ckd as on a modality although some refer to conservative care as a modality

Revised the manuscript as indicated in the underlined sections below (lines 96-99 and line 106):

“In the case of non-ESRD CKD, the utilization of HC may vary based on patient’s age and comorbidities and, in the case of ESRD, it may vary based on the severity of illness and therapy type. HC services may help support ESRD patients who have chosen conservative care.”

“On the other hand, the intensity of HC services received may reduce the number of hospitalizations and subsequent health system costs ... regardless of the stage of CKD and the type of therapy for ESRD.”
5. Could the authors be more explicit re conservative kidney care – it looks like it wasn’t rarely reported on. I think the readership will be interested in this gap and it could be expanded upon. The whole terminology turmoil makes it difficult to follow at times in the wider literature as some use ESRD to mean only RRT (some only Dx), some all stage 5 and so on.

Conservative care was considered within the framework of palliative care in this study. As indicated below, two sections were added on a) the palliative care studies that were excluded from this study (lines 131-135) and b) how new studies can contribute to the literature (lines 407-413):

“In the case of palliative care, support services for CKD patients could be provided in their home or at a hospice. This study focused on home-based end-of-life care. Studies that examined palliative care without providing information about the specific services patients received in their community and those that did not separately report on subgroups of patients who received home-based support services [38-42] were excluded from our SR.”

“The lack of studies on the impact home palliative care has on patients with CKD was another gap in the literature that was identified by our SR. The quality of life considerations for CKD patients who are at the advance stages of their disease require focus on several issues including the management of their physical and psychosocial symptoms and the development of an advanced care plan that sets the goals for their care [70-74]. Studies that examine the impact home palliative care has on patients with CKD who are at the advance stages of their disease will help further advance the integration of palliative and renal care.”

6. The final date searched – to present or may 12 ( librarian search )

Included final date of hand searches (lines 182-183):

“Hand searches, completed on September 20, 2013, were coupled with consultations with experts in the field.”

7. Line 293 the 15/19 seem a bit random – fatigue and creatinine !! perhaps worth an explanation ( I know its in table 2 )

Included more information (lines 329-333):

“The HD study with a comparator [62] concluded that patients in HC group had improved on 15 of the 19 outcomes considered (including decreases in nausea, vomiting, headache, bone pain, weakness and fatigue and itching and improvements in general condition and the levels of creatinine, potassium and phosphorus of the blood).”

8. When making ref to ref 59 – the authors refer to preDx and Dx comparators - do they mean predx or conservative care – please be explicit

Revised in Table 2 and, as indicated below, revised one section (lines 227-230) & added a section (lines 335-340):
In contrast to the general trend of studies included in this SR where the focus was exclusively on the dialysis phase of care for patients, one study [64] included information from both the dialysis and pre-dialysis phases of care for PD and HD patients. This study explored the impact HC has on patients in one hospital in the United Kingdom.

**Pre-dialysis and Dialysis**

Based on survey results, more than three-fourths of the PD and HD patients were very satisfied with the pre-dialysis and dialysis phase of their care after the implementation of HC program [64]. The HC team consisting of three nurses and one renal care assistant provided continuous social support to patients. The HC team also collected information about patients’ life goals and provided information to them about their dialysis modalities.

9. **Table 2 Bummer – in the HD costs is that Maintenance HD – could that be made explicit**

In Table 2, indicated that the results are related to the ongoing costs.

10. **Wilde ref – Lencester or Leicester?**

Revised: “Leicester”

11. **In ref to CCI – perhaps the index doesn’t contain sufficient re functionality / motivation - ? an additional sentence or 2.**

As indicated below, revised abstract, included a section (lines 346-355) and revised a section (lines 383-386):

“While most studies adjusted for age and comorbidities, information about multidimensional prognostic indices that take into account physical, psychological, cognitive, functional and social factors among CKD patients was not easily available.”

“The CCI summarizes the impact comorbid conditions have on survival by assigning higher weights to more severe coexisting conditions such as metastatic carcinoma and lower weights to less severe ones such as dementia [65-67]. While CCI is one of the most widely used risk adjustment techniques in observational studies, the characteristics of CKD populations may require multidimensional prognostic indices that take into account physical, psychological, cognitive, functional and social factors [68]. One of the studies included in this SR reported on the physical performance of patients using Karnofsky Scale in addition to providing information on their comorbidity scores [59]. Apart from the descriptive information incorporated in the latter study, there were no studies that incorporated multidimensional indices as another confounding variable in their analysis.”

