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## A Qualitative Analysis of Four Appalachian Cervical Cancer Patient Navigators Interviews

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Steven Hiestand, Student

F. Douglas Scutchfield, MD, Committee Chair

Linda Alexander, EdD, Director of Graduate Studies

**A QUALITATIVE ANALYSIS OF FOUR APPALACHIAN  
CERVICAL CANCER PATIENT NAVIGATOR  
INTERVIEWS**

**CAPSTONE PROJECT PAPER**

**A paper submitted in partial fulfillment of the requirements for the  
degree of Master of Public Health in the University of Kentucky College  
of Public Health**

**By  
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Powell, Ohio**

**Lexington, Kentucky  
July 21<sup>st</sup>, 2015**

**Abstract**

Despite widespread incorporation of patient navigation into cancer care programs, there remains little consensus on the definition or core competencies which distinguish the patient navigator role within health care. In order to determine the definition and core competencies, the experiences and insights of patient navigators must be understood. Four patient navigators participating in a 2010 Appalachian Cervical Cancer intervention were interviewed. I qualitatively analyzed these interviews for important themes relating to the definition of patient navigation as well as important skills and competencies. The patient navigators identified patient navigation as being patient-centric and focused on overcoming barriers to cancer care. Key skills identified were interpersonal and self-motivational skills. The themes identified in the interviews strengthen the understanding of what it means to be an effective patient navigator.

**Introduction**

Patient navigators go by many names – lay health workers, *promotoras*, patient advocates, etc. This variety in nomenclature demonstrates patient navigators as being flexible positions which are primarily there to serve patients of chronic disease. Traditionally, patient navigators work with medically underserved populations in order to eliminate barriers to adequate cancer care. Despite rapid growth in adoption since their introduction in the early 1990's, there is little consensus on the definition of what a patient navigator precisely is. The discrepancy in definition leads to further discrepancy within patient navigator training programs. Because there is no set definition, and because patient navigator programs are so varied across the nation, there is no consensus on core competencies which are necessary for successful patient navigation. In order to

be able to adequately quantify the effectiveness of patient navigation (both in terms of cost and outcomes), the practice needs to be standardized. This study qualitatively analyzes interviews with four patient navigators who took part in a 2010 Appalachian Cervical Cancer intervention. Key ideas and themes from these interviews are presented to influence the definition and core training competencies based on what is important according to the navigators themselves.

## **Literature Review**

### *History of Patient Navigation*

In 1989, the American Cancer Society issued a “Report to the Nation on Cancer in the Poor” stating that significant disparities in cancer outcomes still existed in the United States because of a disproportionate burden it placed on the poor.<sup>1</sup> Poor people regularly faced higher rates of cancer incidence, lower rates of diagnosis, and worse overall outcomes. This burden was due to five critical issues that faced poor people with cancer: Barriers to obtaining affordable care, poor people and families must often make extreme sacrifices to obtain and pay for care, fatalism about cancer is prevalent among the poor, cancer education programs are often culturally insensitive and irrelevant to many poor individuals, and poor people ultimately endure greater pain and suffering from cancer than other Americans.<sup>2</sup> As a result of this report, the ACS issued a call for an intervention which could potentially help eliminate these barriers to adequate cancer care for the poor and minorities.

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<sup>1</sup> Freeman, H.P. and Rodriguez, R.L. 2011. pg. 3540

<sup>2</sup> Freeman, H.P. 2012. pg. 1614

In 1990, Dr. Harold P. Freeman started the first Patient Navigator program at Harlem Hospital in New York.<sup>3</sup> Implementation of the program was a direct result of the ACS report and was aimed at eliminating documented disparities in cancer outcomes among the poor, medically underserved population of Harlem, New York. Dr. Freeman targeted underserved populations because, according to him, they faced more pain and suffering from cancer than the rest of the population.<sup>4</sup> The overarching goal of the program was to improve cancer outcomes by reducing the time between diagnosis and treatment so that the cancer was diagnosed and treated before it reached later stages.<sup>5</sup> The program intervention consisted of two parts – the provision of free or low-cost examinations/mammograms and then patient navigation after diagnosis. Before the intervention, the population of 606 patients (94% black) treated at Harlem Hospital Center saw 6% with stage 1 while 49% had stage 3 or 4, with a 5-year survival rate of only 39%. After the intervention, the population of 325 patients saw 41% with stage 0 or 1 breast cancer, while only 21% of patients had stage 3 or 4 cancer and the 5-year survival rate was 70%.<sup>6</sup> This significant increase in early stage detections and the improved 5-year survival rate was attributed to the incorporation of affordable detection measures and the inclusion of patient navigation which ensured timely diagnosis and treatment of the disease.

