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Involving Clients to Inform Development and Implementation of Combined Type 2 Diabetes and Chronic Kidney Disease Care Using *Discovery Interview* Technique

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ABSTRACT

Introduction: The development of chronic kidney disease in persons with Type 2 diabetes has been described as an epidemic. Standard outpatient care for these associated conditions is routinely provided separately, resulting in missed opportunities to implement preventative and early management strategies. Historically, care delivery for these combined conditions has fallen within the remit of medical professionals, evidenced by a dearth of information pertaining to the contribution of advanced practice nursing for this cohort. Clients report an uncoordinated impersonal approach to care delivery for associated conditions, however incorporating their experience is vital to the delivery of patient centered care and will be included in this study through their stories. The primary aim of this participatory action research (PAR) study is to utilize the client care stories and health-care professional perspectives to inform development and implementation of a new combined Type 2 diabetes and chronic kidney disease service in the context of advanced practice nursing. **Methodology:** This study adopted a PAR approach informed by patient discovery interviews and key stakeholders focus groups. Transcripts will be developed from discovery interviews and focus groups and analyzed using thematic analysis. **Results:** The PAR will utilize thematic analysis outcomes to inform the primary aim and clinical outcomes from combined care will be evaluated after 9 months by retrospective chart review. **Conclusion:** The approach adopted in this study represents a departure from traditional medically led care strategies. Outcomes may elucidate potential challenges to the development and delivery of innovative care delivery for underserved patient cohorts in the context of advanced practice nursing.

Keywords: Advanced nurse practice, Chronic kidney disease, Discovery interview, Participatory action research, Patient story, Type 2 diabetes

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Introduction

It is estimated that 425 million (8.8%) of adults globally have diabetes[1] and as the incidence of people with Type 2 diabetes is set to increase, this is also likely to increase the number who will also develop chronic kidney disease. The National Health Service (NHS) (2011–2012) estimates that 18–30% of those with Type 2 diabetes will develop chronic kidney disease.[2] Approximately 40% of people with Type 2 diabetes in the United States develop chronic kidney disease.[3] In Ireland, up to 280,000 persons have chronic kidney disease, many of whom are unaware of their

diagnosis.[4] There is a lack of national data regarding the prevalence of chronic kidney disease in cohorts with Type 2 diabetes and efforts are afoot to develop a national register of the prevalence of kidney disease and contributing causes. Type 2 diabetes and chronic kidney disease are correlated with increased economic burden, patient suffering, and mortality and morbidity risk.[5-7] Seminal randomized controlled trials such as the Advance Collaborative Group,[8] Adler *et al*.,[9] and Intensive blood-glucose control with sulphonylureas or insulin compared with conventional treatment and risk of complications in people with Type 2 diabetes (UKPDS 33)[10] have demonstrated optimal blood glucose and blood pressure control reduces the risk for the development and progression of chronic kidney disease in patients with Type 2 diabetes.

There is some evidence to support improved client outcomes when a combined Type 2 diabetes and chronic kidney disease management approach are adopted.[11-13] These include decreased length of hospitalization, emergency admission, fistula formation, and improved symptom management.[14] Despite the fact that advanced nurse practitioners provide high quality and safe and effective care,[15] there is a lack of information regarding their direct contribution to combined Type 2 diabetes with chronic kidney disease care nationally and internationally.

From the perspective of the individual with chronic illness, many report a limited approach to personalized care, in which their chronic illnesses are treated by separate health-care professionals in a system which they have to self-navigate.[16] The development and implementation of health-care services have traditionally fallen within the remit of health-care planners and professionals.[17] Opportunities to collect and utilize information from service users regarding their health-care experiences and expectations to inform development and implementation of services are frequently missed.[18] The World Health Organization (2013) indicates client experience of care must be utilized if reform and improvement in health-care processes is to be achieved and sustained.[19] This view is supported by the Department of Health (2016) of Ireland Statement of Strategy which indicates that new models of health-care delivery are required which are integrated, continuous, person centered, and delivered at the lowest level of complexity consistent with patient safety.[20]

