

DIABETES CARE IN OKLAHOMA - A FORMATIVE
ASSESSMENT

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CHAPTER I

INTRODUCTION

Diabetes decreases “average life expectancy by 15 years, increases the likelihood of cardiovascular disease two to fourfold, and is the most common cause of kidney failure, lower limb amputation, and adult blindness”.¹ In the United States of America, diabetes affects greater than 20% of people older than 65 years.² Diabetes is a concern for many Oklahomans, especially for the elderly living in areas where access to adequate information and care is of great concern. The average prevalence of diagnosed diabetes in Oklahoma is 5.6%.³ Prevalence of diabetes among the elderly (65 yrs +) population in Oklahoma has been on the rise, with 19.8% of the population having been told by a doctor that they have diabetes in 2006, which is up from 16.8% in 2004, and 18.9% in 2005.⁴ Specific regions of Oklahoma have higher rates of diabetes, with the “west/southwest portion of the state having a higher rate of diabetes”.⁵ Counties in this region with percents of the total populations diagnosed with diabetes being greater than the average for Oklahoma include Beckham County (11.5%), Jackson County (12.9%), and Kiowa County (15.9%).⁶

Strategic relations among health care and education entities are essential for properly addressing the issues of any community's health needs. For the sake of this project, community refers to a collective of individuals receiving and providing services. A myriad of models exist that detail strategic relations among health care and education resources. Applying the model that will allow greatest efficiency in delivery of services is critical for achieving successful community health outcomes. The stakeholder model is a type of strategic relation "in which each organization assumes a leading role in the operation or 'productive process' of its partner".⁷ In other words, each organization engages in actions that address the missions of the other organizations to ensure that core objectives are met.⁷ With this model in place, management of community health issues takes on a collaborative approach that builds alliances between health care and education organizations.⁷ While the stakeholder model supplies a framework that fosters inter-organizational efforts, it would be incomplete without application of facilitative management techniques.

Successful management of community health issues relies on proper management techniques. Management takes on as many forms as there are people involved with a given health issue; multiple perspectives of what information and services are to be provided and received exist with health issues, such as with diabetes. Relations between health care and education agencies and among these agencies and the people they serve can be "described along three broad dimensions".⁷

In no particular order, the three dimensions within/among which "diverse and complex relations" take shape are *strategic attributes*, *functional attributes*, and *structural attributes*.⁷ Strategic attributes refer to the "motivations, goals, and objectives"

of the various alliances among the health care providers.⁷ Functional attributes refer to the “range of activities and operations . . . jointly carr[ied] out” among the health care providers and “delineate the individuals, groups, and populations reached by these collective activities”.⁷ Structural attributes refer to the mechanisms of interaction among health care providers and “offer an indication of the strength and durability of such associations”.⁷ Based on the aforementioned dimensions of collaborative relations, delivery of health care and health education initiatives come to fruition as collective health planning and policy development programs.⁷

PROBLEM STATEMENT

Based on communication between Cooperative Extension Service educators and State Specialists, there is a disconnection between the needs of the community and educators’ ability to deliver desired services. Some County Educators, who are not Registered Dietitians, did not feel comfortable addressing diabetes related questions from community members. Additionally, paraprofessionals, or Nutrition Education Assistants (NEAs), who are funded through a Supplemental Nutrition Assistance Program grant, are not allowed to address delivery of medical nutrition therapy due to grant restrictions. Community members are seeking assistance from educators who are incapable of delivering required health information due to legal constraints, ethical issues, or lack of knowledge. This situation is exacerbated by a *gap* in services between health care and education organizations.

RESEARCH QUESTION

How does the community perceive the processes through which diabetes related health care and health education are delivered?

PURPOSE

Explore the community perspective of diabetes care.

OBJECTIVES

The degree to which community health is impacted by health agencies relies on the interaction between such agencies and, therefore is guided by their views on “strategic, functional, and structured alliances”.⁷ Using the stakeholder model as a guide, we will investigate existing alliances and the potential for developing new alliances in an effort to determine factors, such as:

- how the community views diabetes care, including their responsibilities to contributing to the handling and managing of diabetes

CHAPTER II

REVIEW OF LITERATURE

The following literature review will focus on the management of diabetes care. The analysis of outcome measures and the evaluation of the process of care are two perspectives on how to assess management of diabetes care. This literature review reveals the differences in the processes and practical applications of the two perspectives.

Outcome Measures

A cross-sectional study was done to explore “whether patients’ own assessment of their self-management correlates with glycemic control and key aspects of high-quality diabetes care.”⁸ Using multivariable regression, researchers examined “the associations of patients’ reported self-management with HbA_{1c} level and receipt of diabetes process of care” by analyzing patients’ medical records and answers to a Diabetes Quality Improvement Program survey, which included “a five-item scale assessing the patients’ diabetes self-management.”⁸ The assessment of self-care was comprised of five areas of diabetes care – taking medications, exercising, following an eating plan, blood glucose monitoring, and foot care.⁸ The question on the survey asked participants “Over the past year, how difficult has it been for you to do each of the following exactly as the doctor who takes care of your diabetes suggested?”⁸ There were five valid response categories

that ranged from “So difficult that I couldn’t do it at all” to “Not difficult, I got it exactly right.”⁸ The mean age of patients included in this study was 67 years.⁸

Based on their analysis, researchers found that “higher patient self-ratings of diabetes self-management were significantly associated with lower HbA_{1c} levels.”⁸ What the researchers do not provide is any indication of what those HbA_{1c} levels are. Lower HbA_{1c} levels associated with higher self-ratings of diabetes self-management does not mean that the values were within healthy ranges. Analysis also revealed that the “separate domains of taking medications, monitoring blood glucose levels, exercising regularly, and following a diabetes diet were each independently associated with glycemic control.”⁸ Researchers stated that their “multivariable model accounted for only 11% of variability in HbA_{1c} values.”⁸ What they found was that at this one point in time, their multivariable model examining the self-management scale accounted for “11% of the variance in HbA_{1c} values.”⁸ The authors noted that this small variability was not surprising “in light of the complex set of factors that contribute to glycemic control”, but it “was clinically significant.”⁸

From their findings, it may also be concluded that 89% of variance in HbA_{1c} values are accounted for by things other than their multivariable model. And what does that mean anyway, that the multivariable model accounted for 11% of variability? How does that model equate to the actual human experience of engaging in the process of diabetes care? What is more confusing is that after the researchers stated their conclusion (patients’ assessments of their diabetes self-care using a simple five-question instrument were significantly associated with actual HbA_{1c} control and with receiving recommended diabetes services), they later state that, due to their research design, they are not allowed

to “establish that patients’ assessment of their diabetes self-management was causally associated with glycemic control or receipt of diabetes services.”⁸ The difference between their concluding statement and their closing statement – causality. But this does not inhibit the researchers from stating that “this scale may serve as a proxy for self-care behaviors that lead to improved glycemic control.”⁸ How can a once a year five question survey function as a proxy for something as complex as behaviors associated with diabetes self-care? Especially when you take into account that a few paragraphs later the researchers state that “patients who receive more recommended services may also have better reported self-management for another reason not measured in our analyses.”⁸ Another statistic to consider is the overall health status of their study population, which was rated as “poor” or “fair” by 60% of participants.⁸ Based on that rating, it seems worthy to investigate viability of current diabetes guidelines for care.

A study by McCall et al. conducted a cross-sectional analysis of “Medicare claims data from Colorado during a 2-year period from January 1997 through December 1998” to investigate whether low-income elderly patients were at risk for poor diabetes care.² The study focused on dual-eligible (DE) Medicare/Medicaid patients because diabetes is common among this population.² A total of “9,453 patients aged 65-75” [mean age 71] *participated* in their study.² Measures used to assess quality of diabetes care were “1) annual A1c; 2) biennial ophthalmologic examination; and 3) biennial lipid measurement.”² Statistical analysis included the use of χ^2 , *t* test, and the Wilcoxon two-sample test to compare “the proportion of patients receiving the individual diabetes care measures with the variable of interest, DE status.”² Researchers also used logistic

analysis as a means of determining if “DE status was independently associated with the likelihood of receiving care.”²

Analysis revealed that, among the total 9,453 patients, 2,096 (22%) were DE.² The DE patients were “significantly less likely” to receive the three indicators of quality diabetes care compared to non-DE patients.² Their logistic regression analysis “revealed that the odds ratios of DE patients receiving diabetes care was significantly lower compared with non-DE patients.”²

Based on their findings, the researchers concluded that “DE Medicare patients were less likely to receive routine diabetes care.”² An important point to consider is that, even though the measures of diabetes care quality chosen for this study were “consistent with those of the Diabetes Quality Improvement Project initiative, they admittedly reflect the minimal accepted care standards.”² This implies that DE patients are not only receiving less diabetes care, but they are not even meeting the minimal standards of quality diabetes care. This lends some insight to the finding of this study that “DE patients were significantly more likely to . . . access emergency department care compared with non-DE patients.”²

The reasons behind the “disparate diabetes preventive care among low-income DE Medicare/Medicaid patients” were not addressed in this study, but “the extent to which the patient’s socioeconomic status contribute[d] to [their] findings . . . is likely to be substantial.”² A partial explanation for why researchers of this study could not address the reasons behind the poor quality of care for DE patients is because the *participants* of their study were not the patients. Medicare claim forms were the participants of this study, and as such, could do little to clarify reasons pertaining to the

perspective of DE patients as to why their quality of care is poor. Based on what these researchers gleaned from other research projects addressing disease management, they suggest future research should address the issues related to low socioeconomic status, such as financial means, literacy, and unconscious bias of physicians, which may function as barriers to enhance the gap in care between the DE and their non-DE counterparts.² For even though there is a preponderance of “published evidence-based standards of care . . . detailing the effectiveness of diabetes preventive care, many Medicare patients remain at risk of not receiving such care.”²

A retrospective study involving outpatient management of type 1 and type 2 diabetes investigated the “discord between the evidence based [diabetes] guidelines . . . and current treatment outcomes.”⁹ This study involved the retrospective analysis of 12 months of data on “weight, height, control and treatment of glycemia, blood pressure and serum lipids, and prevalence of diabetic microvascular complications” of 96 patients with type 1 diabetes [mean age 44.4 years] and 509 patients with type 2 diabetes [mean age 64.4 years].⁹

Only 13% of patients with type 1 diabetes and 30% of patients with type 2 diabetes maintained HbA_{1C} levels that “satisfied the ADA [American Diabetes Association] target of <7%.”⁹ The percentage of type 1 diabetes patients receiving antihypertensive medicine was 35% and only 29% of those patients had “blood pressure readings at or below the ADA target of 130/80 mmHg.”⁹ Sixty percent of the type 1 diabetes patients not receiving medication met the ADA blood pressure target.⁹ The percentage of type 2 diabetes patients receiving antihypertensive medicine was 71% and only 24% of those patients met the ADA blood pressure target.⁹ Thirty-eight percent of

the type 2 diabetes patients not receiving medication met the ADA blood pressure target.⁹ Retinopathy was documented in 52% of patients with type 1 diabetes and 18% of patients with type 2 diabetes.⁹

To account for the discord between guideline targets “advocated by physicians, and current treatment outcomes” noted in this study, the authors offered *their* thoughts regarding potential barriers to achieving said outcomes.⁹ Drug interactions, side effects, inadequate counseling of patients, ethnicity and racial factors, and prescribing restrictions were listed as potential barriers to preventing achievement of diabetes guidelines.⁹ Barriers mentioned by the researchers were not directly related to data analyzed for their study, but were pulled from findings of other studies listed in their references, which leaves us with the question asked in the title of their article – Diabetes guidelines: easier to preach than to practice? Their research methods and findings did not address this question because neither were involved with investigating the practice (or process) associated with diabetes care. However, their findings did offer another round of statistics to add to the ever-growing pile of data illustrating disconnect between outcome measures and processes of care.

The following cross-sectional study focused on evaluating the “quality of diabetes care in a cohort of patients with type 2 diabetes in rural Alberta, Canada [based on] information about clinical status and treatment patterns.”¹⁰ Researchers collected “patient interviews, drug histories, physical and laboratory assessments, and a self-report questionnaire” from 368 patients [mean age 63.4 years] with type 2 diabetes.¹⁰

Descriptive analyses providing means and frequencies revealed treatment gaps “in the pharmacological management [of] hyperglycemia, hypertension, and dyslipidemia.”¹⁰

Researchers noted that “of the 111 patients who were not at the . . . guideline target for glycemic control (A1C < 7.0%), 14.4% were receiving no therapy, and an additional 50.5% were receiving only one oral agent.”¹⁰ Additionally, “27.5% of patients whose blood pressures were above the target level were not receiving any antihypertensive drugs . . . [while] 86.7% of patients whose LDL levels were greater than 100 mg/dl” were not receiving any lipid-lowering medication.¹⁰ The researchers point this out as being of interest because “most clinical practice guidelines advise that patients with type 2 diabetes are at very high risk for coronary artery disease and should start receiving drug therapy.”¹⁰

In discussing their results, the researchers made several assumptions to fill in the gaps created by their analyses of data. In response to data revealing that patients were not receiving medication or only receiving one medication for a particular condition, researchers referred to “physician reluctance” to administer therapy.¹⁰ Additional reasons proposed for the lack of a pharmacological response were the high number of drugs already consumed by the patient (an average of 5 per patient), and the relative newness of the emphasis on lowering lipid levels in diabetes patients.¹⁰ It was “assumed” that patients who began receiving pharmacotherapy did so because “diet and exercise therapies were not sufficient.”¹⁰ As stated, the researchers’ motivation for completing this study was due to increasing concern “regarding access to and quality of diabetes care in rural and underserved areas.”¹⁰ After noting that the rural setting was a potential factor in determining quality of care in that “specialist care was available only at distant centers”, the researchers tied this to findings of previous studies suggesting that “quality of care for patients with diabetes and compliance with guidelines [were] suboptimal in

rural areas.”¹⁰ Because the researchers did not have insight regarding perspectives of either physicians or patients in relation to the phenomena of interest, their assumptions supplant physician and patient perspectives with their own. At best, the researchers relied on previous studies as an attempt to provide substance to their statistical data.