Due to the success of the Harlem patient navigator program and its ability to overcome cancer care barriers which are common among poor or underserved populations, the use of patient navigation in cancer care quickly spread. In 2003, 2 bills

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<sup>3</sup> Ibid. pg. 3540

<sup>4</sup> Freeman, H.P. 2006. pg. 139.

<sup>5</sup> Freeman, H.P. et. al. 1995.

<sup>6</sup> Freeman, H.P. and Rodriguez, R.L. 2011. pg. 3541

were presented in U.S. Congress which proposed federal support of patient navigator programs and, in 2005, the National Institutes of Health (NIH) planned “to commit \$55 million to support research on the effectiveness and cost effectiveness of patient navigator programs.”<sup>7</sup> One of these bills, the Patient Navigator Outreach and Chronic Disease Prevention Act was signed into law in 2005 and authorized demonstration programs nationwide.<sup>8</sup> Two years later, patient navigator programs were implemented in over 200 cancer care sites in the United States.<sup>9</sup> This rapid expansion of patient navigation within the cancer care process lead to support from numerous governmental and non-governmental agencies in an effort to study its effect on the cancer care continuum. In fact, language recognizing patient navigation as a unique approach to tackling cancer care issues in medically underserved populations is even included within the Affordable Care Act.<sup>10</sup> Patient navigation was implemented so widely, it has even been considered in Canada.<sup>11</sup>

Perhaps the most influential navigator program was the National Cancer Institute’s Patient Navigation Research Program (PNRP) which ran from 2005 until 2010 and focused on studying both the impact which patient navigators have upon cancer treatment in medically underserved populations as well as the development of new and innovative patient navigation approaches.<sup>12</sup> While it admitted that patient navigation could be used to address a number of clinical care issues, the program itself focused on four major forms of cancer: breast, cervical, colorectal, and prostate. An evaluation of

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<sup>7</sup> Dohan, D. and Schrag, D. 2005. pg. 849.

<sup>8</sup> Paskett, E.D. et al. 2011. pg. 238.

<sup>9</sup> Schwaderer, K.A. et al 2007.

<sup>10</sup> Freeman, H.P. 2012. pg. 1615.

<sup>11</sup> Fillion, L. et al. 2012. Pg. 58.

<sup>12</sup> Freund, K.M. et al. 2008. pg. 3392.

the program's costs and outcomes acknowledged that, at the start of the PNRP, there was little actual data or research into the efficacy or cost effectiveness of patient navigation.<sup>13</sup> Hence the need for a comprehensive, nationwide programmatic study.

### *Patient Navigation Effectiveness*

The PNRP found that, only under the most optimum of circumstances where time to diagnostic resolution was 6 months shorter for navigated patients, there was a 15% higher probability of obtaining proper follow-up, and that all of the patients lost to follow-up were at the more advanced stages of cancer, only then was patient navigation cost effective.<sup>14</sup> Admittedly, the PNRP was only conducted for 5 years which may not have been enough time to adequately determine the effects of navigation on a large population, but the recommendation was clear: Despite modest improvements in cancer care among navigated patients, at the national level patient navigation was not cost effective and that alternative approaches ought to be considered. This outcome was echoed by a similar study conducted by the Chicago Cancer Navigation Program (CCNP) which studied the cost-effectiveness of navigation on a population of women diagnosed with breast cancer. Only when navigation improved the time to diagnosis and treatment by 6 months did the program become potentially cost-effective.<sup>15</sup> That said, the PNRP did recognize that patient navigation could be more effective if it was targeted at specific, underserved populations. This is demonstrated in a study by Ell, et al, published in the *Journal of Preventive Medicine* which found that patient navigation was a highly effective strategy in improving diagnostic resolution follow-up among low-income,

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<sup>13</sup> Bensink, M.E. et al. 2014. pg. 571.

<sup>14</sup> Ibid. pg. 575.

<sup>15</sup> Markossian, T.W. and Calhoun, E.A. 2011. pg. 57.

ethnic minority breast cancer patients.<sup>16</sup> Also, patient navigation may provide value in other ways such as enhancing patient understanding or satisfaction during the process.<sup>17</sup>

The results of the PNRP become less convincing when one considers the many barriers present in determining patient navigator cost effectiveness. The primary issue is that patient navigation programs are inherently non-uniform because each program is uniquely tailored to the population it is serving.<sup>18</sup> For instance, interventions targeting barriers such as health beliefs and social support need to be highly adapted to the population being served.<sup>19</sup> This means that a community health needs assessment needs to be conducted before a patient navigator program can be implemented, as demonstrated by a patient navigator intervention study conducted on prostate cancer patients.<sup>20</sup> Next, outcomes are a combination of an estimated cost with estimated QALYs to give an estimated cost per estimated life year saved. Simply estimating the impact of detection or treatment delays on the quality of life is complex and difficult for a study that lasts only 5 years.<sup>21</sup> Given these barriers to determining cost effectiveness in patient navigation, the PNRP results, while indicative, cannot be seen as definitive.