Failure to attend for scheduled review also referred to as Did Not Attend (DNA) remains a significant issue in the area of chronic illness management.[21] In the United States, Salameh *et al.* reported that 25.5% of patients with Type 2 diabetes fail to attend for scheduled review.[22] In Ireland, it is estimated that 13% of patients fail to attend for scheduled outpatient appointments.[23] Failure to attend is influenced by a myriad of factors including conflicting work schedules, perceived disrespect by care providers, poor relationship with care provider, forgetfulness, and transportation difficulties.[24] Failure to attend is associated with higher glycated hemoglobin (HbA1C) and all-cause mortality in cohorts with diabetes.[25]

Preventative care strategies such as meeting recommended clinical targets for blood pressure, blood glucose, and lipid profile have been identified as the most effective means by which to reduce development and progression of chronic kidney disease in patients with Type 2 diabetes.[26] However, evidence indicates that as few as 18.8% of people with Type 2 diabetes meet all three clinical target recommendations for blood pressure, blood glucose, or low-density lipoproteins cholesterol.[27]

The current health-care delivery strategies which facilitate separate care for Type 2 diabetes and chronic kidney disease are failing to achieve the best practice targets or meet the expectations of participants in care. Provision of combined Type 2 diabetes and chronic kidney disease care by advanced nurse practitioners represents a significant departure from traditional care delivery strategies, in which care for these associated conditions is medically led and provided separately. This study protocol will outline how participatory action research (PAR) methodology will be used to inform combined Type 2 diabetes and chronic kidney disease care led by advanced nurse practitioners.

Aims

The aim of this paper is to outline the protocol for a PAR project designed with one primary aim: To utilize cocreated knowledge between health-care professionals and patients to inform development and implementation of combined Type 2 diabetes and chronic kidney disease care in the context of advanced practice nursing.

Objectives

This study has three main objectives:

- To identify factors which influence attendance and features of care client's value when attending for scheduled Type 2 diabetes and chronic kidney disease outpatient consultation. This information will be utilized to inform future service development.
- To examine if the development and implementation of combined Type 2 diabetes and chronic kidney disease care delivery in the context of advanced practice nursing can achieve the best practice clinical target recommendations.
- To explore the views of health-care teams and clients regarding a combined Type 2 diabetes and chronic kidney disease care delivery in the context of advanced practice nursing.

Methodology

This study is informed by the philosophical thinking of critical theory and post-modernism and will be operationalized

utilizing PAR methodology which is responsive to problems at practice level and has the potential to address significant health-care delivery issues.

Setting, participants, recruitment, and consent

Setting

The study will be undertaken in five geographically diverse specialist diabetes and nephrology care centers across academic teaching hospitals in the Republic of Ireland.

Participants

This study will include (1) a PAR group consisting of 17 key stakeholders with expertise across the patient journey including medical, nursing, dietetic, and podiatry health-care professionals, hospital management, and administrative personnel, (2) 10 patients with Type 2 diabetes and chronic kidney disease will be invited to participate in a discovery interview, and (3) four focus groups comprising key medical and nursing stakeholders with expertise in the management of Type 2 diabetes and/or chronic kidney disease.

Recruitment and consent

Patient participants will be recruited from specialist secondary care renal and diabetes outpatient services and are required to meet the outlined eligibility criteria [Figure 1]. Patients meeting these criteria will be provided with a participant information leaflet on the day of their routine outpatient consultation by their attending clinician and given time to consider their participation as well as the opportunity to discuss the study with their family, health-care professionals, and members of the research team. When patients have read the patient information leaflet and have decided to participate, informed consent and baseline data will be obtained at a location and time convenient for the participant.

Key stakeholders are required to meet the outlined eligibility criteria [Figure 2]. The principal investigator and coinvestigators will use purposeful sampling to identify health-care professionals with expertise in the management of diabetes and/or chronic kidney disease and the patient care journey. Potential participants will be provided with an information pack including an expression of interest in participation form for completion and return by stamped addressed envelope to the study coordinator and arrangements will be made to undertake informed consent.