“Apart from one study [59] that described comorbidity and physical performance in their study population, there were no studies that incorporated multidimensional indices that take into account physical, psychological, cognitive, functional and social factors as another confounding variable in their analysis.”
12. – It may not be politically correct but many of the studies are not in highest citation index journals – does that underscore the value we put on these important research studies? Or is it a feature of quality??

As indicated in #11 above, the new section on CCI discusses the lack of multidimensional indices in these studies (lines 346-355) and also revised another section (lines 383-386):

I enjoyed reading it
Level of interest: An article of importance in its field
Quality of written English: Acceptable
Statistical review: No, the manuscript does not need to be seen by a statistician.
Declaration of competing interests:
'I declare that I have no competing interests'

Reviewer's report
Title: Home care utilization in chronic kidney disease: a systematic review
Version: 1 Date: 27 March 2014

Reviewer: Gianfranca Cabiddu

Reviewer's report:

Major points:

1. The paper deals only with dialysis patients, and the title is on CKD. Even if the Authors searched also data on CKD, the title should be coherent with the findings.

Thanks for the helpful comments.

We do have one article in the systematic review that has incorporated information on both the dialysis and pre-dialysis phases of care provided for patients (Wilde et al., 2001). As indicated below, revised abstract and one section (lines 227-230) & added a section (lines 335-340) about Wilde et al., 2001 to make this clear:
“Sixteen studies focused on the dialysis phase of care for their study samples and one study included information from both the dialysis and pre-dialysis phases of care.”

“In contrast to the general trend of studies included in this SR where the focus was exclusively on the dialysis phase of care for patients, one study [64] included information from both the dialysis and pre-dialysis phases of care for PD and HD patients. This study explored the impact of HC on patients in one hospital in the United Kingdom.”

“Pre-dialysis and Dialysis
Based on survey results, more than three-fourths of the PD and HD patients were very satisfied with the pre-dialysis and dialysis phase of their care after the implementation of HC program [64]. The HC team consisting of three nurses and one renal care assistant provided continuous social support to patients. The HC team also collected information about patients’ life goals and provided information to them about their dialysis modalities.”

2. The search strategy should be reported, instead of a long list of "conceptualizations" that in effect are not in line with the finding; for example on CKD, as no study was found on this issue. The lack of studies is a finding that should be commented upon.

a) Included MEDLINE search strategy as an Appendix and revised the manuscript as indicated in the underlined section below (lines 177-178):

“Electronic databases included MEDLINE, EMBASE, CINAHL, PsycINFO, EconLit, Cochrane CENTRAL, Cochrane Methodology Register, Cochrane Database of Systematic Reviews, Centre for Reviews and Dissemination (DARE, HTA and NHS EED), ACP Journal Club and Web of Science (final search for MEDLINE is incorporated in the Appendix; final searches for other databases are available from the corresponding author).”

b) Commented on the lack of studies among non-ESRD CKD (lines 395-405):

“One of the gaps in the literature that was identified by our SR is related to the provision of HC services among non-ESRD CKD populations. Apart from one study [64] that incorporated information about patient experiences with the implementation of a HC program that affected both the dialysis and pre-dialysis phases of their care, there were no studies that explored the impact of HC on non-ESRD CKD populations. It is well known that CKD is often accompanied by several comorbid conditions, is common among older people and its prevalence increases with age. As emphasized by the World Kidney Day 2014 Steering Committee [69], these characteristics of CKD coupled with increased life expectancy worldwide call for further explorations into ways of optimizing health for elderly populations. The impact varying HC services might have in improving health among non-ESRD CKD patients is one such area that deserves further explorations.”

c) Added that the definitions reported guided the initial development of the SR and the conceptualizations further developed/refined as study progressed (lines 158 & 167-170):

“These classifications guided the development phase of our SR.”
“Initially, HC conceptualization for this SR was guided by these definitions. These conceptualizations were further refined during the course of this study as we attempted to standardize terminology for our SR based on the HC services covered in the included studies.”

3. The lack of explicit search strategy is a major point in particular on a subject for which MESH terms are hardly found, and in a field in which the definitions (CKD first) remarkably changed over time.

Added terminology changes as a limitation of the study (lines 431-437):

“Our study has several limitations. One of the limitations of our study is arising from the subject matter itself. HC, as encompassing a diverse set of medical and psycho-social services, is one of the health services research areas that are constantly evolving with limited standardization in terminology. Our study which focused on the intersection of home care with CKD faced additional challenges given the changes in CKD definition itself in the past years that is continuing through today [75]. We made an attempt to balance this fundamental limitation by conducting comprehensive database searches, extensive hand searches and expert consultations.”