What is more definitive, however, is the fact that patient navigation decreases time between patient diagnosis and treatment. A study conducted at the Denver PNRP, for example, found that patient navigation reduced the time between detection and treatment and increased the percentage of patients who reached diagnostic resolution by a

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<sup>16</sup> Ell, K. et al. 2007. pg. 28.

<sup>17</sup> Bensink, M.E. et al. 2014. pg. 576.

<sup>18</sup> Ramsey, S. et al. 2009. pg. 1636.

<sup>19</sup> Eggleston, K.S. et al. 2007. Pg. 312.

<sup>20</sup> Nonzee, N.J. et al. 2012. Pg. 3.

<sup>21</sup> Ramsey, S. et al. 2009. pg. 5398.

significant time period.<sup>22</sup> A separate study showed that patient navigation was successful in assisting breast cancer patients who faced barriers such as a lack of health insurance or racial barriers.<sup>23</sup> Highlighting an important issue, an article looking at patient-reported outcomes and patient navigation states that there is no established way of truly assessing the effectiveness of patient navigation.<sup>24</sup> Is one to judge patient navigation by its cost-effectiveness? By the clinical outcomes of navigated cancer patients? By the reported outcomes or satisfaction of those patients themselves? Despite the rapid expansion of patient navigation into the health care field, there remains a lack of consensus about its effectiveness or how one should even go about determining effectiveness. Two points are clear, though. First, patient navigation is rather expensive when compared to the traditional means of caring for cancer patients. Second, it does have an appreciable impact on improving the care of traditionally underserved cancer patients. In order to adequately judge the success of patient navigation programs, the first steps are to identify the precise definition of what a patient navigator is and the primary objective of patient navigator programs.

### *Patient Navigator Definition*

According to Harold Freeman, the core function of patient navigation is to improve cancer outcomes by eliminating barriers to timely care.<sup>25</sup> This sentiment was repeated by all of the other articles focusing on patient navigation and cancer care. The wording of that function, however, is extremely broad. The skills and expertise required

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<sup>22</sup> Raich, P.C. et al. 2012. pg. 1629.

<sup>23</sup> Meredith, S.M. 2013. Pg. 55.

<sup>24</sup> Fiscella, K. et al. 2011. pg. 3604.

<sup>25</sup> Freeman, H.P. and Rodriguez, R.L. 2011. pg. 3541.

by a patient navigator change based on the barriers they are attempting to eliminate and the population with which they are working. Freeman then proceeds to state that patient navigators need to have a clear scope of practice for which they are qualified.<sup>26</sup> In order to establish this clear scope of practice, however, a consensus must be reached about the definition and scope of patient navigation within the health care setting.

Similar to the lack of consensus about the effectiveness of patient navigation, there is also a lack of consensus regarding the definition of what a patient navigator precisely is.<sup>27</sup> In a literature review article aimed at updating the science of patient navigation, it was clear that there was no consensus regarding the definition, necessary qualifications, or impact of patient navigation within the cancer care continuum.<sup>28</sup> There are four main areas within which patient navigators may generally work; prevention and early detection, health access and coordination, insurance coverage and continuity, and diversity and cultural competency.<sup>29</sup> Beyond that, however, the role of the patient navigator varies from program to program.

While complete standardization of patient navigation will be difficult, it will be vital if programs and interventions which utilize it are to be empirically evaluated. This means that a common definition for patient navigation which details primary objectives and necessary qualifications needs to be adopted. Further, the definition should be focused on the barriers which navigators confront instead of the specific functions those navigators carry out because those functions vary at the program level and so a definition

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<sup>26</sup> Ibid., pg. 3541.

<sup>27</sup> Steinberg, M.L. et al. 2006. pg. 2670.

<sup>28</sup> Paskett, E.D. et al. 2011. pg. 237.