Ethical approval

Ethical approval has been obtained from the Human Ethics Committee at each participating site and an exemption from a University Human Research Ethics Committee.

Inclusion criteria	Exclusion criteria
1. Over 18 years 2. Living with type 2 diabetes and chronic kidney disease with a glomerular filtration rate < 60 ml/min 3. Are informed and have confirmed an understanding of their diagnosis 4. Have the ability to speak and understand English to contribute to the data collection required for the research 5. Capable of providing written and informed consent	1. Considered by their clinician to be too unwell to participate 2. Included in another research study simultaneously 3. Declined participation

Figure 1: Patient inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
1. Clinical and or professional knowledge in the care of patients with type 2 diabetes and or chronic kidney disease 2. Permanent member of staff of the specialist diabetes or nephrology unit at the participating site or general practitioner in the primary care setting	1. Declined participation

Figure 2: Key stakeholders: Inclusion and exclusion criteria

Research design

PAR has been used extensively within health-care settings.[28] It is particularly beneficial in the improvement of care delivery systems/coordination of care[29] and in situations where there is poor uptake of preventative services.[30] PAR involves identification of a problem followed by planning, acting, evaluating, and repetition of these cycles, undertaken in at least three cycles.[31]

Within this study, the first step of PAR cycle [Figure 3a] will commence with a collaborative dialogic activity in which key stakeholders begin by constructing what the issues are, this may be in a provisional capacity and provides the means to plan and take action.[31]

In the second step, discovery interview and focus group information will be fed into the PAR group planning stage, which provides the basis to plan the next step leading to the first or series of actions [Figure 3b].

In the final step of the cycle, the PAR group considers as to whether the initial construction fitted, potential intended and unintended consequences and agreement on future cycle actions [Figure 3c].

Data collection

Discovery interview and focus group information will be utilized by the PAR group to inform the development and implementation of a new combined Type 2 diabetes and chronic kidney disease service in the context of advanced practice nursing informed by the best practice.[32,33] Clients with a new diagnosis of Type 2 diabetes and chronic kidney disease will be given the choice to attend standard medically