As far as to what is effecting the quality of diabetes care, the researchers propose several barriers, but do not propose any ways to address the barriers other than to state that “there is substantial room for improvement, especially in terms of achieving various clinical targets by administering combinations of drugs rather than monotherapy.”¹⁰ This is an appropriate conclusion to make based on the circular logic supported by their descriptive analyses of cross-sectional data regarding “clinical status and treatment patterns [in order] to assess [physician] compliance with the current clinical practice guidelines.”¹⁰

With outcome measures based on clinical status, treatment patterns, and compliance, the researchers evaluated the quality of diabetes care based on outcome measures that were a direct result of the process of care. They did not investigate the *process* of care and how it influences clinical status, treatment patterns, and compliance, and its subsequent impact on the *quality* of care. As such, the process of care has been replaced by focusing on clinical targets with no mention as to how to achieve those targets. Similarly, the process of care is addressed by proxy through listing of barriers. In essence, these barriers are treated as outcome measures for the process of care, while neglecting to offer any understanding, either from the perspective of the physician or the patient as to how the process functions to impact quality of care.

Process of Care

By assessing the “relationship between decision making and successful diabetes self-management”, a study by Lipka et al. was more successful than the previously discussed projects at addressing the process of diabetes care.¹¹ Their study conducted 18 individual interviews related to task analysis in an attempt to analyze “problem detection, functional relationships, problem-solving strategies, and types of knowledge used to make self-management decisions” with participants who had type 2 diabetes.¹¹ The majority of participants were “brought in by friends or relatives enrolled in introductory psychology courses”, as well as through use of flyers at grocery stores and pharmacies.¹¹ The participants ranged in age from 19-76 years, with a mean age of 53.9.¹¹ Interviews were transcribed and coded “using a method designed to capture meaningful content . . . in semantic units, each encompassing a single complete idea.”¹¹

Through their research they illustrated that although diabetes self-management “is often approached using simple rules and procedures”, it falls short due to the lack of focus on experiential learning.¹¹ When participants were “asked for the appropriate response to low and high blood glucose, 12 and 11 participants, respectively, reported the correct action . . . [but] when describing their actions during an actual incident of low or high blood glucose, only 5 and 4 respectively, took the correct action.”¹¹ So while information for achieving diabetes guidelines that are ADA approved and physician advocated is provided in abundance, it may lack the appropriate contextual impact to ensure practical application outside of a clinical setting.

The researchers suggest expanding diabetes education to include “experiential knowledge of the functional dynamics of the disease and decision-support training.”¹¹ As

such, the training “must go beyond facts and rules . . . focusing less on didactic more on experiential forms of learning.”¹¹ This way “when patients encounter problems not directly covered [by traditional] education”, they can formulate a more informed response to their particular situation.¹¹ Through the use of individual interviews, this study addressed the process of diabetes care from the perspective of people actively engaged in the care process rather than relying on outcome measures as a proxy for the process of care. The content of the interviews provided context for understanding issues occurring in the real world that impact self-management of diabetes, which is an integral component of diabetes care. As a result of orienting their project from the perspective of participants, these researchers were able to contribute significant suggestions for an improved process of diabetes care.

Similar attention to the process of diabetes care was given by Vijan et al. in their attempt to evaluate “barriers to following dietary recommendations in patients with type 2 diabetes.”¹² Their study involved quantitative and qualitative components. The quantitative component, completed by 197 participants [mean age 62.1 years], consisted of a likert-scale survey aimed at evaluating patients’ rating of the “burden of diet, oral agents, and insulin . . . [as well as] how closely they followed recommendations for prescribed therapies.”¹² The non-parametric Wilcoxon sign-rank test for paired comparisons was used to analyze “simple comparisons between ratings for various hyperglycaemic treatments” due to “non-normal distributions of ratings of treatments.”¹² Researchers used contingency tables and χ^2 tests of independence to compare categorical variables.¹² Due to non-normality and heteroscedasticity of residuals, researchers

conducted “multivariate analyses using linear regression with robust Huber/White sandwich estimators of variance.”¹²

The qualitative component consisted of six focus groups with 6-12 participants per group completed as a means to “have patients express their views towards various aspects of diabetes care and to provide insight into barriers to their ability to follow recommended interventions.”¹² Participants for the study were recruited “from the primary care population of a large academic medical centre and two VA hospitals.”¹² The mean age of focus group participants was 61 years.¹² Focus group discussions were audio-taped, transcribed, and “statements were coded based on their content (e.g. related to diet, insulin therapy, or oral agents) using Q.S.R. NUD*IST™ qualitative software.”¹² The diet portions of the transcripts “were compiled, and the statements reviewed by seven experts in diabetes care . . . [in an effort] to identify content areas that reflected major barriers or concerns that patients had regarding their ability to comply with a diabetes diet.”¹² These portions were then independently reviewed by three members of the research team, followed by a group meeting to sort out any disagreements through consensus.¹²

Survey results revealed that a moderate diet (sugar & fat reduction w/minimal calorie reduction) was viewed as more burdensome than pills, but less burdensome than twice-daily insulin injections.¹² A strict diet (sugar, fat, & calorie reduction aimed at weight loss) was “rated as similar to twice-daily insulin injections.”¹² Survey analysis revealed that the “burden of diet was viewed as higher in subjects who had frequent visits to a dietitian with each visit accounting for a 0.07 increase in burden on a seven-point scale.¹² Although the moderate diet was rated “as less burdensome than insulin”, patients

responded that they were “much less likely to report following a diet than taking insulin as prescribed.”¹² Data revealed that patients followed “their diet somewhat more than half the time, but always or almost always followed insulin prescriptions.”¹² Similarly, it was found that patients were “less likely to follow their diet than take oral agents.”¹²

The qualitative part of the study revealed patient views that aided in elucidating survey responses. Upon analysis of focus group data, expense, portion size, support/family, quality of life/lifestyle, and confusion were identified as major concerns relating to diet adherence.¹² Comments, such as “What they tell you to eat, the stuff that you are supposed to eat that is good for you, most people cannot afford”, “I get \$700 a month. After rent and all, I can’t afford to buy the vegetables and some of the things that they are talking about buying” and “. . . we spend about \$250 a month now for food for the wife and I. It would have been \$450 the other way . . . so we have to buy the cheap stuff” reveal expense as an issue and how differing realities lend toward creating gaps in care for patients.¹² In these cases, resources are available (diet education and foods necessary to foster diets), but access to those resources is conflicting, limited, or unviable.

“You couldn’t live on that diet . . . you have to eat twice as much as they want you to eat”, and “. . . you are only supposed to have three ounces of meat a day, or was it four? I forget, but it all amounts to is a little piece of meat like this. That is what makes dieting so hard” are comments revealing that portion size creates conflict with diet adherence.¹² Even when patients put the diet into practice, factors common in the real world function to interfere with compliance, and therefore potentially impact outcome measures and present as a gap in the care process. Real world situations influence the

viability of ideal world prescriptions, as revealed by the following comments related to social/family support: “Mine are really supportive but it is really their attitude. Like I am a biting dog. Don’t get near that, he can’t have that, you know” and “I don’t know if my wife helps me or not. She came home last night with a chocolate cake and says, you can’t have any.”¹²

Gaps in the process of diabetes care may also be a result of quality of life issues that may be inadequately addressed by all parties when putting together a therapeutic diet. While the health care employee and the patient have a shared focus – diabetes, the way they feel about making changes to behaviors in order to address the issue may be different. For example, comments, such as “I’m not going to sacrifice everything, what do you want to be a real old man and you can’t eat, what the hell, you got to have something in life”, “I feel deprived, I guess that is what it is” and “If I’m going to be alive today, I am going to eat what I want. Otherwise, there is no sense in being here, if you can’t enjoy something about it” reveal that participants are not always on the same plane of acceptance or understanding as the health care employee regarding therapeutic diets.¹² Quality of life and lifestyle may pose a barrier impacting outcome measures that result in a gap in care. And while a survey alone may provide a researcher with knowledge of the barriers like *quality of life* and *lifestyle*, it would not provide them with the context needed to address those barriers so as to improve the process of diabetes care.

With the aforementioned views effecting adherence to a therapeutic diet it is no wonder that confusion also influences diet. When patients state that “They tell me that I’m supposed to have so many portions of this and so many portions of that . . . I have no clue what portions mean”, “One ounce of this and a half teaspoon of that, 2 g of this, I

mean it's crazy . . . it confuses you too”, and “they put me on diets that I try to follow with, but it is hard and expensive. It is hard . . . it is really confusing a lot of the times” it becomes apparent that a gap in care may stem from a lack of understanding from each side of the diabetes care issue .¹²

When reading comments like “The only thing I got to say about the diet thing is that when you go to a nutritionist, I have no clue of what they are talking about”, “You are talking to me and you don't know what my economical position, my economics position, is. You don't know how I am situated. You don't know the community that I live in, but you are talking to me like I am Richie Cunningham of Happy Days and that is the problem I have”, and “You don't take into consideration how much money is available to me, the community that I live in, and the sources, my resources, that is available to me” the researcher is provided with a well-rounded depiction of real world experiences. These experiences provide perspective and context to survey data, such as the finding that each visit to a dietitian increased by 0.07 on a seven-point scale the view that diet was a burden, and provide a direction for developing improved practices of diabetes care.¹²

Just as Lippa et al. suggested that patients would benefit from experiential training, so to would providers of care, such as dietitians and educators. Experiential training would provide them insight regarding factors that influence patient adherence, such as economics, community, family, culture, and health literacy as it applies to portion sizes and application of jargon familiar to the care provider but foreign to the patient.^{11, 12} It was through use of research methods that took into account perspectives of people engaged with the care process, such as interviews and focus groups that enabled

researchers to form tangible connections between poor outcome measures, barriers to adherence to prescribed schemes of care and participants' inability to comply.

Research projects investigating diabetes care that incorporate perspectives of the people engaged in the care process produce results that provide context and clarification to things associated with the care process, such as barriers and unmet outcome measures. Clear communication between the provider and recipient of diabetes care is essential to eliminating barriers and meeting outcome measures. By engaging the process of diabetes care through the use of individual interviews and focus group discussions, researchers were able to uncover crucial insights regarding aspects of diabetes care that would have been overlooked with use of surveys alone.

A study by Wens et al. examined "physicians' expectations of their diabetes patients' compliance/adherence" in an attempt to "elicit problems physicians encounter" related to patients' compliance/adherence to recommendations for treatment.¹³ Five focus groups were completed that involved a total of 40 general practitioners who were interested in participating in the study (GPs).¹³ Coding and categorization of transcribed focus group discussions via content analysis enabled the structuring of themes.¹³

The theme of *barrier to compliance/adherence* included GPs' perceptions of "two kinds of patients: 'motivated' patients and 'not-to-be-motivated' patients."¹³ Physicians viewed motivated patients as "good" patients who tried their best to follow prescribed regimens. Physicians viewed the not-to-be-motivated patients as "bad" patients due in part because the patients thought they had "everything under control but they were neglectful which was frustrating for the GPs."¹³ The reflexive nature of the interview process enabled the physicians to recognize their own contribution to barriers of

compliance/adherence, and therefore contribute to the creation of a more dynamic theme, as is evident by comments, such as “choosing the easiest way out” when dealing with difficult patients and displaying a “supposed lack of respect for the patient.”¹³

Additionally recognized as a barrier by physicians were many patients’ belief that diabetes was an “infirmity of old age, an age disease” and were therefore unmotivated to follow any type of diet or therapy.¹³ As depicted by these findings, what may appear on the surface as a good patient versus bad patient issue regarding compliance/adherence is revealed to be a more complex issue of communication between patient and physician.

Another theme – *solutions* – addressed the concept of communication as a means of increasing compliance/adherence.¹³ The physicians noted the importance of being aware of the patient’s state of mind when supplying advice on how to handle a given situation, such as a “bad result . . . after a blood sample.”¹³ In discussing their findings, the authors noted that “strictly promoting evidence-based diabetes objectives” to patients is not indicative of “good” diabetes care.¹³ Effective communication is more than just handing out the standard spiel; it is being aware of the patient’s perspective and adjusting advice accordingly in an effort to build a sense of rapport between patient and physician.

Through effective communication the physician can help foster a partnership with the patient in that the patient has the potential to contribute to decisions regarding treatment.¹³ Communication between health care employees and patients may also help uncover barriers to compliance/adherence, such as “cultural motives, financial problems, and strict personal reasons” that may require introduction of additional personnel to help address concerns functioning as barriers.¹³ Making an effort to ensure that the “patients’ perspectives and concerns are not forgotten” may go a long way toward providing a

“solution for better compliance/adherence” and having a positive impact on outcome measures associated with the management of chronic diseases, such as diabetes.¹³ Once again, we see that what may appear to be a gap in care may actually be a gap in understanding between physician and patient. In this case, if assessment of diabetes care was limited to analysis of outcome measures, the situation promoting the poor outcome measures would have remained unseen.

A third theme produced through analysis of interview transcripts was *coping mechanisms*.¹³ It was a common response for physicians to take on a directing and paternalistic demeanor in order to cope with patients “who always put the blame on somebody else.”¹³ With these types of patients, if “something bad happens, they’ll tell you you’ve never explained enough, never emphasized enough or never frightened them enough.”¹³ The physicians reported that they felt that “for some people, the only option is to make them afraid. Otherwise, they won’t do it and then they blame you for not doing it.”¹³ The insights gained from this research may prove valuable in how physicians are trained to communicate with patients.¹³

When taken within the context of this study, the barrier to compliance/adherence may actually be a function of the GPs unwillingness to accept their own communication shortcomings and instead “shift the blame of failing on an inappropriate system or other extrinsic factors.”¹³ What we can gather from these and other previously discussed findings is that the process of care associated with the management of diabetes is a complex mesh of ideal world expectations in a real world setting. Wens et al. suggest a process of diabetes care that is based on a “joint patient-provider perspective.”¹³ Wens et al. propose that because patients “may have clear reasons, narrowly related to their health

beliefs, for adhering or not adhering to treatment recommendations . . . it will help patients to set their own desirable goals [which will] give the GPs consult more value and depth.”¹³ An important point to consider in support of this notion is that increased patient satisfaction may have the potential of “contributing to improved clinical outcomes.”¹³ Because of the role that “patients’ perspectives and concerns” contribute to their degree of compliance/adherence, assessing diabetes care through the evaluation of the process of care would offer a means of addressing patient, as well as physician concerns.