4. Furthermore, the study selection, in the methods is not fully clear.

Layered approach taken in the study selection is incorporated as another limitation of the study (lines 438-443). Also revised study selection section (lines 186-189):

“Second limitation of our study is the layered approach followed in study selection. Third limitation is the focus on studies published in English. Given the diversity of HC services, resource and time considerations were crucial factors in our decision to follow a layered study selection approach and to focus on studies published in English. As indicated above, we made an attempt to balance these limitations by conducting comprehensive database searches, extensive hand searches and expert consultations.”

“Second limitation of our study is the layered approach followed in study selection. Third limitation is the focus on studies published in English. Given the diversity of HC services, resource and time considerations were crucial factors in our decision to follow a layered study selection approach and to focus on studies published in English. As indicated above, we made an attempt to balance these limitations by conducting comprehensive database searches, extensive hand searches and expert consultations.”

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5. There is no clear definition of the interventions: more data should be given on the type of help: for example on PD: each dialysis, once in a while. In the table this is not clear and adding the frequency of the visits is very important. Furthermore, under the heading of home care intervention we find how the nurses etc are paid and not the type of intervention (how often, how long etc).

Included intervention information in Table 2 and, as indicated below, added 2 sections, one in Home Care Intervention section (lines 253-271) and another one in the Discussion section (lines 388-393).
“There are several factors, such as the severity of illness of the patients, the scope of HC provision and the requirements of dialysis technique used, that will influence the characteristics of a HC intervention. While patients on continuous cycling PD (CCPD) will mostly require two visits per day, those on continuous ambulatory PD (CAPD) may require one to four visits based on the severity of their disability [56, 58]. The time that a HC worker spends at a CAPD patient’s home is dependent on the CAPD system used. PD exchange help for a patient on an ultraviolet non-disconnect CAPD system will usually require less time (about 10-15 minutes) compared to the time (about 30-45 minutes) needed for a patient on a double-bag disconnect CAPD system [55].

Based on studies with pertinent information, patients in Canada [53, 54] were offered 14 visits per week for help with their PD exchanges and for the provision of clinical and social support. These patients received, on average, 5.8 visits per week during the first year of their dialysis [53]. In a USA program, a routine visit to a new PD patient was carried out to ensure proper installation of the cycler for an effective dialysis and non-routine visits were made only on an as-needed basis [61]. In this program, a visit took approximately four hours. Another USA program focused on ESRD patients with multiple medical and social problems [60]. In this program, a visit to help patients with their PD exchanges and to provide clinical and social support took, on average, 13 hours. In a HD study from Iran, the HC intervention was designed to conduct one visit per week before the HD schedule for clinical support and retraining [62].”

“The studies included in this SR provided limited information about the characteristics of the HC interventions. In general, technical requirements imposed on HC intervention based on the dialysis type used are well known among the CKD community. Additional studies that consider HC interventions with varying scope and frequency and duration of visits in different CKD populations will provide helpful information to the CKD community, especially for those who are considering HC programs for their own clinic/practice.”

6. **As they are now, the tables have several pitfalls: table 1 reports only few data, table 2 too many.**

Table 1 now incorporates type of study, setting, data source, data period & country.

7. **Table 2 is complex, not well summarized and almost impossible to read: it may be split in 2, or for example the information of Country, type of study and setting and period could be merged to table 1.**

Table 2 now incorporates study population, type of home care intervention & results.

8. **Table 3 reports only on the outcomes chosen, but doesn’t add, in my opinion to the reader’s knowledge unless the results are also added.**

Table 2 now has outcome headings; Table 3 is deleted.
9. Table 4 is a quality analysis that could be summarized for example by moving the headers in a legend, leaving the Y-N-P in a single (readable) row.

New Table 3 replaces old Table 4 and incorporates the risk of bias and confounding information in a compact form.

10. As a consequence of the lack of precision in the definition and description of the interventions, the discussion is quite generic and I think that the Authors should make an effort not only in highlighting the gaps in the knowledge (well known by any expert who'd go to read the paper) but in suggesting something useful for the dialysis clinicians who want to organise or adapt a network of home care.

As indicated below, incorporated a section (lines 388-393; please also see # 5 above):

“The studies included in this SR provided limited information about the characteristics of the HC interventions. In general, technical requirements imposed on HC intervention based on the dialysis type used are well known among the CKD community. Additional studies that consider HC interventions with varying scope and frequency and duration of visits in different CKD populations will provide helpful information to the CKD community, especially for those who are considering HC programs for their own clinic/practice.”