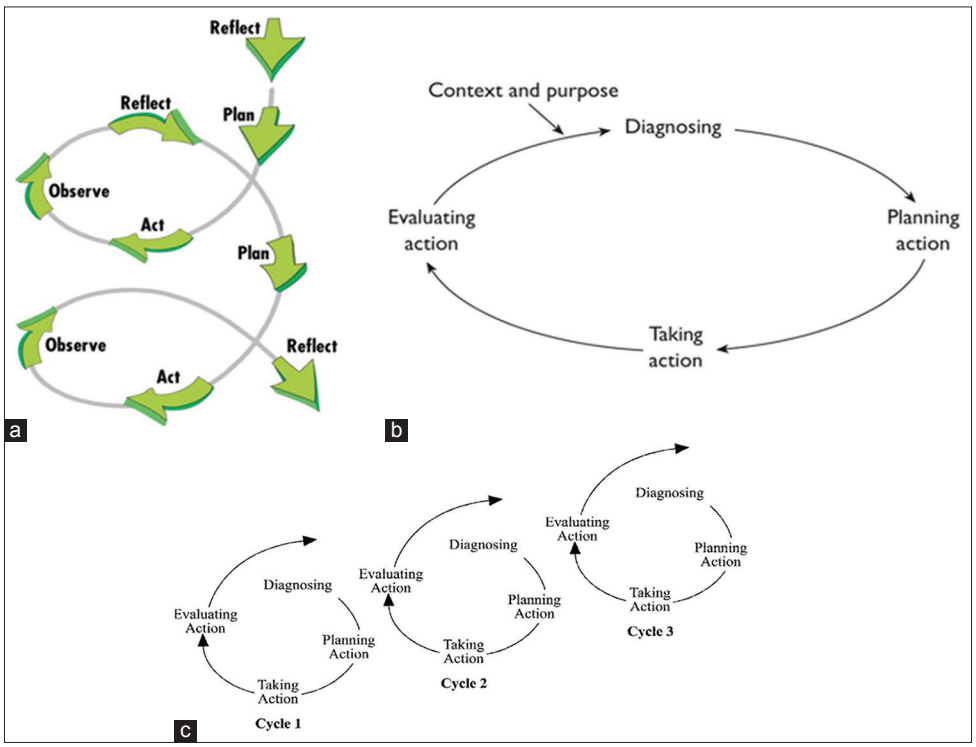

Figure 3: (a) Step 1 action research cycle. (b) Step 2 action research cycle. (c) Step 3 action research cycle

led diabetes care or the new combined care service in the context of advanced practice nursing.

After 9 months, a retrospective chart review (RCR) will be used to evaluate the outcomes from patients attending the new combined care service. RCR involves using pre-recorded patient-centered data such as diagnostic tests and medical notes to answer one or more research question.[34] RCR provides a valuable contribution as a reflection of routine, real-world health care.[35] The RCR will extract the following data which is collected in the context of routine care from the healthcare record: Age, gender, body mass index, blood pressure, Hba1C, total cholesterol, albumin-creatinine ratio, renal function (glomerular filtration rate), exercise, presence of neuropathy and retinopathy, smoking history, alcohol intake, and patient attendance.

As focus groups and RCR have been utilized broadly in health care and social sciences, it is not the intention of this discussion to outline these data collection methods in detail. Within contemporary literary discourse, there is a lack of discussion regarding the "how to" use discovery interviews within PAR research. The purpose of this article is to outline how PAR informed by discovery interview technique is operationalized, which may assist future researchers considering this approach.

Discovery interviews

Discovery interviews were developed in the United Kingdom by the NHS as a service improvement tool, in which the primary aim was to involve patients in the development of services. Discovery interviews are face-to-face semi-structured interviews which are "particularly useful when clinical and other practice-based teams want to directly learn about patient needs and use this understanding to stimulate improvement ideas."[36. p. 4]

It is recommended that discovery interviews are not a standalone process and are used as a component linked to continuous quality improvement (CQI) which enables "people to improve the processes within which they work."[36. p. 7] Interprofessional clinical improvement team's benefit from using a clear framework or structure to guide CQI initiatives. PAR has been used extensively within health care to guide change and improvement[37. p. 49] and will be used in this study to provide structure for improvement and change.

How to utilize discovery interview technique

The discovery interview process has three stages which are outlined in reference to this study: (1) Setting up the process, (2) undertaking interviews, and (3) using stories to improve care.

Stage 1: Setting up the process

Planning: Organizational priorities, local management arrangements, and commitments

A key planning prerequisite for undertaking discovery interview is a commitment from health-care planners to

provide adequate resources, equipment, and personnel. It is necessary to involve key stakeholders such as patients, senior management, nursing, and medical staff to ensure that the discovery interview process fits with organizational priorities and patient participation strategy.[36] In this study, the PAR group will assume responsibility for planning the following "setting up" steps.

Involving patients

Participation of patients occurs within three modes; informing, consulting, and partnership at individual or group level within strategic policy-making, service development, and treatment processes.[36] This study will utilize all three participation modes using discovery interview outcomes to inform health-care delivery policy change nationally (strategic policy-making), using patient stories to develop and implement services informed by the best practice recommendations (service development and treatment processes).

Choosing a patient group

It is necessary to identify a subgroup of patients to inform the specific area for improvement. This approach is based on qualitative inquiry the focus of which, is to identify patients who are the emphasis of the enquiry.[36] As the aim of this study is to develop and implement combined Type 2 diabetes and chronic kidney disease care, thus it is necessary to enroll participants with both conditions.