In an attempt to investigate why patients with type 2 diabetes achieve targeted blood pressure (BP) less than 50% of the time, the study by Cotton et al. demonstrated how physician-patient communication can contribute to effective treatment that goes beyond solely relying on outcome measures as a factor for determining care.¹⁴ Nine physicians were interviewed regarding their patients with BP >130/80 who had been seen in the prior two weeks but had no change in management for BP documented in patient records.¹⁴ Participants were selected from the Oklahoma Physicians Resource/Research Network, which is a “primary care practice-based research network with 160 physician members.”¹⁴ Through the use of a random numbers table, twelve physicians were invited to participate, of which nine agreed.¹⁴ The mean age of patients related to this study was “62.8, with a range of 33 to 88.”¹⁴ The researchers were investigating the clinical-decision making process for blood pressure management of patients with type 2 diabetes.¹⁴ Each of the interviews as audio-recorded and transcribed.¹⁴ Each of the four members of the research team “reviewed the transcripts . . . to identify and categorize reasons for nonintervention.”¹⁴ The “reasons, categories, and subcategories were determined by consensus . . . [and] data were entered into QSR N-Vivo, coded and

analyzed.”¹⁴ Using SimStat v.2.1, descriptive statistics “were computed for patient gender, age, BP at time of visit, insurance coverage, and number of BP medications.”¹⁴

What they found through analysis of data was that there are multiple factors that impact physicians’ decisions to address BP >130/80 in patients with diabetes. The outcome measure alone is not the determining factor in deciding a course of action for addressing a BP reading > 130/80 in a patient with diabetes. Patients presenting with high BP may already be in the process of addressing factors impacting BP. The physician is waiting “for the full effect of current interventions” before engaging in other types of management.¹⁴ Examples of this scenario include a woman who was about to retire, and both physician and patient were thinking that after she did, she would “watch her diet more closely and exercise more”, another patient had been losing weight and decreasing his BP over “the last 3 visits from 150/70 to 140/90 to 130/80”, so the physician was “hoping to get there with his weight loss.”¹⁴ While looking at the chart it may appear that the physicians were neglecting the management of the patients’ BP, upon further investigation it was apparent that a plan of action was already in place.

Other reasons provided by physicians for not changing management of BP were that some patients were already on “multiple medications and the risk-to-benefit ratio of adding another was too high to warrant a change” and for one patient in particular, a 90 year old man, the physician did not believe that “lowering his BP to ADA standards [was] going to substantially improve either his length or quality of life at this point.”¹⁴ A “lack of a consistent trend”, the high cost of medications coupled with inadequate insurance, adverse side effects, and comorbidities, such as alcoholism were also given as circumstances limiting treatment options.¹⁴

It was not the intent of this particular project to lay blame on either the physician or the patient for lack of BP management, but to determine reasons for the “apparent quality deficit” in BP management.¹⁴ In using a clinical outcome measure for BP as a means of identifying a “quality deficit” in BP management, the clinical outcome measure functioned to supersede the *process of care* used to manage BP. What we find upon investigation of the matter is that the issue is not about a failure to address high BP, or a quality deficit in management of BP, but about making a decision to not intervene based on a “patient’s unique situation at a particular point in time.”¹⁴

The findings of this study, completed in Oklahoma, are similar to findings discussed in the previous study by Toth et al., completed in rural Canada, regarding quality of care of patients with type 2 diabetes. In both studies, established targeted measures were not being met due to mitigating circumstances impacting attainment of clinical outcome measures. What differed between the two studies was that, unlike the research by Toth et al., research conducted by Cotton et al. included the perspectives of people involved in the process of care by conducting individual interviews. These perspectives provided an understanding of *why* clinical outcome measures were not being met, rather than just describing barriers alone. Cotton et al. caution that evidence-based “recommendations for BP control in diabetics serve as a valuable guide but do not fit all patients or all clinical scenarios.”¹⁴ Based on communication between the physician and patient, it was determined that there was more to the process of diabetes care than meeting the standard of clinical outcome measures. For future research, the authors suggest focusing on “understanding the perspectives of both physicians and patients in

the decision-making process and on ways to accurately assess quality of care at is relates to patient-oriented outcomes.”¹⁴

A study by Nagelkerk et al. investigated barriers faced by adults with type 2 diabetes living in a rural setting.¹⁵ Additionally, researchers investigated “effective strategies that people with diabetes successfully use to incorporate plans of care into their lifestyles.”¹⁵ Their study involved 24 adults who participated in “one of three audio-taped focus groups.”¹⁵ Participants were selected via a purposive sampling method to “ensure that data would be representative of the target population.”¹⁵ The age of participants ranged from 62-78 in focus group number one (mean age of 70.3), 50-66 in focus group number two (mean age of 57.83), and 26-75 in focus groups number three (mean age of 59.25).¹⁵

Focus group discussions were audio-taped and transcribed for analysis.¹⁵ A trained observer “documented the non-verbal behaviour of each focus group member and compared this to the transcripts for verification and clarification of intent of their comments.”¹⁵ Researchers and an expert panel independently categorized data into themes.¹⁵ An additional round of coding was completed “by an independent researcher with qualitative training.”¹⁵ All resulting theme categories “were compared and any minor discrepancies were reviewed and discussed until consensus was achieved.”¹⁵ Researchers strengthened validity by having an expert committee review the interpretation of findings.¹⁵

Findings revealed that diet was perceived as a barrier.¹⁵ Participants felt like they were never given a clear description of what constitutes a proper diet plan.¹⁵ For example, one participant stated that “I think that is the biggest problem that I have is not

knowing what I can and what I can't (eat)."¹⁵ Care was also viewed as a barrier, in that participants were frustrated with dealing with plans of care "that were too general or not individualized."¹⁵ Helplessness/frustration was identified as a barrier.¹⁵ Participants felt very discouraged because despite adherence they still had a lack of glycaemic control.¹⁵ Participants stated, "No matter how good, I was failure", and "What happens, happens – I guess I have a bad attitude. It's as bad as cancer as far as I am concerned . . . you are either going to lose your eyesight, your kidneys, it does all your organs."¹⁵ Resources, in that they were limited or inadequate, were also identified as a barrier.¹⁵ Participants stated that "My husband is still working and he should be retired but he can't retire because he has no drug coverage. I don't have insurance so he keeps on working" and "We should not have to put everything away and live in a cave just to have our medicine keep us alive."¹⁵ Group education was viewed as posing barriers due to the fact that topics did not necessarily apply to participants' personal needs for diabetes care.¹⁵ For example, one participant stated that "The problem I had was the meeting that I did go to was about types of blood sugar problems . . . I really don't understand all types."¹⁵ Medication had barriers associated with it in that some participants, such as the one quoted here found it "hard to remember my pills. I have to take them and I am so involved with my personal life and I don't think of them."¹⁵

Researchers also uncovered several effective strategies that were used by participants to reduce impact of potential barriers discussed above. Barriers related to care were not present when participants were able to establish a collaborative relationship with their care providers.¹⁵ Participant comments, such as "I think the biggest help for me has been my (practitioner) . . . in helping me figure out when I should test my blood

and how often . . . both have given me things I should stay away from, things that I could eat and that has been a big help”, indicate that when care is based on the individual’s needs, it helps increase feelings of empowerment.¹⁵ By addressing one barrier, such as the care issue described above, there is the potential to eliminate or reduce the impact of other barriers, such as helplessness and frustration, and diet concerns. Just as collaborative relationships between health care workers and patients can help reduce barriers to care, so to can collaborative relationships between family members help reduce barriers associated with diet. Social support came out as a strategy for coping with diet, as indicated by statements like “My wife has helped me stay on my diet. She has made sure that we have stuff in the house so I won’t go off my diet; she asked me every day whether I walked or not . . . I have to answer to a higher authority.”¹⁵

Other strategies involved development of creative solutions that enhance the process of care.¹⁵ For example, in relation to inadequate resources, such as poor drug coverage, one participant stated that “Last year I spent \$8,000.00 in prescriptions. I am now buying my medicine (from) Canada at an 86% discount . . . it was either a matter of going through Canada or not taking them, because we do need to pay our light bill and phone bill, eat.”¹⁵ In dealing with remembering to take medications, many participants developed a system that eased the process of keeping track, such as the participant explaining that “We have a system that we developed . . . it will hold a whole week supply of pills. I don’t know how many I have to take, but it is a terrific number. Our highlight is Saturday evening when we sit down and fill up our pill boxes.”¹⁵

As Nagelkerk et al. point out, how people “react to their disease process differs depending on [events] they encounter in their social situations and internal and external

environments.”¹⁵ This project highlights the importance of evaluating the process of care from the perspective of those involved in the care process. For example, it is not enough to know that there is a lack of glycemic control based on clinical outcome measures for a particular patient. In order to enhance glycemic control we must be informed as to what is interfering with the process of care. Based on an understanding of what is inhibiting glycemic control, effective strategies, perhaps along the lines of those discussed above, can be implemented to facilitate a functional process of care. Strategies or changes in the care process that alleviate the impact of barriers and eliminate gaps in care can only be identified and developed if there is an awareness of what needs to be addressed.

Understanding the perspectives of the older population regarding diabetes care is of importance because type 2 diabetes “constitutes a leading and increasing cause of morbidity and mortality among elderly adults.”¹ While previously discussed research in this literature review had participants with mean ages ranging from 44 to 67 years, the following study focused on older adults in an effort to specifically address their perspectives regarding diabetes care. Because the study was framed with older adults in mind, it offers an opportunity to gain insight regarding this segment of the population.

The project by Schoenberg et al. was aimed at enhancing their understanding of diabetes self-care by conducting in-depth interviews with 20 people “age 55 +, diagnosed with type 2 diabetes from each of . . . four groups – African Americans [mean age 69.3], Mexican Americans [mean age 69.6], Native Americans [mean age 66.15] , and rural Whites [mean age 65.5].”¹ Researchers used a purposive sampling approach to recruit participants from dental clinics, senior centers, and federally qualified health clinics.¹

Interviews were tape-recorded and transcribed.¹ Following content analysis procedures, a team of five researchers “engaged in line-by-line coding of a mixed subset of the transcripts” and identified “core categories that appeared on a recurring basis.”¹ After each researcher put together a draft codebook, a combined and refined codebook was created by two of the researchers, and distributed to the team for future use of coding the remaining interviews.¹

According to the researchers, “most elders in [their] sample described how resource challenges influenced what they could and could not afford to do for their diabetes.”¹ Many participants revealed difficulties “with affording blood sugar testing equipment or the foods that they have been advised to eat.”¹ One 66 year old man stated, “I got the (blood sugar testing) machine. No problem with that. But I can’t hardly pay for the strips you got to use, so what’s the good of the machine?”¹ Another example of how resource challenges impacted care practices was offered by a 62 year old woman raising grandchildren who stated, “Dinner’s macaroni and cheese or hamburgers or something. It may not be just what the doctor tells me to eat, but the kids won’t eat that and I can’t be making different dinners for me and them. I don’t have the time or the money for that.”¹

The setting or environment in which participants lived functioned to negatively impact self-care, even when adhering to management strategies.¹ For example, a 78 year old man stated, “Because with me living with a guy that is a drug addict, I been having a hard time with that son-of-a-gun. I mean he’s always . . . drugged up, you know. He makes me so mad. That’s when my sugar was up a lot. When I get mad it’s dangerous, dangerous.”¹ A 60 year old woman stated, “I have a full time job and two part time jobs .

. . . I work some days 12, 14 hours a day and later sleep a little bit. Take my kids to school and later come back and go to the other job and later go back and cook something. Well, when I got too much tension, too much worry about something and I start eating, like I say, things I don't have to and I love breads.”¹

The respect for and authority of physicians had an influence in directing stronger adherence to some aspects of care over others.¹ The authors stated that because “physicians *prescribe* medications and, at most, only *recommend* other self-care components, participants may prioritize medications over dietary or exercise regimens.”¹ Medications were viewed, in general, to be a relatively easy way to manage diabetes, for example, a 66 year old woman stated, “. . . like your meals. They are hard to change after a lifetime of eating what you're not supposed to (laughs). But that insulin, you just learn to do it. You learn to give yourself the insulin and you know that's going to control your sugar. I can do that.”¹

Overall, there were similarities in self-care “across these four race/ethnicity/residence groups [which] suggests that common circumstances rather than culture may be driving self-care patterns.”¹ Insight gained from this type of research, which addresses the process of care from the perspective of people involved in the care process, provides potential avenues of exploration toward enhancement of the process of diabetes care. Unlike the research by McCall et al.², which was based on data from Medicare claim forms and offered no new areas of investigation specific to their research findings, the research findings by Schoenberg et al.¹ highlighted specific areas of diabetes management that could be addressed in an effort to improve the process of care. Suggestions made by these researchers as future research initiatives include projects that

“shed light on the pathways that connect poverty, ethnicity, and health behavior [by] more fully explicating the contextual backdrop of health decision making.”¹ Future research needs to address “challenges to optimal diabetes outcomes, particularly as rates of diabetes escalate.”¹ Rather than focusing research efforts on the outcome measures, shifting focus to evaluating the practices or processes of care recommended to reach outcome measures would be more beneficial to people with diabetes.

Health care assessments that tend to focus on outcome measures are not incorrect, but they are incomplete, and at times misguided when attempting to address quality of care issues. Outcome measures in the traditional sense only address part of any health care issue. Health care assessments focusing on traditional outcome measures stem from the biomedical model.¹⁶ Functioning within this paradigm there is the belief that “phenomena can be reduced to their constituent parts, measured and then causal relationships deduced.”¹⁶ A contrasting view stresses a “holistic understanding and the importance of context.”¹⁶ Functioning within this paradigm there is the belief that there should be a “move away from reductionist approaches”, and that emphasis should be placed on *understanding* rather than *measurement*.¹⁶

Although this project used similar research perspectives and methods described in the preceding literature review, it was different from previous research in that it focused on a unique population of people in southwestern Oklahoma. This project addressed a gap in understanding how community members in southwestern Oklahoma communities viewed the process of diabetes care and education. By engaging community members involved on both sides of the care and education process (delivering and receiving care and education), it provided an opportunity to increase awareness and enhance

understanding of perspectives relating to diabetes care and education in communities in southwestern Oklahoma.

CHAPTER III

METHODOLOGY:

PROJECT FOUNDATION, DESCRIPTION OF METHODS, AND APPLICATION OF METHODS

PROJECT FOUNDATION

I. Outcome Measures VS Process of Care

Numerous outcome measures have been generated and analyzed by decades of cross-sectional studies, randomized controlled trials, and retrospective analyses that have had their constituent parts quantitatively analyzed in an effort to delineate cause and effect associations.^{16, 17} Many researchers would offer that these types of findings provide powerful analytical evidence by establishing “statistical linkages” between a specified health issue and mortality.¹⁷ The “ideal world” conditions under which evidence based theories are developed are quite different from conditions of the “real world” in which the theories are applied.¹⁸ Statistically speaking, the findings may be significant in the clinical world, but when applied to the real world, the statistical significance may lose *power*.

When investigating diabetes care it would be informative to be able to understand the process from the perception of those involved in the process, rather than from the

perception provided by cross-sectional data, randomized controlled trials, and retrospective analysis of data measuring outcomes of the process. In the latter case, health professionals still have no idea about what was impacting the individual as they went through the diabetes care process, or why it was they did or did not have a diabetes care process through which to proceed. What has been lost is knowledge about the process of care. There are plenty of outcome measures with which scientists can justify processes of care that science says will bring about said outcomes, but health professionals are left without credible understanding of gaps in care and how these gaps are perceived as impacting individuals involved in the care process. By shifting to focus on the process of care rather than outcomes, assessment of the process of care may catch up with the outcomes used to create their associative processes. A potential benefit of shifting focus in the assessment of diabetes care could be development of outcome measures based on perceived needs of participants.

II. Stakeholder Model

Many projects relating to health care and health education have focused on outcome measurements, however an “alternative approach to outcome measurement is to focus on the process of care [and education].”¹⁹ Having shared “understanding of professional ethos and identity [as] a prerequisite for mutual confidence between” organizations is necessary for effective complimentary delivery of health care and health education programs.²⁰ The stakeholder model represented a matrix within which the types of strategic relations between health care and education agencies became enumerated.⁷

As a backdrop, the stakeholder model enabled investigation of “emerging diverse and complex relations” between health care and education agencies.⁷ Community members’ perceptions, or those people served by the aforementioned agencies, and relations that take place among them were included in the process of care and/or education delivery in order to address the multifaceted exchange of “elements that [were] not immediately explicit.”¹⁹ As each individual has a role in directing the impact of the delivery and reception of care, each interviewee was viewed as a stakeholder in the care process. To potentiate the stakeholder model, it was important to “describe and conceptualize the processes involved when” public and private health care and education agencies and community members interact.²¹ “Symbolic interactionistic perspectives” provided a “guiding framework to explore how” public and private health care and education workers defined their role and situation within the community and vice versa.²¹ An “explanatory theory of these processes . . . [was developed] to understand the interaction between” those entities that participated in this project.²¹

III. Symbolic Interactionism

This project was framed using symbolic interactionistic perspectives in an attempt to investigate relations between public and private health care and education agencies and among these agencies and the people they serve. Symbolic interactionism offered a unique look at issues explored for this project in that it informed us as to how participants acted toward their environment “on the basis of how [they saw] it.”²² Focusing on “understanding the participant’s world . . . [in an effort] to understand the dynamic and

processual nature of [their] behavior” was fundamental in identifying hidden gaps in delivery/reception of diabetes health care and/or health education.²³

Addressing issues framed using symbolic interactionistic perspectives was different from the typical scientific research approach which would view the participant as acting “on the basis of how [the environment] would appear to outside observers.”²² In following the later approach, it has been suggested that “the objective observer is likely to fill in the process of interpretation with his own surmises in place of catching the process as it occurs in the experience of the acting unit which uses it.”²² Using symbolic interactionistic perspectives, the “basic research assumption . . . consistent with this view is that if one wants to understand the interaction between” public and private health care and education agencies and among these agencies and the communities they serve, “one needs to see their experiences as they see them.”²¹ In other words, a “researcher must . . . actively interact with the persons being researched and see things from their point of view and in their context.”²¹ In order to “catch the interpretive process” symbolic interactionism requires use of methods that provide a rich, valid, and robust account of said interpretive processes. Methods utilized to foment symbolic interactionistic perspectives and “develop a well grounded theory that describes, explains, interprets and predicts the phenomenon of interest” are features of grounded theory research, which are discussed below.²¹

IV. Grounded Theory

Rooted in symbolic interactionism, grounded theory is a method for capturing and analyzing perspectives of the audience of study. Developed by Glaser and Strauss in the

1960s, grounded theory allows the researcher to engage in “close inspection of qualitative data gathered from concrete settings.”²⁴ Implicit in the previous statement is that grounded theory “not only refers to the theory generated through an inductive method but also refers to a system of analysis.”²⁴ Research stemming from grounded theory aims “to develop substantive or formal theory, and thus [provides] a means of exploring social processes.”²¹ Exploration of social processes experienced by participating parties of this project enabled us to address our research questions and objectives. Construction of grounded theory developed throughout this project was guided by the writings of Charmaz (2006), who views “grounded theory methods as a set of principles and practices” that enables researchers to “gather sufficient data to fit [their] task and to give [them] as full a picture of the topic as possible within the parameters of [their] task.”²⁵ Using the stakeholder model as a guide, and framed within symbolic interactionistic perspectives, the following grounded theory methods were used to complete this project.

DESCRIPTION OF METHODS

V. Theoretical Saturation

When engaged in qualitative research, more important than the number of interviews completed is the process through which participants are recruited, and the way in which subsequent data are analyzed in an effort to “illuminate complicated social phenomena and develop theories about their workings.”¹⁶ Keeping that in mind, the standard for determining the number of interviews required for a particular qualitative study is thematic or theoretical saturation.²⁶⁻²⁹

The processes of sampling and data analysis are more important than a specified number of interviews because it is through maintenance of stringent sampling, and analysis processes that thematic or theoretical saturation is achieved. Firstly, the “researcher’s conceptual framework for the study and existing literature on the topic guide the initial sampling process.”²⁸ As discussed in Chapter 1, feedback from Extension Educators regarding their experiences in the communities where they work was the impetus for the project. Based on data garnered from initial interviews, subsequent interviews are pursued. The process of guiding sample selection based on analysis of preceding interviews is referred to as theoretical sampling, which will be discussed in detail below.^{26, 27, 29}

The way in which theoretical development occurs in order to drive the identification and selection of new participants, and ultimately theoretical saturation is through the process of analysis referred to as the constant comparison method.^{27, 30} The constant comparison method, which will be discussed in further detail below, involves continual analysis of data throughout the research process via coding. By “conceptualizing data by constant comparison of incident with incident, and incident with concept . . . categories emerge upon comparison and properties emerge upon more comparison.”³⁰

At the point during analysis “where addition of another . . . word, phrase, or sentence, or a series of words, phrases, or sentences. . . to those already grouped under a concept did not appear to generate significantly new insights about the concept, then the concept is *theoretically saturated*.”³⁰ At this point, regardless of how many interviews that have been undertaken, enough have been completed to construct a theoretically

saturated concept. By following the process of purposeful sampling, theoretical sampling, and constant comparison of coded materials, “this simple, but rigorous process carries with it verification, correction, and saturation” and supplies a set of formal tools that determine how many interviews are enough.³⁰

VI. Constant Comparative Method

Grounded theory places the researcher “*within* the research process.”²⁵ Using methods that foster a constructivist approach and hold true to tenets of symbolic interactionistic practices is imperative if the researcher is “to take the role of the [participant and avoid filling] in the process of interpretation with his own surmises in place of catching the process as it occurs in the experience of the [participant] which uses it.”²² In doing so, the researcher acknowledges that they are “part of what they study, not separate from it” and from this understanding comes the adoption of the constant comparative method in the development of grounded theory.²⁵ In addition to the researcher understanding their orientation to and within their research, the concept of *interaction* becomes a seminal component of grounded theory in that it emanates from your “worldview, standpoints, and situations, arising in the research sites, developing between you and your data, emerging with your ideas, then returning back to the field . . . and moving on to conversations . . . to create meanings and frame actions.”²⁵ Comparing data from the same source over time, or from different sources covering the same time period, or observations with interviews, etc – *throughout the research process*, allows the researcher potential to “gain more awareness of the concepts” and avoid “prejudg[ing] what is happening” by “seeing the world through the [participants’] eyes and

understanding the logic of their experience.”²⁵ Insights gained from this process enables the researcher to “make analytic sense of the material” rather than merely functioning off of preconceived notions tied to popular beliefs engrained in the particular area of study.²⁵ Successful use of constant comparative methods involves the use of a “systematic, objective, quantitative analysis of message characteristics” known as content analysis, which is discussed below.³¹

VII. Content Analysis

Use of content analysis is essential for constant comparison of data collected throughout the research process. Through a series of coding procedures, content analysis “can expose hidden connections among concepts, reveal relationships among ideas that initially seem unconnected, and inform the decision making process” which helps elicit the type of information mentioned in the previous section regarding the constant comparative method.³² Analysis of data related to this project will use four coding strategies – initial coding, *in vivo* codes, focused coding, and theoretical coding.

Initial coding is an informative first step procedure of data analysis that enables the researcher to observe small pieces of large portions of data. Rather than analyzing something as a whole, such as an interview, initial coding, at the line-by-line level, is a useful tool that prompts researchers “to remain open to the data and see nuances in it . . . [and] identify implicit concerns as well as explicit statements.”²⁵

In vivo codes help to further investigate the implicit meanings behind participants’ words.²⁵ *In vivo* codes refer to special terms used by participants that may “consist of widely used terms that participants assume everyone shares” and, therefore, may

condense implicit meaning in an explicit manner.²⁵ Making notice of these codes allows the researcher to probe the participants' frame of reference and "develop a deeper understanding of what is happening and what it means" and anchors analysis "in your research participants' worlds."²⁵

As initial coding and *in vivo* codes are used to analyze pieces of larger portions of data to establish "strong analytic directions", focused coding enables the researcher to "synthesize and explain larger segments of data."²⁵ Focused coding makes use of "initial line-by-line coding to sift through large amounts of data . . . [and] requires decisions about which initial codes make the most analytic sense."²⁵ By using focused coding to further develop links established through the initial coding process, the researcher is able to "categorize [their] data incisively and completely."²⁵ As part of the constant comparative method, focused coding allows the researcher to revisit previous data, as constant analysis of new data, whether generated through interview or site visit, "will make explicit what was once implicit in earlier statements or events."²⁵ Throughout this process, the researcher is able to compare "data to data [and] develop the focused code[s] [which] are more directed, selective, and conceptual" than initial coding.²⁵

As focused coding utilizes initial coding to construct directed conceptualized categories from the data, theoretical coding specifies "possible relationships between categories . . . developed [during] focused coding."²⁵ While theoretical codes may relate to each other and lend to hypotheses construction so as to be "integrated into a theory", it is important to note that "the codes themselves do not stand as objective criteria about which scholars would agree or that they could uncritically apply . . . to an analysis". In other words, theoretical codes are not used to impose a "forced framework", but as a

means of constructing meaning from your specific data and understanding it within the contexts you are studying.²⁵

As previous statements in this section have implied, content analysis “is not an entirely linear process.”²⁵ Coding procedure “checks your preconceptions about the topic” of interest and, as a constant comparative method, allows the researcher to return to earlier data and sources of data, be they participants or physical sites, “and explore topics that had been glossed over, or that may have been too implicit to discern initially or unstated.”²⁵ Content analysis was used to analyze data collected from various means discussed below.

VIII. Confirmatory Analysis

In an effort to enhance trustworthiness of the analysis process, confirmatory analysis was completed by an expert in qualitative data analysis.^{11, 12} A colleague in the Nutritional Sciences Department who is an expert in qualitative data analysis reviewed transcripts, codes, and themes. Recommended changes to two thematic components were discussed and incorporated.

IX. Purposive Sampling

Initial sampling for this project was purposive, in that this technique allows the researcher to “focus . . . and minimize the sample size . . . so as to select only those cases that might best illuminate” the task at hand.³³ While there was not a general hypothesis from which this project stemmed, it was guided by the need to investigate the relations between public and private health care and education agencies and among these agencies

and the people they serve. Impetus for this study stemmed from communication between Cooperative Extension Service educators and state specialists regarding diabetes care for the audience they serve. Therefore, initial participants for this study were contacts within the Cooperative Extension service. Theoretical and snowball sampling procedures, as described below, were used to identify additional participants.

X. Theoretical Sampling

As a component of grounded theory, theoretical sampling, which is a type of purposive sampling, was used during this project to allow the data to flow in *natural* progression. The concept of theoretical sampling is based on the premise that “new observations are selected to pursue analytically relevant distinctions rather than to establish the frequency of phenomena.”²⁶ As such, “participants are sought serially; that is, depending on who and what has come before, so that ongoing sampling supports the emerging theorising (ideas about ideas).”²⁷ With this process of sampling, participants are not chosen randomly, but purposefully based on theoretical development.²⁷ In other words, theoretical sampling allows a researcher to develop “emerging theoretical categories” derived from data analysis of initial sampling by “seeking and collecting data to elaborate and refine” said emerging categories for theory construction.²⁵ Initial sampling was determined by the scope of the task at hand – investigating the relations between public and private health care and education agencies and among these agencies and the people they serve.

XI. Snowball Sampling

Snowball sampling, another type of purposive sampling, allowed for expansion of ideas and created a trail of data from source to source in order to illuminate relationships among individuals and entities interviewed, observed, and analyzed. Involving the use of project participants to identify new participants, snowball sampling used “insider knowledge to maximize the chance that the units included in the final sample [were] strong cases to include in the study.”³³

XII. Group Interviews

Group interviews were completed when teams worked together to disseminate health related information and services to communities. Whether they worked individually one on one with community members or in groups, these educators and health care providers made use of the same information and techniques provided by their supervisory entities and have come to orient themselves in a group setting through trainings and conferences. The concept of group interviews stems from feminist social sciences research.³⁴ Understanding that meaning emerges through interaction, group interviews foster an environment of interaction where people, including the researcher, may “listen to each other’s experiences and . . . interact with each other.”³⁴ This format supports principles of symbolic interactionist perspectives in that it recognizes the need to include the researcher in the exchange. In following, the researcher is not just trying to “catch the interpretive process by remaining aloof as a so-called ‘objective’ observer”, but rather “catching the process as it occurs” by participating in the formative nature of exchange.²²

XIII. Individual Interviews

Rather than using a survey, an open-ended interview using guide questions was used to capture the interviewees' frame of thinking as it pertained to diabetes care. Because "an interview is contextual and negotiated", interviews followed the lead of the interviewee and were not tied to a script.²⁵ Individual interviews were completed in order to gain the perception of the interviewee regarding areas of diabetes care, which is in line with the aforementioned principles of symbolic interactionism.