Choosing and training discovery interviewers

Selecting prospective interviewers is informed by three essential criteria, (1) a role involving front line contact with patients or carers, (2) experience with patient advocacy/voluntary sectors, and (3) familiarity with qualitative research methods. It is also beneficial if interviewers are embedded in the local health-care community facilitating capacity building within the system.[36] Interviewers must also understand the process and purpose of discovery interview within the context of the required improvement and not be involved in direct care provision for patients undertaking the discovery interview. Within this study, a member of the research team (advanced nurse practitioner) has met these criteria.

Planning interviews: Ethical approval and timescale

Ethical approval was obtained before initiating selection, recruitment, and consent procedures. Each interview requires a 6-week planning phase and should not be undertaken if the patient had been recently discharged from hospital or if there has been long period post-contact with the service.[36] The research team will afford cognisance to timing of interviews relevant to illness/patient group and resources/equipment required to undertake interviews. The essential touchstones of Stage 1 are shown in Figure 4.

Stage 2: Undertaking discovery interviews

To prevent self-selection bias, an appropriate means by which to identify potential participants is to involve clinicians in the identification of eligible participants from where random selection can be employed. Interviews should be undertaken across the entire care journey as client stories relate to their experiences and will not necessarily "acknowledge the arbitrary divisions we organize into services as they have to cross them."[36, p. 5]

Within this study, all discovery interview participants will have Type 2 diabetes, various stages of chronic kidney disease, and length of diagnosis. The recommendations for undertaking discovery interview[36] provide a process map which will be adapted and used by the PAR group in this study [Figure 5].

Discovery interview spine development

To facilitate discussion, a "spine" should be developed which provides a minimum of prompts and a starting point from where patients can begin to tell their story. Discovery interview spines are illness/condition specific which provides consistency across interviewers. Spines are developed during the planning phase, by health-care personnel experienced in the care of the specific conditions and patients.[38]

The spine which will be utilized in this study was informed by the (NHS, 2009) recommendations and previous studies utilizing discovery interviews in patients with Type 2 diabetes.[18] This information was used to inform the development of an initial spine in consultation with the principal investigator, local principal investigators, and