XIV. Participant Observation

As mentioned in a previous section, catching the interpretive process as it occurs by taking the role of the participant is an important step in the collection of data that accurately reflects the perceptions of the audience under observation.²² Apart from data collected from group and individual interviews, "remaining open to the setting and the actions of the people in it" allows the researcher to be open to multiple aspects of daily life that may illuminate participants' "taken-for-granted assumptions and rules" regarding "the studied milieu" and its impact on the phenomenon or process of interest.²⁵ Engaging in interaction with participants in various settings within a community allows the researcher to "record the life of a particular group" in an effort to "gain an insider's depiction of the studied world."²⁵ Supplemented with the utilization of field notes, memos, situational maps, and photographs (all of which will be discussed below), participant observation offers an opportunity for the researcher to further contextualize the focus of the study.²⁵

XV. Field Notes / Memos & Situational Mapping

In order for the other methods mentioned above to be effective, supplemental tools must be used to ensure that all data remains relevant and tied to the moment of discovery, as well as the data as a whole. Field notes enable the researcher to maintain “complete, accurate, and detailed” descriptions of interactions and observations engaged in during the research process, in an effort to compile an authentic narrative of accounts.³⁵ Memos function “to catch [researchers’] thoughts, capture the comparisons and connections [researchers] make, and crystallize questions and directions for [the researcher] to pursue.”²⁵ Memos may provide crucial links between pieces of data that are uncovered during the constant comparative method.²⁵ Situational maps contribute to the formation of grounded theory in that they “lay out major human, nonhuman, discursive, and other elements in the research situation of concern and provoke analyses of relations among them.”³⁶ Situational maps provide a means of addressing coded data and become an avenue for “‘opening up’ the data” and “interrogating them in fresh ways” while documenting the unfolding of grounded theory.³⁶

APPLICATION OF METHODS

As this project progressed, the aforementioned research perspectives, methods, and analysis techniques created a robust research project addressing multiple perspectives regarding the process of diabetes care. Operating within the stakeholder model provided an understanding that each person or agency was viewed as a stakeholder in the process of care. Each interviewee, be they a person receiving care or education, or a person providing care or education, was seen as having a stake in the delivery process of

diabetes care or education. The interviewees' unique perspectives and their ownership of the care process were explored using principles of symbolic interactionism.

Because this project focused on how community members viewed the process of diabetes care, it was integral to the data collection process that participants were engaged in such a way as to capture understanding of the issues under study. Group and individual interviews were an effective means to explore participant perceptions. The open-ended interviews allowed the interviewees to elaborate on issues they found important.

Interviews were conducted individually and in groups. The type of interview, individual or group, was dependent on the choice of the interviewees. Participant observation offered an opportunity to become immersed in the environment of the interviewees and enhanced contextual understanding of the interviewee's world. Field notes and memos were important components in keeping data relevant, continuous, and contextually sound.

Situational maps were also important to the process of keeping data continuous, and contextually relevant. The maps offered a way to construct data in a visual manner which allowed for further understanding of factors impacting the process of diabetes care and education. Framing the project using symbolic interactionistic perspectives offered a unique look at issues surrounding the process of diabetes care from the perspective of those individuals directly impacted by the care process. Rather than entering the project guided by a hypothesis related to the diabetes care process, this project explored community perceptions regarding the processes through which diabetes related health care and education were delivered.

Because the project was aimed at exploring community perspectives regarding the delivery process of diabetes care and education, and was focused on development of emergent theory regarding the delivery process, grounded theory proved to be an effective method. Grounded theory facilitated the exploration of social processes experienced by participating parties of this project.

In order to ensure validity and reliability and overall trustworthiness of the data collection and analysis process, several methods were employed. Theoretical saturation was used to enhance trustworthiness of the data collection and analysis processes in that it provided a procedural framework for sampling and data analysis. Theoretical saturation ensured that sampling and data analysis were thorough and guided by theory. Each interview was analyzed as it was collected and data were compared to subsequent data gathered from additional interviews. This constant comparative method kept the flow of data current and continuous so that data gave way to theoretical development and guided the sampling process.

Initial sampling procedures were guided by the impetus for the project, which was feedback from County Educators and NEAs regarding their experiences in the communities where they work. NEAs and a County Educator were initially interviewed. This purposive sampling method provided initial data which were analyzed to reveal additional participants to interview. Purposive sampling gave way to theoretical sampling, which was guided by analyzed content of the interviews. Additionally, snowball sampling was an effective means of identifying new interviewees based on who current interviewees saw as being important contributors to the care process.

Content analysis was used to analyze and code data. Initial coding worked as a means to become acquainted with data and involved line by line coding. *In vivo* coding focused on taking into account implicit meaning of certain words or phrases common to the interviewees. This type of coding enhanced the contextual nature of the data and contributed to a deeper understanding of the interviewee's world. Focused coding allowed for analysis of larger chunks of data. It made use of initial and *in vivo* codes to generate conceptualized categories. Theoretical coding was used as a way to find relationships between the categories created by focused coding and directed the construction of the themes presented later. Confirmatory analysis was used as a means of enhancing trustworthiness of data, and themes generated from the coding process. A colleague in the Nutritional Sciences Department, who is an expert in qualitative data analysis reviewed transcripts, codes, and themes. Recommended changes to two thematic components were discussed and incorporated.

CHAPTER IV

RESULTS AND DISCUSSION

Results stem from a total of 24 interviews involving 32 people. Nine interviews involved 14 people who were receiving some type of care or education relating to diabetes. The ages of interviewees receiving care or education ranged from 37 to 89 years of age, with only two people younger than 60. Interviews of participants were completed at three congregate meal sites in southwestern Oklahoma.

Fifteen interviews involved 18 people who were providing some type of care or education relating to diabetes. Eight participants were OCES employees. Two of the OCES employees were Registered Dietitians. Four of the OCES employees were paraprofessional NEAs. Compiling the other 10 participants were two general practitioners, two Registered Dietitians, two Certified Dietary Managers, one nurse, one Certified Diabetes Educator/nurse, and two directors of diabetes organizations. The directors of the diabetes organizations were both Certified Diabetes Educators, with one also being a Registered Dietitian. They both identified themselves as being directors of their respective organizations, and not specifically as Certified Diabetes Educators or a Registered Dietitian.

Results are presented as themes that have been pulled from a combination of analyses of interviews, observations [including field notes and memos], and situational mapping. Themes are discussed with an attempt to address the Research Question: **How does the community perceive the process through which diabetes related health care and health education are delivered?** The themes are divided into two sections – People Receiving Care & People Providing Care. After each section, results are discussed. Following the results and discussions of both sections, three situational maps developed during the data collection and analysis processes are presented and discussed.

People Receiving Care

RESULTS

People with diabetes viewed the delivery of care as a component of their everyday life. For some people certain components fit better than others and are viewed as an extension or necessity of everyday life. By others, these same components may be viewed as unattainable or contrary to everyday life. The following five themes provide the patients' or participants' views regarding the delivery of diabetes care and education.

Diet Dilemma

Participants conveyed a sense of ambivalence toward diet related diabetes care they received from their general practitioners. They were provided with information about diet. The diet dilemma theme refers to the participants' struggles to apply diet related information to their daily life. The interviewees expressed varying degrees of uncertainty and indecisiveness as to how to go about putting the dietary advice into

action. Dietary information ranged from specific foods to eat and/or avoid, diets based on calorie amounts, diets based on the number of meals to eat throughout the day, and diets based on eating in moderation.

One participant mentioned a visit to her doctor. She stated that she was confused about what to eat and what to avoid and the doctor told her “a big glass of water with small portions”. When she was about to leave the office at the end of the visit, the doctor said “oh by the way, about eating, you can eat anything you want just small portions at a time”. She was instructed to do this 3 or 4 times a day.

Another participant stated that she was instructed to “be on an 1800 calorie six meals a day diet”. She described it as “3 meals, you do breakfast, snack about 10:30, your lunch then another snack about 2:30 or 3:00 and then your supper, and then the last snack before you go to bed”. She said she was comfortable with the schedule and that she does not eat as much as she used to “because you’re not hungry and it maintains my weight real well”. This participant was interviewed with three of her friends who also had diabetes. They all went to the same doctor for their diabetes care. They were told to eat “lots of fruits and vegetables cut out sweets because your fruits have a lot of sugar in them . . . [and] watch your starches”. When asked if it was easy to find the foods they were to eat in order to follow the diet, one interviewee stated (as the others nodded in agreement), “not here, no, not here”. A second interviewee in the group stated that “one small store is all we have and then we have a dollar store that has a little bit of food”. A third interviewee in the group pointed out that that neither store had “diet stuff”. She said that the stores “don’t have diet stuff. They don’t cater to diabetics at all”.

A participant who was recently diagnosed with diabetes was instructed by her doctor to stay “away from all flours, all sugars, apples, anything good, and no sweet-n-lows, no sugar substitutes for right now” until she got her diabetes under control. She was prescribed a pill to help control her blood sugar. When asked whether the doctor went over portion sizes with her or recommended she visit with a dietitian, she said “not right now”, that the doctor wants to see “how things turn out with the list he gave me of the things I couldn’t eat”. When asked how she felt about following the diet, she stated that “it’s kind of hard because I’m used to drinking quite a few pops a day and coffee with sugar in it, with no breads that makes it kind of hard”. She is to return to the doctor in a month to monitor progress.

Don’t Know What We Don’t Know

When asked what other resources for diabetes care or education existed in their community other than their general practitioner, one participant summed up the general perception when he said “we don’t know what we don’t know”. This theme refers to the participants’ lack of awareness regarding resources unrelated to those provided by their general practitioners. Participants put a lot of faith in their general practitioners, which may be one reason why they were not aware of any other services. Even when other services were known, participants felt they were receiving the care they needed from their general practitioners. One participant pointed out, “I am sure that my doctor would get me on a program if he felt like I really needed one”.

Unless doctors make an explicit effort to engage their patients in additional services pertaining to diabetes care and education, the process of care begins and ends

with the general practitioner. As one participant stated, “we don’t know what there is out there to really help us”. Of the fourteen participants interviewed who had received some kind of diabetes care, two had met with both a certified diabetes educator and a registered dietitian. One of these participants is a prominent figure in the community in that he is fairly well-off and owns quite a bit of land. He knows his physician personally and it was he who referred him to the certified diabetes educator and registered dietitian. This participant was aware of and had access to numerous resources addressing diabetes care. The other participant was a younger male, the child of one of the women interviewed as a group at a meal site. He lives in a different city and sees a different doctor than his mother. One other participant had met with a registered dietitian.

Expendable Time

The theme of expendable time appeared as a barrier, regardless of availability of resources and health insurance. Expendable time refers to having the time to pause and take account of one’s health issues on a periodic basis and consequently avoid complications associated with the progressive nature of a medically untreated illness, such as diabetes. This pause refers to going beyond the standard awareness of having diabetes, to acceptance of having diabetes and addressing modifiable risk factors on a daily basis.

Without adequate expendable time, someone who does not have time to pause cannot address or medically treat their diabetes beyond knowing they have it. Diabetes is treated in this sense only when associated complications interfere with daily obligations. As one participant with health insurance stated regarding taking the time to attend a

diabetes education class, “my time is just done, I don’t make time for things like that, but it would be nice”. The day is full and there is not enough expendable time to make use of available resources, as this participant reiterates, “I would like to, but like I said I have to make time . . . when I get out of here [work] I just go straight [home], and it’s like 25 miles”. Another insured participant, when asked what was preventing her from going to a diabetes center stated “Oh the time. Time, that’s all it is to it, time. It’s just the time, that I have to make time, but I never do”. In this sense the process of care is completely separate from the realm in which people find themselves. The process of care is viewed as something that exists parallel to their process of life.

Reluctance

Reluctance is a theme that presented as having an impact on how people perceived the process of diabetes care. This theme describes participants who, despite self-awareness of having diabetes, remained hesitant to address it due to personal connections with the disease. This theme differs from denial because these participants knew that they had diabetes. They knew they had diabetes based on shared experiences with family members. For all participants, the experience of diabetes was not a new one. Participants shared familial introduction to the experience of diabetes through diagnoses of parents, siblings, spouses, aunts, and uncles. Because of familiarity with the consequences and experiences of diabetes, participants were not ready for an official diagnosis, or were reluctant to address their diabetes even after being diagnosed because they were not ready to face whatever it was that they were going to have to do in order to address their condition.

Participants' reluctance to accept diabetes existed despite their self-awareness of symptoms associated with having diabetes. Reasons for reluctance regarding diabetes varied. Despite having a strong family history of diabetes, one participant stated [in reference to recently being diagnosed as having diabetes] "I am sure that I have had it for awhile, but I procrastinated and wouldn't go. What I don't know I always said would not hurt me". She continued to say "I didn't want to have to deal with having to do – my first thought was I was going to have to do insulin. I thought I was going to have to do the shots". Her past encounters with family members having diabetes influenced how she perceived the delivery process of diabetes care and contributed to her reluctance toward addressing diabetes.

This participant's experiences with diabetes went beyond family members. She worked in the dietary section of a hospital for 10 years where she learned to cook for people with diabetes and understood the concepts of food exchanges and portion sizes. Four other participants had similar backgrounds. They currently worked or had worked at a facility that addressed the needs of people with diabetes and claimed to be familiar with dietary education pertaining to diabetes care.

This particular participant has had conversations with her doctor and they both agreed that she knows what she needs to do to address her diabetes, but "It's just the doing it, that's all it's just the doing it" [she stated as she laughed]. Upon further discussion it became clear that there were other factors contributing to her reluctance in seeking an official diagnosis of her diabetes. Her work schedule creates an environment that makes it difficult to address needed lifestyle changes. In putting off an official diagnosis, perhaps she was avoiding additional pressure that she was not ready to handle.

Even with a diagnosis, repeated complications, and a strong family history of diabetes with complications one participant continues to be reluctant to fully address the fact that she has diabetes. She stated that “I just don’t want to accept that I have diabetes, which my body shows all the time”. She has insurance and access to a doctor and diabetes education classes. She has insulin, meters, and strips and refuses to use them on a regular basis. Reacting to a recent hospitalization of her mother due to complications from diabetes, she stated, “I see how sick my mom has been. She has been really sick having to do with diabetes and was in the hospital for like six months and you know it still doesn’t really ring a bell. I guess I just don’t want to accept that I have diabetes that bad”.

Support/Exchange Experience

This theme highlighted what appeared to be a separation between medical care for diabetes and maintenance of prescribed behaviors. The theme refers to participants’ needs and resulting struggles as they attempt to apply practitioner conveyed advice in the community environment. When discussing the process of diabetes care, participants continually referred to their general practitioners as their sole source of care. When asked what other services would be beneficial for diabetes care, the common response was “I don’t know” or something similar to what was mentioned in a previous theme (*Don’t Know What We Don’t Know*). A common follow-up statement to “I don’t know” was something similar to “a support group would be nice”. Participants were looking for a venue to “exchange ideas” and for “hints on how to keep [their] blood sugar down and stuff like that”.

Participants were also finding support on the internet. They were looking for more personalized advice than what they received from their general practitioner. One participant stated that she “got on the computer and found out more stuff that [she] could eat or not eat and kind of went that way to get a plan for what [she] could eat or not”. At one group interview a participant stated “I go on the internet a lot myself, and then if I find something I think is good then I share it”. People were looking for ways to address their diabetes within their own environment.