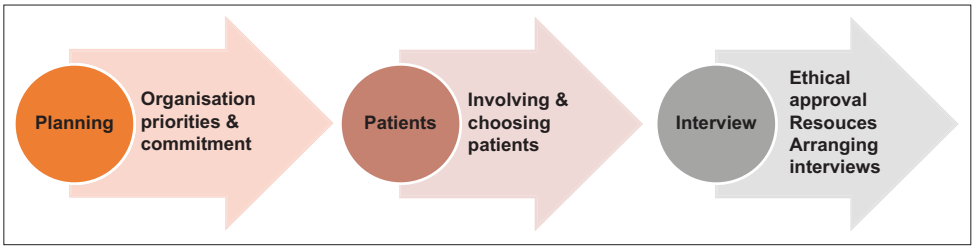

Figure 4: Essential touchstones Stage 1

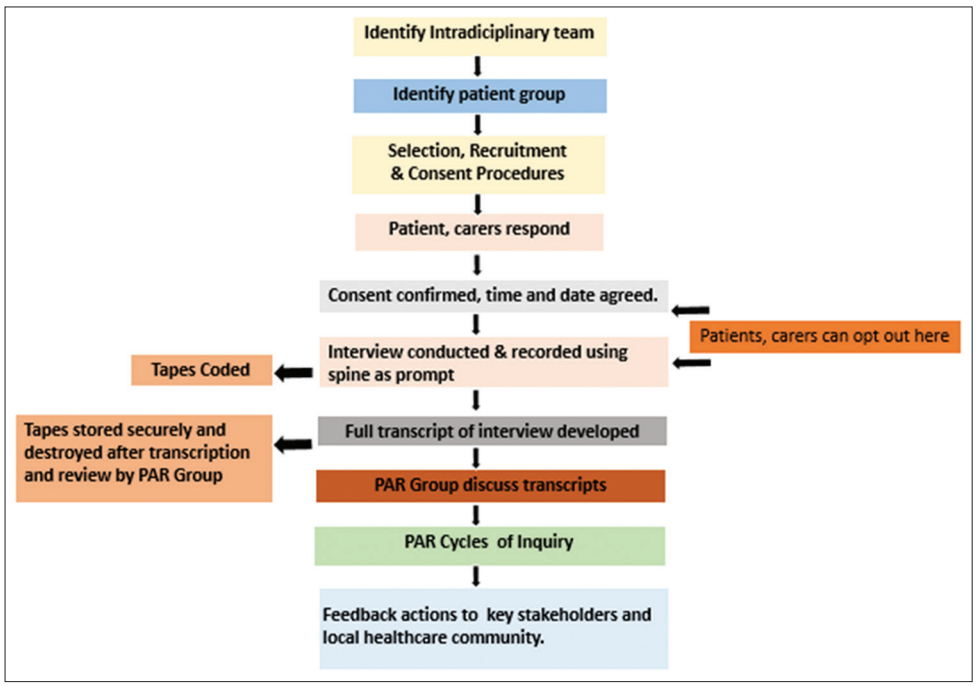

Figure 5: Discovery interview process map

coinvestigators at each participating site for feedback. This resulted in the development of the final discovery interview spine [Figure 6].

Gaining consent, undertaking the interview, and responding to distress

Consent procedures have been previously outlined. When undertaking discovery interview, the interviewer will provide an introduction, identify their role in respect of the interview and highlight that they are not a member of the health-care team. If a patient or carer was to become distressed, it may be necessary to terminate the interview and arrange the necessary supports as outlined in the ethical approval application.

Recording the interview and coding

A separate code should be allocated to each interview containing, the type of interviewee, for example, Patient A or Carer B, number of the interview, initials of the interviewer, date of the interview, and diagnostic category as necessary and undertaken over a period of 45 min.[36] These recommendations were included in the ethical approval application and study protocol. Stage 2 essential touchstones are shown in Figure 7.

Stage 3: Using discovery interview stories to improve care

Transcribing audio recorded tapes

In the planning phase, it is recommended that adequate resources are allocated to undertake transcription which is time and resource dependent. At the first PAR group meeting, these issues will be discussed including membership roles and required resources.

Preparing with clinical teams and generating dialogue

Improvements in care informed by discovery interviews are only successful where clinical teams have been involved from inception of the improvement.[8] Specialist diabetes and nephrology secondary and primary care health-care professionals will form the PAR group and will be involved from inception to plan future service improvements.

A vital component of using discovery interview to improve care is generating dialogue within teams through hearing the patient/carers story in their own words, and in this study, the PAR group provides the forum to generate dialogue. As patients cross care boundaries, sharing information across teams and disciplines may be beneficial in terms of developing, implementing, and maintaining improvements in care.[36] Within this study, it is anticipated that the inclusion of diverse geographical areas, multiple hospital groups, and extensive PAR membership will promote information sharing across teams and disciplines to inform service improvement.

Creating improvements

Discovery interviews provide the means by which patients relate their stories of care which may require many changes or improvements in care. The NHS (2009) recommends that teams adopt the following questioning approach to prioritize changes for improvement which will be used by the PAR group in this study.[36]

- Are chosen improvements important to patients, carers, and staff?
- Are linked to key service goals if possible
- Do they pertain to high volume/high leverage/high cost areas
- Are manageable, organizationally realistic, and simple to measure
- Should commence as early in the patients journey if possible.

Feeding back outcomes

Feedback to patients and carers regarding how their stories facilitated improvement is a critical step in the process. Suggestions for providing feedback include liaison with primary and secondary health-care providers, publication at local and national forums, feedback through quality improvement initiatives, and patient meetings.[36] These mechanisms will be considered by the PAR group to identify the means by which key stakeholders and patients can receive feedback regarding how their stories informed improvements in care. Stage 3 essential touchstones are shown in Figure 8.

Figure 6: Discovery interview spine

Discovery interviewing facilitates a greater understanding by key stakeholders regarding the patients experience of illness and care received and using these stories for improvement and change.[36] It is anticipated that completion of this study will inform further discussion regarding the utility of discovery interviews within PAR methodology.

Study cycles

This study will be undertaken in three PAR cycles over an 18-month period [Figure 9].

Data management

Participants will be identified by a unique study number and privacy will be maintained. All data collected will be treated with confidentiality throughout the study and during dissemination of results. All computerized data will be stored in password protected documents on an encrypted password protected laptop computer stored in a secure location and all collected data will be accessible only to the principal investigator and lead coinvestigator.

Statistical analysis

For the purpose of this study, quantitative data analysis will be entered into Microsoft Word Excel spreadsheets. The six-phase framework for thematic analysis by Clarke and Braun offers "a toolkit" to undertake robust and sophisticated analysis of qualitative data and will be utilized in this study.[39]

Trustworthiness

This study will be informed by the trustworthiness criteria of credibility, dependability, confirmability, and transferability by Lincoln and Guba.[40] It is proposed that trustworthiness can be achieved by detailed and prolonged engagement with the data, triangulation, member checking, documentation of decision-making processes, and reflexive journaling. These criteria offer "pragmatic choice's for researchers concerned with the acceptability and usefulness of their work for a variety of stakeholders and are widely used."[41, p. 3]

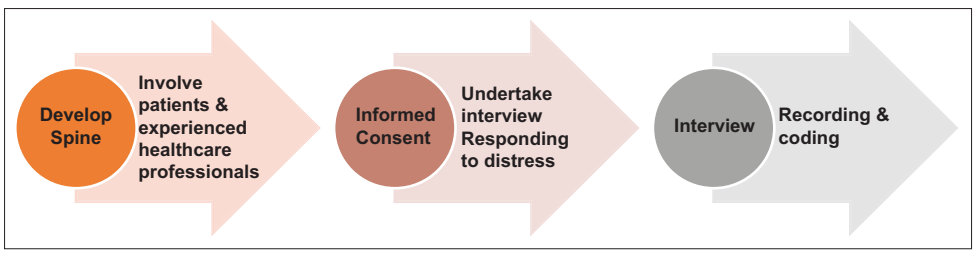

Figure 7: Stage 2 essential touchstones

Discussion

The prevalence of Type 2 diabetes is increasing across the age spectrum nationally and internationally and confers a higher risk for the development of chronic kidney disease, which is a progressive condition linked to increased economic burden, mortality, morbidity, and patient suffering.[1]

Evidence from contemporary literary discourse indicates that early intervention strategies have benefits in terms of improved clinical outcomes, patient survival, and reduced economic burden. Opportunities to instigate early intervention and management strategies in line with the best practice recommendations are frequently missed within current health-care delivery structures which provide separate Type 2 diabetes and chronic kidney disease care.[13] Factors attributable to this missed care scenario include a lack of health-care professional expertise in combined management of these associated conditions and finite resources.[14]

Many patients DNA for their scheduled review and report an impersonal uncoordinated approach to the management of associated conditions delivered in a system which patients have to self-navigate resulting in poorer clinical outcomes and a failure to meet patient expectations of care. Despite the fact that advanced nurse practitioners provide high quality and effective care,[14] their contribution to the combined management of Type 2 diabetes and chronic kidney disease has yet to be elucidated.

PAR research methodology is dependent on participation, without which the study may fail to be successfully operationalized. This potential limitation is countered with the following commentary "PAR promotes social empowerment, strengthens local levels of health systems, and promotes links between knowledge generation, translation, and action."[42. p.15] The cycles of PAR provide a vehicle to undertake research which incorporates the contextual influences found in clinical practice which ultimately impact the ability to undertake research with sustainable outcomes.[37]

The aims of this study are to adopt a coordinated approach to combined Type 2 diabetes and chronic kidney disease care delivery in line with the best practice recommendations informed by key stakeholders including patients at system, provider, and service user levels. One of the advantages of this intervention is the heterogeneity of diabetes services included in this study which has the potential to enable generalizability to a large proportion of diabetes service providers nationally. The outcomes from data analysis may provide useful insights into the outcomes from alternative models of health-care delivery in the context of advanced practice nursing which may be extrapolated into other areas and services.