DISCUSSION

This project explored community perceptions of the delivery process associated with diabetes care and education. This portion of the project, pertaining to recipients of care and education and their perception of the delivery process revealed results consistent with previous studies investigating similar scenarios. The themes of *Diet Dilemma*, *Don't Know What We Don't Know*, *Expendable Time*, *Reluctance*, and *Support/Exchange Experience* pointed to a breakdown in the process of care that impacted participants' perceptions of the care process and their abilities to apply care and education practices. Once out of the doctor's office, the onus of applying the doctor's advice was solely on the shoulders of participants. When discussions veered into territory related to putting the doctors' orders into action, it became evident application was hindered.

The process of care is viewed as something that exists parallel to many people's processes of life. Participants' lives seemed more in tune with an integrative approach to delivering care. Recognizing “patients as individuals, who require individualized care”, and as important members of the team involved in the process of delivering care, is

associated with a more integrative model.³⁷ This concept of care places more “emphasis on the treatment of the whole person in his/her social, environmental and cultural context.”³⁷ The manner in which this study was conducted facilitated exploration of issues impacting the *whole person* in terms of the delivery and application of care.

The interview process allowed for exploration of issues impacting application of prescribed guidelines. What the interviews revealed was dissatisfaction with applying information received from general practitioners. In line with the findings by Vijan et al., quality of life plays a role in how one perceives the process of care.¹² Especially when dealing with older patients, recommending drastic dietary changes could lead to complete refusal to engage in the care process.¹²

Along the lines of the study by Lippa et al., use of interviews to investigate the process of care uncovered areas leading to deficits in care.¹¹ Findings by Lippa et al. highlighted the importance of experiential learning for patients.¹¹ Participants of this project would also have benefited from such learning.¹¹ They were provided with diets and suggestions for healthful eating, but they were not instructed on how to apply that knowledge, such as how to go about incorporating healthier food options into their diets. For example, there was no communication about how the types of foods they were currently eating differed from the foods they were told to eat and how to prepare those foods in a way that would still be appetizing while fulfilling their dietary needs.

Just as Nagelkerk et al. demonstrated in their study, the interview process used for this study was essential in both uncovering barriers impacting the care process and detecting strategies employed by people to eliminate barriers.¹⁵ The usefulness of the internet as a source of supplemental information and the exchange of ideas between

community members at a congregate meal site were coping mechanisms that came to light during the interview process. Findings from this project echo the findings of Nagelkerk et al., in that social support is a viable strategy for coping with dietary issues, particularly in a rural setting.¹⁵

This project was investigating perspectives regarding the delivery process of diabetes care and education. Findings from this project support the work by Wens et al. that proposes a process of care based on a “joint patient-provider perspective.”¹³ How a person orients themselves to the process of care is an important factor to consider. This study indicated that when people are placed in situations of extreme pressure, the process of care may seem like a burden that is not worth exploring. In some situations, it is not a lack of motivation, but a lack of time that inhibits access to the process of care. When investigating community perspectives regarding diabetes care and education delivery processes, it is important to keep in mind perspectives from both sides. Focus will now shift to the results and discussion of perspectives pertaining to people involved in the delivery of diabetes care and education.

People Providing Care

RESULTS

The form of care and education addressing diabetes follows its function. In other words, how professionals and paraprofessionals perceive the process of delivering their care and/or education is determined by their role in the process. This perception of the delivery process gave shape to four associative themes.

Indirect Services

The theme of indirect services refers to health or education services that do not directly address a medical issue. For this study indirect services are services that assist the participant with making positive changes toward healthful behaviors without specifically addressing diabetes.

Oklahoma Cooperative Extension Service (OCES) employees deliver services to program participants. According to one OCES employee, The Community Nutrition Education Programs (CNEP) covers “basic nutrition which would be the MyPyramid”. Nutrition Education Assistants (NEAs) stated that areas of focus include portion control, reading labels, understanding ingredients, recipes, and food preparation. One of the perceived restrictions of this federally funded program is that it does not allow for medical therapy diet information to be delivered to participants.

As such, the delivery of nutrition education to program participants with diabetes is an indirect service in that the information helps these participants put into action what has been provided to them by their general practitioners. For example, a program participant who has been diagnosed with diabetes and instructed by their doctor to follow a 1800 calorie diet, or to modify their diet by reducing carbohydrate and fat intake, can visit with a Nutrition Education Assistant through the CNEP program and learn the basics of nutrition education. It is not uncommon for participants to visit with NEAs after seeing a doctor. One NEA said that participants go to the doctor and ask for diet advice and are told “oh, just follow a diet”. She stated that the doctors “don’t tell you what kind of diet and they don’t tell you where you can go”. In this way, the OCES employee is not directly providing a meal plan to treat diabetes, but assisting participants in figuring out

healthier food options by understanding the nutritive content of foods and the importance of portion control.

In general, according to one OCES employee, educators “can help people identify some foods and how to prepare those in a more healthy way than what they may have eaten in the past . . . [which is] probably the role that most would generalize what Cooperative Extension is doing”. Other forms of indirect services delivered by Cooperative Extension include fact sheets, internet based information transfer, and referrals to agencies that may provide more direct services to help with diabetes care.

Direct Services

The theme of direct services refers to the delivery of care or education that directly addresses a patient’s medical issues. For this study direct services are services that assist the patient with making positive changes toward healthful behaviors by specifically addressing issues contributing to onset or complications of diabetes.

Delivery of direct care by the general practitioner involves screening for diabetes, if not already diagnosed and initial counseling, treatment, and management of the diabetes. According to one general practitioner commenting on addressing dietary issues, he stated that “we do it ourself, we discuss 1800 calorie diet. We give them some papers about it, but there is nothing else”. Another general practitioner stated that what she normally does “is just kind of do a rough outline of what types of foods to eat and to not eat. We certainly have handouts for calorie counts – I haven’t found those to be terribly successful, but certainly we talk about the foods to avoid, the fried foods, the fatty foods, limit foods that are higher in carbohydrates, certainly to cut out the sweets and the things

with refined sugar in them – talk about eating more lean meats, more fruits, and vegetables”.

Patients are monitored every three months with blood work that looks at, among other things hemoglobin A1c. When asked what the common treatment is when positive changes in blood work are not occurring, one practitioner stated that “we’ll go up on the meds”. It was noted that upping medications was often easier than making changes to dietary habits. Given the barriers to changing dietary habits, such as cost, availability, and preference, medications are a well received alternative. It was pointed out that insurance will cover purchase of medications, but not purchase of healthier foods.

The delivery of care at a diabetes clinic addressed similar aspects of care, but with greater detail. This clinic is located in a different county than the general practitioners mentioned above. The clinic supplies education to patients who are referred by their doctors. The regular procedure is an eight hour day split into two four hour periods. According to the certified diabetes educator at the clinic, the first four hour period addresses the ins and outs of diabetes – providing information, how to handle medications, warning signs and symptoms, and explaining how it is going to affect the patient. The second four hour period addresses dietary issues. According to the registered dietitian at the clinic, the patient is taught “how to figure out what they can and can’t eat because there really is no uneatable food and there’s no perfect food and so we try to show them how to find what they need from nutrition labels and how to understand what they need from teaching them about carb counting and how many carbs they should have a day so they can figure out how to balance and how much of certain foods they can have”. The clinic keeps tabs on its patients for up to one year by conducting surveys.

The registered dietitian stated that “some people have a hard time with it and don’t want to follow it or don’t follow it and we see plenty of people come back here and they haven’t really listened or heard what we’ve said or they know what to do and they just sometimes choose not to”.

A nurse working at a department of public health has fewer resources for delivering care. She stated that “right now we can do screens basically if they want to come in and do a finger stick we are able to do that. If there is a concern we do have the drinks that they can drink and then do that. We are no longer doing even screens here because of funding, so we won’t be able to do anything after March”. That is the extent of diabetes care at the health department. In this particular county she stated that there are not any diabetes clinics, or free clinics.

Disrupted Care

The theme of disrupted care refers to the acknowledgment among care and education providers that a gap exists between the delivery of care to recipients and the recipients’ application of care. Interviewees providing care and/or education reported that additional forms of support were needed in the process of diabetes care. The type of support varied, but the overall reason behind providing extra support was the same. From education to medicine, there exists a gap in taking what is provided and then applying it to individual needs.

As one OCES employee noted, “it’s worth understanding that it takes a lot of resources to manage the disease . . . I truly feel sorry for those people that don’t have the motivation, don’t have the family support, don’t have the resources, including insurance

or money for the out-of-pocket, or even just the intelligence to pull it off”. Taking into account the people with whom you are engaged in the care process is important for success. She stated that, “we need to understand that diabetes education isn’t one size fits all for people. There are a lot of ways to get that message across. You need to keep in mind that people have different levels of their ability to learn and to package it that way because changes can make a difference”. Care providers acknowledged that patients had some difficulty adhering to prescribed care. Because of this, counseling beyond what the general practitioner provides was mentioned as an area of concern.

As noted from above, providing direction for newly diagnosed patients was an area of concern. A dietary manager at an adult living center stated that “you’d be surprised how many people come in here, family members, and they say my dad or my daughter, or my so and so has just been diagnosed with diabetes and I don’t know what to do”. General practitioners echoed this concern with comments, such as “it’s not like every new diabetic I can say well I can set up for some kind of magic diabetes class because I don’t know where those are around here other than hit and miss”. There was a concern that smaller communities were not able to support the types of services required for additional care due to “the small number utilizing the service” when compared to larger cities.

Smaller communities lacked the facilities to provide follow-up care. As a nurse at a public health department pointed out, “some people don’t go to the doctors because they can’t afford it”. The likelihood of a free clinic taking hold in these small communities is small due to the lack of resources. The nurse elaborated that “you are going to have docs, and more than likely you are going to have to have pharmacy reps

that are willing to give enough samples to supply some samples to give them”. In communities where services are decreasing, such as access to maternity clinics and free diabetes screening, community members are forced to travel farther away from home for services.

Fragmented Alliances

The theme of fragmented alliances refers to the sense of discontinuity between parties involved in delivering direct and indirect services associated with diabetes care and education. The fragmentation of services impacted the process of delivering diabetes care. Similar to sentiments expressed by people receiving diabetes care, people providing diabetes care expressed a certain degree of unawareness regarding diabetes related services in their communities. For example, certified diabetes educators, general practitioners, nurses, and other care providers had varying degrees of awareness of Cooperative Extension services in their communities, which ranged from “I have heard of Cooperative Extension” to “I just happen to see it in the paper”. Oklahoma Cooperative Extension Service employees at various levels acknowledged the role of fragmentation of services as impacting the health of its citizenry, as one OCES employee stated, “it’s a little bit more fragmented than what we would like to have in our state . . . especially since we are above the national average in diabetes”.

While a couple providers have taken part in Cooperative Extension services, many others are unfamiliar with the services that Cooperative Extension can provide. As one general practitioner stated, “occasionally the OSU extension office offers us a few classes and stuff and I try to keep up with that”. However, when asked if anyone had

contacted them about setting up some kind of referral network, practitioners, nurses, and certified diabetes educators said they had not.

There was not a sense of cohesion between the different entities interviewed. The care they provided seemed to end at the door, in that there was not a clear hand-off to the next step in care. Follow-up was viewed in some cases as a way to evaluate the delivery of the service offered and not as a measure of patients' abilities to address their situation. As one registered dietitian working at a diabetes clinic stated, "everybody always says the educators are either very good or excellent. When we track blood sugar, when we ask them about their A1c, things like that it varies. Some people have lost weight, some people have gained. Some people stay the same. Some people's A1c are still high, some people's blood sugars are still high. Some people say they are following the meal plan, some people say they're not. Some people say they're checking their feet, some people say they're not, but in general they still have good things to say about the program whether or not they are actively trying to control their blood sugars". So while services rendered were given high marks, even people who offered those services were unaware of the patients' capacity to follow through with long-term success at the time of delivering the service.

DISCUSSION

Successful delivery of diabetes care and education is a complex task. Effective communication is the cornerstone in constructing a viable process of care and education. The themes of *Indirect Services*, *Direct Services*, *Disrupted Care*, and *Fragmented Alliances* demonstrated the importance of communication to the care process. Extension

Educators are able to fill a need in the care process by communicating with participants when general practitioners cannot. Wens et al. pointed out that effective communication facilitates a partnership between patient and physician, or in this case between participant and educator.¹³ The setting in which Extension Educators meet with participants may help in establishing rapport, which is conducive to gaining trust. An Extension Educator has the opportunity to meet in the home of the participant or in small group settings.