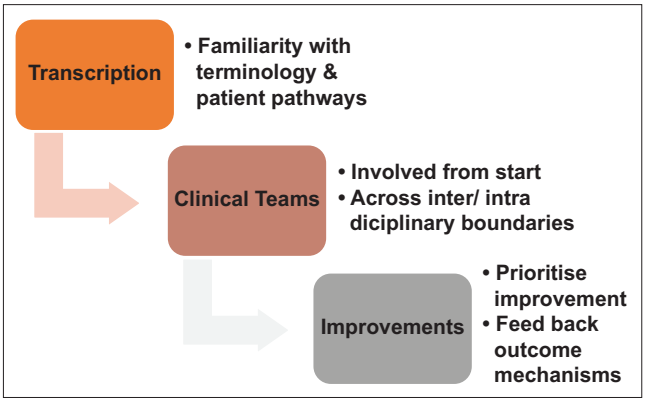

Figure 8: Essential touchstones Stage 3

Conclusion

This study will provide a nationally and internationally unique approach to combined care delivery, representing a departure from traditional health-care delivery strategies, which will facilitate insights into the contribution of advanced practice nursing for this patient cohort.

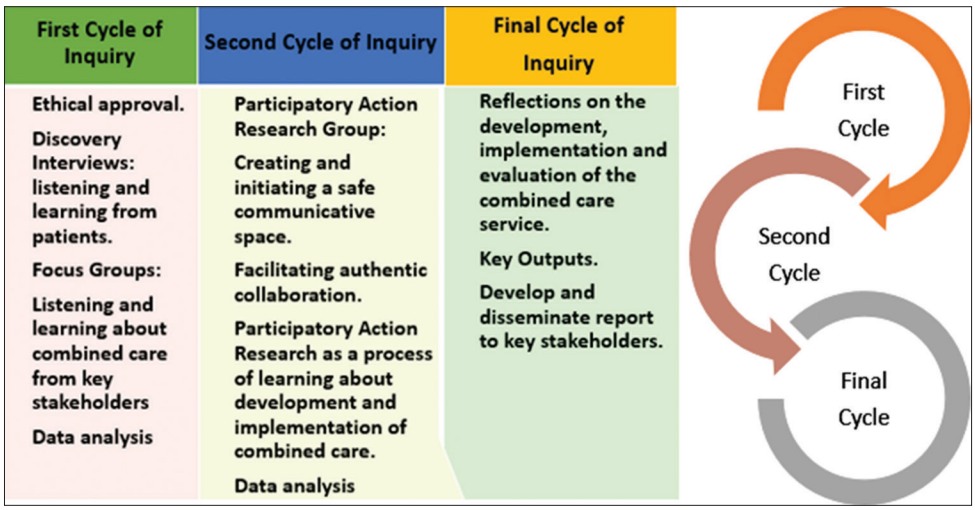

Figure 9: Three cycles of inquiry

It is contended that a combined care delivery strategy informed by cogenerated knowledge and actions between key stakeholders including patients in the context of advanced practice nursing informed by the best practice may prove useful to meet the underserved needs of this patient cohort and future service planning.

Implications for nursing

- Internationally unique approach to the development and implementation of combined chronic disease care in the context of advanced practice nursing
- Generalizability of the study findings enhanced by insights and experiences of key stakeholders including patients
- Findings have potential to inform development and implementation of future health-care service delivery in the context of chronic illnesses led by nursing practice
- PAR informed by discovery interviews provides the means by which the impact of the contribution of nursing care to health-care services can be developed, implemented, and evaluated
- Solutions are identified by those affected by the issues, thus promoting suitable and sustainable solutions led by the discipline of nursing.

Limitations

- Implementing and disseminating change may be influenced by issues pertaining to power and politics
- Considerations should be afforded to the potential implications regarding implementing change and the potential influence of organizational power and politics
- PAR is time consuming and requires active involvement which may prove challenging
- The dearth of similar research inhibits comparative analysis with similar studies.

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