Compliance with recommended and prescribed care is a major part of ensuring successful treatment of diabetes. A person may have every intention of complying with a process of care, but the environment in which they work and live interferes with their ability to comply. Doctors, nurses and other care providers stated that they were aware of factors inhibiting the care process. In many cases it appeared as if the standard of care remained status quo regardless of the setting. This type of care is in contrast to what Wens et al. described as the “joint patient-provider perspective.”¹³ It provides further insight as to why “strictly promoting evidence-based diabetes objectives” to patients is not indicative of “good” diabetes care.¹³ Situations such as this have a tendency to benefit only those patients that are more affluent and “better able to negotiate their way around the system by seeking out advice.”³⁷

The setting and manner in which treatments are introduced may impact the delivery of care. Schoenberg et al. stated that the authority of doctors may highlight certain components of care over others.¹ One example witnessed in this project was the doctors’ tones toward prescribing medication over getting too involved with manipulation of diet. It boils down to semantics – the meaning behind words. In this case, the difference between prescribing medication, and recommending dietary changes.¹ While

not attempting to reduce the beneficial role of medications in treatment of diabetes, it is worthy to note the sense of power and authority behind a written prescription for medication. The doctor's perceived confidence in prescribing medication versus recommending diet information may influence a patient's perception of their relative importance in treating diabetes. A doctor's willingness to prescribe medication, while offering generic dietary advice that requires a complete change of eating habits sets up potential for creating disconnect in the care process. Addressing disconnect like this is not an easy task. Once medications are introduced, the likelihood of complying with even a moderately altered diet is reduced. The study by Vijan et al. demonstrated that diabetes patients were much more likely to comply with pill prescriptions than diet recommendations.¹²

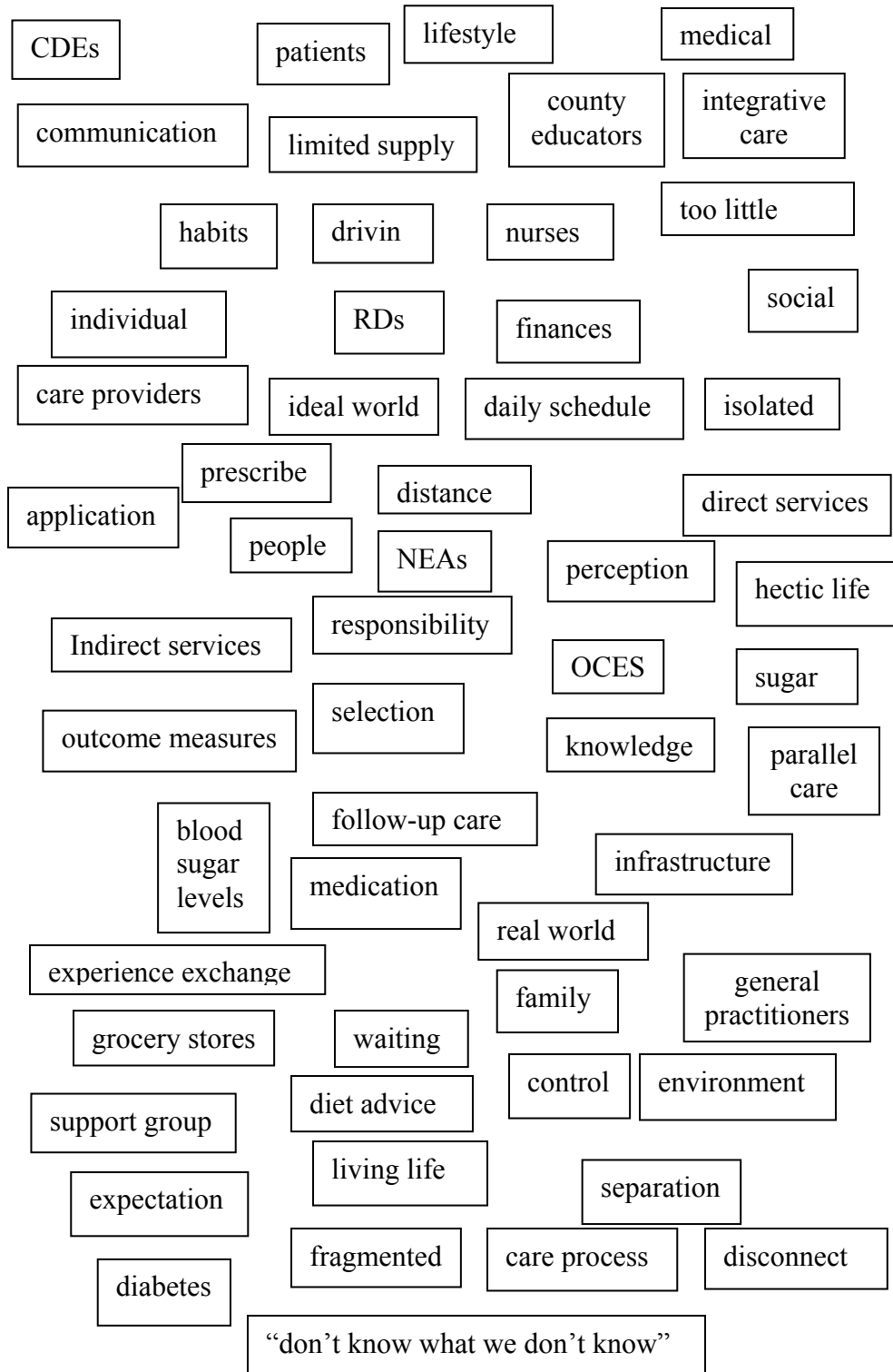
Communication does not only establish a clear line of understanding between provider and patient or provider and participant it also facilitates awareness between service entities. As demonstrated by the findings of Tod et al., "failed communication systems . . . [contributed to the] lack of clarity of how, when, and who refers" patients.³⁷ In the case of this project, based on the perceptions of people providing the care, there is a definite lack of communication between service agencies. Poor communication has lead to ignorance regarding potential services a community may have to offer its citizens.

Having an awareness of difficulties faced by patients and providers is a start; however it is not enough. Providers of care and education pertaining to diabetes must be aware of all options associated with the delivery process, be they direct or indirect in nature. Opening channels of communication and establishing a network of care that embraces the process of delivery of services has the potential to shift the focus of

attention from adhering to standards driven care to patient oriented care. Focusing only on clinical outcome measures over patient-driven outcome measures may lead to ignoring alternative avenues of care.¹⁴ Being aware of factors impacting a person's ability to address their diabetes, coupled with comprehensive knowledge of what services are available to aid in alleviating barriers to care creates a delivery process based on a person's situation. Opening up communication between providers of care has the potential to facilitate this type of patient-driven care because providers will have greater access to different types of care options. The following situational maps [**Figure 1**, **Figure 2 & Figure 3**] offer visual representations of the care process and in so doing address the communication component mentioned in discussions above.

Figure 1 is the abstract situational map built throughout the data collection process. This map aided in looking at the context in which action – the care process – was taking place.³⁶ The abstract map was a continuous project stemming from information gathered during participant interviews and observations. The map is comprised of elements associated with the care process as “framed by those in it and by the analyst.”³⁹ It is called a *working version* because it was used in conjunction with other data to develop themes. The phrase “don't know what we don't know” appears in the map as just that, a phrase spoken by an interviewee. This phrase developed into a theme based on data analysis associated with the constant comparative method. This working version of an abstract situation map was helpful in that it functioned as a visual representation of elements impacting the care process, as well as providing additional stimulus for the development of themes pulled from interviewees' perspectives.

Figure 1: Abstract Situational Map – Working Version.



The abstract situational map contributed to the construction of two relational situational maps. Guided by the abstract situational map and themes stemming from this project, the following relational situational maps [**Figure 2 & Figure 3**] provide a visual representation of the care process as expressed by two different models of the care process. The relational situational maps depict two separate processes of care that unfolded during analysis of data and illustrate how the flow of communication can impact application of care.

Figure 2 is a relational situational map depicting the biomedical model as the process of diabetes care currently utilized. This process of care is based on outcome measures developed using biomedical world situations, such as clinical trials and cross-sectional studies. Some sources, such as Certified Diabetes Educators (CDEs), Registered Dietitians (RDs), nurses, and general practitioners only provide direct services. Other sources, such as the OCES, and their county educators are capable of providing both direct and indirect services pertaining to diabetes care, thus the two color designation in the map.

As the arrows traveling directly from the various agencies to patients/participants indicate, agencies delivering care function on their own with little or no awareness of alternative agencies that could contribute to the care process. Information generally flows in one direction. The person receiving care is viewed as a receptacle of information and medication. To achieve desired biomedical outcomes, one only need follow the advice of the caregiver. What is missing from this model is any recognition of outside influences impacting an individual's ability to apply the advice of the caregiver. Themes, such as *Diet Dilemma*, *We Don't Know What We Don't Know*, *Expendable*

Time, Reluctance, Disrupted Care, and Fragmented Alliances are associated with this parallel process of care and function as barriers to application of care and achievement of outcomes as illustrated in the map. The lack of communication among caregivers and between caregivers and patients/participants results in gaps in the process of care.

Figure 2: Relational Situational Map – Biomedical Model of the Process of Care.

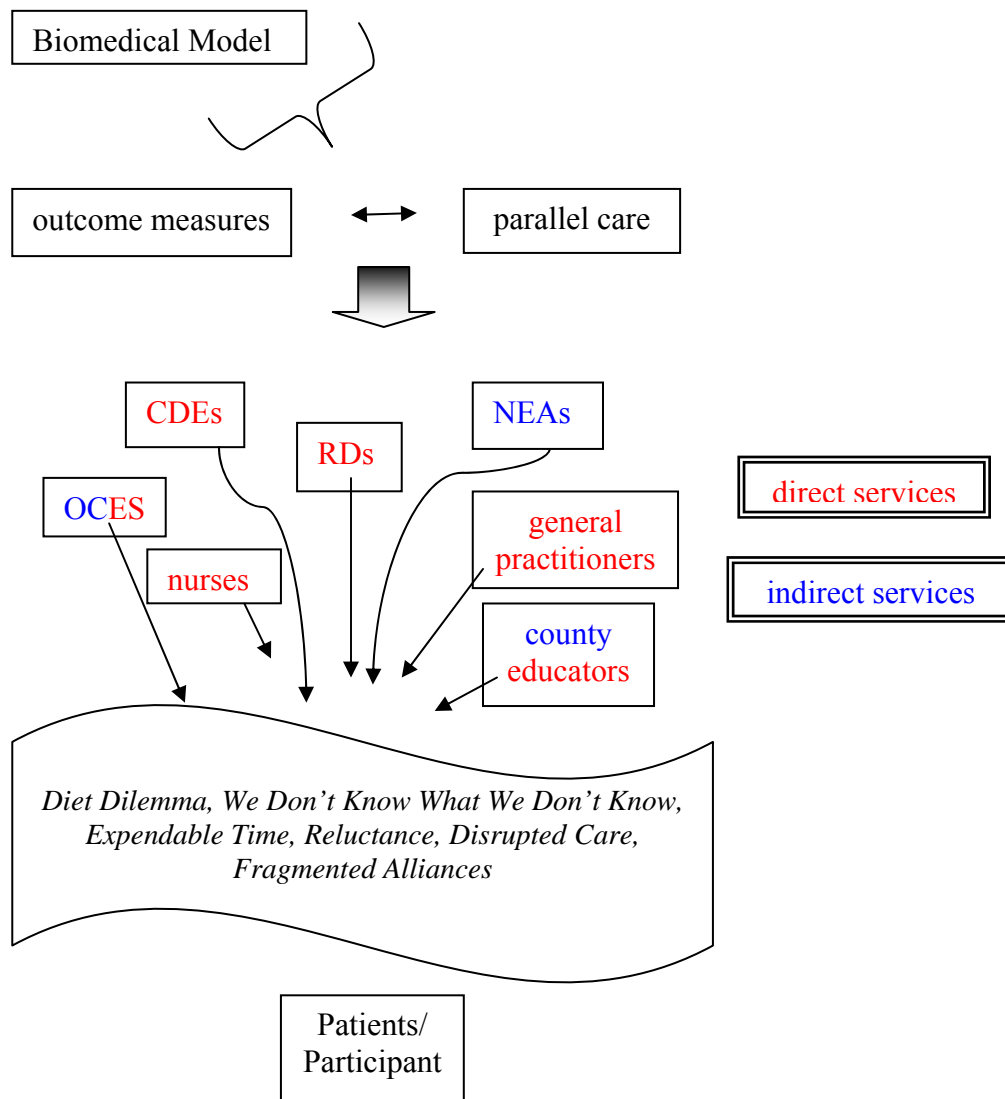
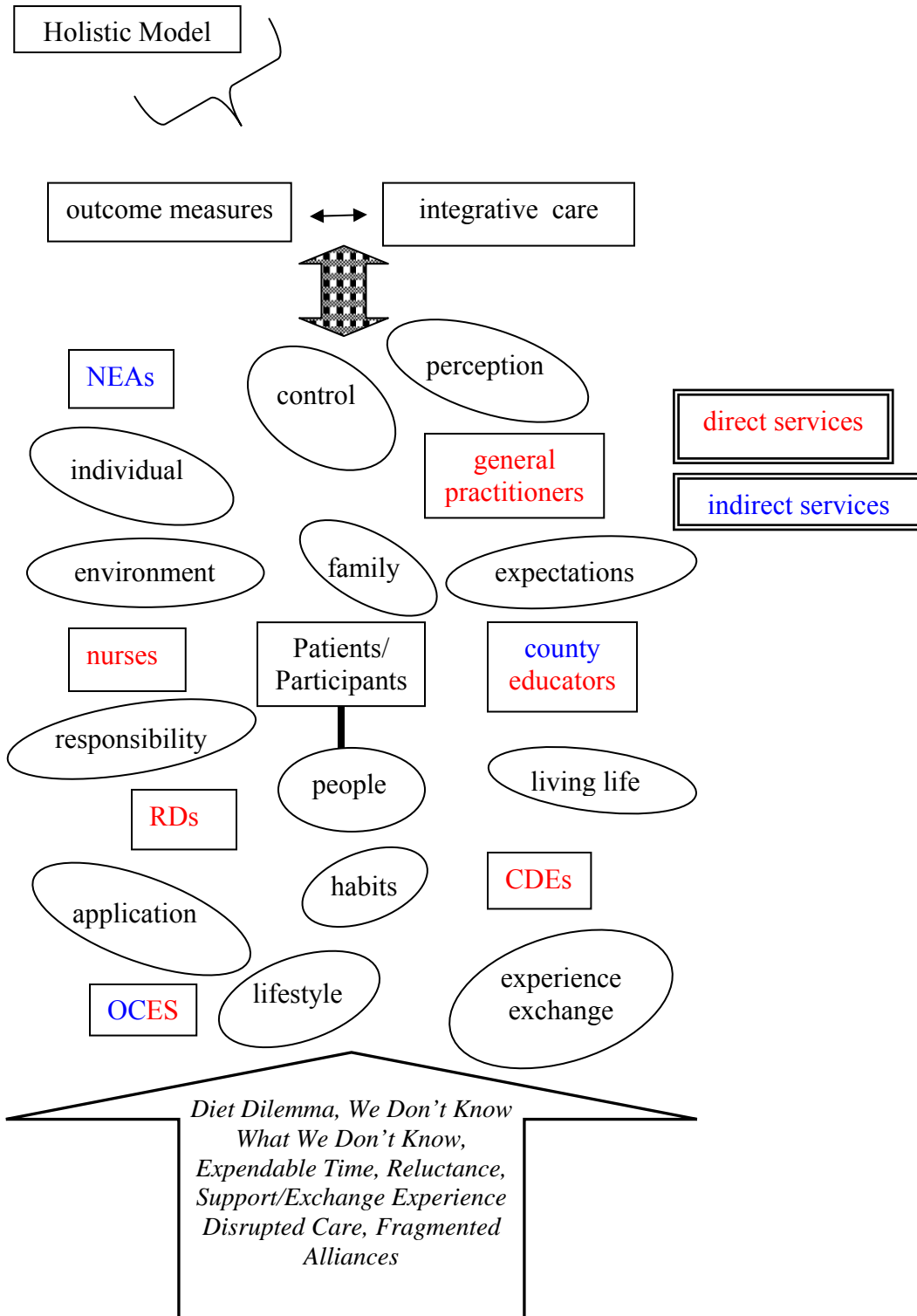


Figure 3 depicts a process of care that may prove more beneficial to caregivers and those who receive their care. Based on the abstract situational map and themes pulled from data, this integrative process of care is founded on a holistic model that is more in line with interviewee perceptions of what is needed to address diabetes care. Information flows in multiple directions to maximize understanding between the various entities involved in the care process. Recognizing patients and participants as people who face numerous issues that impact their ability to participate in the care process may facilitate development of strategies that positively impact health outcomes. As displayed by sharing the oval shape, patients are people who have many issues impacting the care process. By placing the care and education agencies within the array of issues impacting people, this map illustrates the functionality of the integrative process of care in taking into consideration factors influencing quality of care outside the realm of patient orientation. The upward facing arrow containing the themes *Diet Dilemma*, *We Don't Know What We Don't Know*, *Expendable Time*, *Reluctance*, *Support/Exchange Experience*, *Disrupted Care*, and *Fragmented Alliances* illustrates that increased communication between the people providing care and the people receiving care results in both parties becoming aware of factors influencing the process of care. Outcome measures that apply to an individual person's/patient's needs could be developed to create a more sustainable process of care beyond that offered by a more parallel process.

Figure 3: Relational Situational Map – Holistic Model of the Process of Care.



CHAPTER V

SUMMARY, CONCLUSIONS, IMPLICATIONS FOR RESEARCH & PRACTICE, AND LIMITATIONS

SUMMARY

Through a series of interviews guided by the tenets of grounded theory, this study explored the community's perspectives regarding the delivery process of diabetes care and education. For the sake of this project, community referred to a collective of individuals receiving and providing services. As each individual has a role in directing the impact of the delivery and reception of care, each interviewee was viewed as a stakeholder in the care process. Investigating this collective of perspectives on the delivery process of diabetes care and education provided an opportunity to gain an insider's point of view. Through content analysis, themes were developed and reported along with associative results in an effort to investigate existing alliances between parties engaged in the handling and management of diabetes, and to uncover potential for developing new alliances.

CONCLUSIONS

This study illuminated an array of issues facing the process of delivering diabetes care and education. Reflected in the perceptions of individuals engaged in the process of

diabetes care and education are opportunities for improving the delivery process. One opportunity in particular is to facilitate a move away from parallel care practices to a more integrated approach guided by “consensus building, mutual respect, and a shared vision of health care that permits each practitioner and the patient to contribute their particular knowledge and skill within the context of a shared, synergistically charged plan of care”.³⁷ A major objective in completing this project was to evaluate the potential for developing alliances between parties engaged in handling and management of diabetes. Based on the results of this project many avenues exist for potential implementation of alliances in order to maximize the impact of strategic, functional, and structural attributes of care and education providers.⁷

In particular, Cooperative Extension has an enormous opportunity to lay the ground work for revolutionizing diabetes care for low-income older Oklahomans. Services currently available coupled with the introduction of additional services would facilitate a state-wide effort to reduce and/or control diabetes among disparate populations throughout Oklahoma. The OCES Family & Consumer Sciences programs are grassroots-focused community-based programs that currently reach out to 76 of Oklahoma’s 77 counties. Associated with these programs are County Educators and State Specialists who provide individual and community-based programs to positively impact citizens of Oklahoma.⁴⁰ Found in approximately 40 counties are paraprofessionals (NEAs) working through CNEP to offer health and wellness, and nutrition education programming to recipients of federally funded food assistance, as well as children in qualifying schools.⁴⁰ By linking with local entities, such as general practitioners, clinics, assisted living centers, and congregate meal sites, the OCES could

establish a line of communication to increase awareness of the types of programs that Cooperative Extension has to offer. The OCES could also function in a referral capacity to channel community members to services that may best meet their needs.

Current infrastructure, along with potential to develop new resources enables the OCES to lead the way in facilitating prevention of diabetes and its associative complications by directly impacting the citizenry of Oklahoma at the individual and community levels. The nature of the Oklahoma Cooperative Extension Service makes it the perfect conduit for leading the way in alleviating the impact of diabetes.

Reestablishing ties with the ediba® Diabetes Center of Excellence has the potential to increase the knowledge base of Extension employees, from County Educators to NEAs. Another potential partnership worth investigating is a link with AmeriCorps VISTA members. VISTA members commit to a year-long full-time project at a non-profit or public agency.⁴¹ One area of focus with which VISTA members are involved is improvement of health services.⁴¹ Functioning as the “domestic Peace Corps”, AmeriCorps may be a viable, low-cost partnership opportunity to assist in addressing the health needs of Oklahomans.⁴¹ By exploring suggestions discussed above, as well as investigating the proceeding avenues of action, associative factors which lead to development of the themes *Diet Dilemma*, *Don’t Know What We Don’t Know*, *Expendable Time*, *Reluctance*, *Support/Exchange Experience*, *Disrupted Care*, and *Framgmented Alliances* may be illuminated and addressed.

IMPLICATIONS FOR RESEARCH & PRACTICE

While the findings of this study provide direction for addressing issues regarding diabetes care and education, they are by no means complete. Additional investigation into other regions of the state encompassing a greater number of Cooperative Extension personnel and participants is required. Additional agencies, such as Diabetes Solutions, ediba® Diabetes Center of Excellence, AmeriCorps, and the Harold Hamm Oklahoma Diabetes Center established by the University of Oklahoma should be contacted and explored with the intention of establishing alliances in order to maximize awareness of programs and construct a well-informed referral process. Community profiles should be completed so that all possible entities have an opportunity to participate in the referral process.

The following web-addresses provide links to profiles that are currently under use and construction: <http://rd.okstate.edu/health/ok/county/coindex.html> is a site put together by the Rural Health Works that has health related data for each county in Oklahoma.⁴² The information is presented in a format that is appropriate for academic use. The information could be reformatted so that it would be appropriate for use by the general public; <http://healthycommunities.okstate.edu/> is a Healthy Communities site put together by the Oklahoma Cooperative Extension Service.⁴³ This site is currently under construction, but will have links to sites that citizens may find useful, such as sites that provide information about community infrastructure and rural transportation; <http://www.dsok.net/countyContactsMap.php> is a site established by Diabetes Solutions of Oklahoma.⁴⁴ This site has links to each county in Oklahoma. The links provide information about support services in the county and surrounding areas for people with

diabetes. This site may offer a place where Extension Educators and/or paraprofessionals could be listed as a potential source for support for community members; <http://www.extension.iastate.edu/hunger/existingdata.htm> is a site put together by the Iowa State University Cooperative Extension Service.⁴⁵ The site has links to information about poverty and food needs for each county in the state. It has county specific information about the types of foods available and the types of stores that are in a specific county. This site could be used as a template for designing a similar site for the OCES. An effort should be made to make use of these profiles to develop collaborative relationships between Extension agencies, university departments, and community agencies to form multidisciplinary strategies addressing the health needs of Oklahomans. Efforts addressing the impact of culture and history on the delivery and reception of care and education are needed in order to enhance the contextual framework of potential strategies.

LIMITATIONS

Due to the qualitative nature of this study, the results lack generalizability because they represent the perceptions of the study population. The methods used for this study can be used to investigate perceptions of other populations. Comparisons between populations can be made in order to uncover commonalities and unique features.

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APPENDICES

APPENDIX A
OKLAHOMA STATE UNIVERSITY
INSTITUTIONAL REVIEW BOARD

Oklahoma State University Institutional Review Board

Date: Friday, May 30, 2008
IRB Application No HE0827
Proposal Title: Diabetes Care in Oklahoma - A Formative Assessment

Reviewed and Expedited
Processed as:

Status Recommended by Reviewer(s): Approved Protocol Expires: 5/29/2009

Principal

Investigator(s):

Joshua Phelps	Janice Hermann
301 HES	301 HES
Stillwater, OK 74078	Stillwater, OK 74078

The IRB application referenced above has been approved. It is the judgment of the reviewers that the rights and welfare of individuals who may be asked to participate in this study will be respected, and that the research will be conducted in a manner consistent with the IRB requirements as outlined in section 45 CFR 46.

The final versions of any printed recruitment, consent and assent documents bearing the IRB approval stamp are attached to this letter. These are the versions that must be used during the study.

As Principal Investigator, it is your responsibility to do the following:

1. Conduct this study exactly as it has been approved. Any modifications to the research protocol must be submitted with the appropriate signatures for IRB approval.
2. Submit a request for continuation if the study extends beyond the approval period of one calendar year. This continuation must receive IRB review and approval before the research can continue.
3. Report any adverse events to the IRB Chair promptly. Adverse events are those which are unanticipated and impact the subjects during the course of this research; and
4. Notify the IRB office in writing when your research project is complete.

Please note that approved protocols are subject to monitoring by the IRB and that the IRB office has the authority to inspect research records associated with this protocol at any time. If you have questions about the IRB procedures or need any assistance from the Board, please contact Beth McTernan in 219 Cordell North (phone: 405-744-5700, beth.mcternan@okstate.edu).

Sincerely,



Sheila Kennison, Chair
Institutional Review Board

Oklahoma State University Institutional Review Board

Date: Monday, January 12, 2009 Protocol Expires: 5/29/2009
IRB Application No: HE0827
Proposal Title: Diabetes Care in Oklahoma - A Formative Assessment

Reviewed and Processed as: Expedited
Modification

Status Recommended by Reviewer(s) **Approved**

Principal Investigator(s):

Joshua Phelps	Janice Hermann
301 HES	301 HES
Stillwater, OK 74078	Stillwater, OK 74078

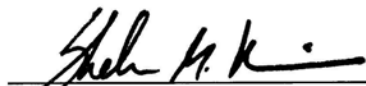
The requested modification to this IRB protocol has been approved. Please note that the original expiration date of the protocol has not changed. The IRB office **MUST** be notified in writing when a project is complete. All approved projects are subject to monitoring by the IRB.

- The final versions of any printed recruitment, consent and assent documents bearing the IRB approval stamp are attached to this letter. These are the versions that must be used during the study.

The reviewer(s) had these comments:

The addition of a demographic questionnaire to the protocol is approved.

Signature :



Sheila Kennison, Chair, Institutional Review Board

Monday, January 12, 2009
Date

Oklahoma State University Institutional Review Board

Date: Tuesday, April 14, 2009 Protocol Expires: 4/13/2010
IRB Application No: HE0827
Proposal Title: Diabetes Care in Oklahoma - A Formative Assessment

Reviewed and Processed as: Expedited
Continuation

Status Recommended by Reviewer(s) **Approved**

Principal Investigator(s)

Joshua Phelps
301 HES
Stillwater, OK 74078

Janice Hermann
301 HES
Stillwater, OK 74078

Approvals are valid for one calendar year, after which time a request for continuation must be submitted. Any modifications to the research project approved by the IRB must be submitted for approval with the advisor's signature. The IRB office MUST be notified in writing when a project is complete. Approved projects are subject to monitoring by the IRB. Expedited and exempt projects may be reviewed by the full Institutional Review Board.

The final versions of any printed recruitment, consent and assent documents bearing the IRB approval stamp are attached to this letter. These are the versions that must be used during the study.

The reviewer(s) had these comments:

Approved for continued data analysis only. Should additional data collection be necessary or desired, a modification request must be submitted to the IRB for review and approval prior to implementation.

Signature 
Sheila Kennison, Chair, Institutional Review Board

Tuesday, April 14, 2009
Date

VITA

Joshua A. Phelps

Candidate for the Degree of

Doctor of Philosophy

Dissertation: DIABETES CARE IN OKLAHOMA – A FORMATIVE ASSESSMENT

Major Field: Human Environmental Sciences

Education:

Received a Bachelor of Arts degree in Anthropology from the University of Michigan, in Ann Arbor, Michigan in 1992; received a Master of Science degree from Oklahoma State University in 2001; completed the requirements for the Doctor of Philosophy Degree in Human Environmental Sciences at Oklahoma State University, Stillwater, Oklahoma in July, 2009.

Experience:

Assistant Nutrition Specialist, Program Director, Community Nutrition Education Programs, Oklahoma State University Cooperative Extension Service, 6/08 – Present; Lecturer, Nutritional Sciences Department, Oklahoma State University, Stillwater, OK, 7/05- 5/08; Program Assistant, Community Nutrition Education Programs, Oklahoma State University Cooperative Extension Service, 7/01-7/05; Agricultural Extension, Peace Corps Volunteer, Biotechnology Center, University of the West Indies, Kingston, Jamaica, 5/95-7/96; Teacher, Peace Corps Volunteer, The Ministry of Education, St. Elizabeth, Jamaica, 9/94-5/95; Columnist, Daily O'Collegian, Oklahoma State University, Stillwater, OK, 1/94-5/94; Site Surveyor, University of Michigan, Ann Arbor, MI, 4/92.

Professional Memberships:

American Anthropological Association

Name: Joshua A. Phelps

Date of Degree: July, 2009

Institution: Oklahoma State University

Location: Stillwater, Oklahoma

Title of Study: DIABETES CARE IN OKLAHOMA – A FORMATIVE ASSESSMENT

Pages in Study: 88

Candidate for the Degree of Doctor of Philosophy

Major Field: Human Environmental Sciences

Scope and Method of Study:

Through a series of interviews guided by the tenets of grounded theory, this study explored the community's perspectives regarding the delivery process of diabetes care and education. For the sake of this project, community referred to a collective of individuals receiving and providing services. As each individual has a role in directing the impact of the delivery and reception of care, each interviewee was viewed as a stakeholder in the care process. Investigating this collective of perspectives on the delivery process of diabetes care and education provided an opportunity to gain an insider's point of view. Through content analysis, themes were developed and reported along with associative results in an effort to investigate existing alliances between parties engaged in the handling and management of diabetes, and to uncover potential for developing new alliances.

Findings and Conclusions:

This study illuminated an array of issues facing the process of delivering diabetes care and education. Reflected in the perceptions of individuals engaged in the process of diabetes care and education are opportunities for improving the delivery process. One opportunity in particular is to facilitate a move away from parallel care practices to a more integrated approach. A major objective in completing this project was to evaluate the potential for developing alliances between parties engaged in handling and management of diabetes. Based on the results of this project many avenues exist for potential implementation of alliances. In particular, Cooperative Extension has an enormous opportunity to lay the ground work for revolutionizing diabetes care for low-income older Oklahomans. Services currently available coupled with the introduction of additional services would facilitate a state-wide effort to reduce and/or control diabetes among disparate populations throughout Oklahoma. By exploring these alliances and investigating additional avenues of action, associative factors which lead to development of the themes *Diet Dilemma*, *Don't Know What We Don't Know*, *Expendable Time*, *Reluctance*, *Support/Exchange Experience*, *Disrupted Care*, and *Fragmented Alliances* may be illuminated and addressed.

ADVISER'S APPROVAL: Janice Hermann