<sup>29</sup> Natale-Pereira, A. et al. 2011. pg. 3548.

focused on functions would lack specificity.<sup>30</sup> An example of a proper, barrier-focused definition is the one utilized by the PNRP. According to the PNRP, patient navigation is “support and guidance offered to individuals who have an abnormal cancer screening test or a cancer diagnosis with the objective of accessing the cancer care system and overcoming barriers to timely, quality care.”<sup>31</sup>

The PNRP definition highlights two important aspects of patient navigation. First, it must be patient-centric or otherwise tailored to the patient’s unique needs. Second, it is aimed at overcoming barriers, specifically barriers to timeliness of care. One aspect missing from the definitions of patient navigation in the literature is the qualifications needed by a patient navigator. For instance, the PNRP definition could apply to any clinical or non-clinical worker within the health care setting. Nurses which work closely with patients, for instance, certainly work to overcome barriers to the timeliness and quality of care. However, it is uncertain whether these nurses would identify themselves as patient navigators or not. This is an issue because programs which utilize clinically trained navigators, such as nurses who double as navigators, will significantly differ from lay patient navigator programs in terms of function and cost. If patient navigation programs were significantly cost-effective, then this would be less of an issue. According to the results of the PNRP study, however, patient navigation was either marginally cost-effective or not at all.<sup>32</sup> The uncertainty of cost-effectiveness demonstrates a need for proper training so that supervision costs can be minimized and

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<sup>30</sup> Dohan, D. and Schrag, D. 2005. pg. 850.

<sup>31</sup> Wells, K.J. et al. 2008. pg. 2007.

<sup>32</sup> Bensink, M.E. et al. 2014. pg. 571.

outcomes improved. In order to properly structure a patient navigator training program, core competencies must be identified.

In order to understand the role of patient navigation, the perspective of patient navigators should be considered. In through analysis of two similar qualitative studies of patient navigator reflections in interviews, the primary theme which became apparent is that patient navigators are acutely aware of psychosocial barriers to proper cancer care.<sup>33,34</sup> Both of these studies used insights from interviews of patient navigators to gain perspectives into the unique relationship between patient navigators and cancer patients. However, studies such as these are relatively new and uncommon. Further qualitative analysis of patient navigator insights is warranted.<sup>35</sup>

### *Core Competencies*

The 2005 article by Dohan and Schrag called for a clear definition of patient navigation so that a standardized system of training can be established.<sup>36</sup> Because of the vague definition, patient navigator tasks can vary widely from program to program. Examples of navigator tasks include education and outreach, assisting with screening, helping with the diagnoses and staging, helping with follow-up cancer treatment, and even potentially helping with cancer survivors.<sup>37</sup> While a clear definition has not been established, an attempt at a standardized patient navigator training program was made. In June of 2006, the PNRP along with the ACS's Patient Navigation Program and the CMS

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<sup>33</sup> Phillips, S. et al. 2014. Pg. 344.

<sup>34</sup> Jean-Pierre, P. et al. 2011. Pg. 111.

<sup>35</sup> Ibid., pg. 119.

<sup>36</sup> Dohan, D. and Schrag, D. 2005. pg. 850.

<sup>37</sup> Braun, K.L. et al. 2012. Pg. 6.

held a three day training program for patient navigators.<sup>38</sup> The training program was used by patient navigators with a wide variety of backgrounds ranging from no clinical experience to advanced practice nurses. The primary objectives of the training program were to provide basic knowledge and skills required by patient navigators, enhance professional development of existing patient navigators, to promote collaboration between navigators from across the country, and to provide an open forum so that navigators could discuss their roles.<sup>39</sup> At the end of the training program, patient navigators were able to submit topics which they felt needed to be included in navigator training. Among the topics listed, the most common were dealing with difficult patients / discussing death / dealing with fear, more advanced training regarding cancer treatments, more information about Medicare and Medicaid, and how to deal with stress or avoid burnout.<sup>40</sup>

A recent study of nine patient navigator programs sought to describe what patient navigators actually do in an effort to clarify their role in facilitating cancer care.<sup>41</sup> The uncertainty regarding the precise role of patient navigation – let alone if they are effective or not – is surprising given the considerable amount of research and number of programs with which they have been associated. According to the literature, patient navigators tend to spend most of their time networking. This means reaching out to patients in an attempt to make contact with them, answer questions about the cancer care process or insurance, and then help schedule appointments. Further, navigators spend a lot of time speaking with clinical staff and secretaries. Most patient navigators are overseen by a

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<sup>38</sup> Calhoun, E.A. et al. 2010. pg. 208.

<sup>39</sup> Ibid., 209.

<sup>40</sup> Calhoun, E.A. et al. 2010. pg. 213

<sup>41</sup> Clark, J.A. et al. 2014. Pg. 90.

nurse manager who they regularly report back to. Further, they do not select the patients themselves but rather are given patient files by the nurse manager.

A phrase which is common in the literature is that patient navigators serve to bridge the gap between underserved populations and health care providers.<sup>42</sup> While serving to overcome barriers to adequate cancer care is the primary focus, the literature places less emphasis on the ability for patient navigators to provide emotional support and guidance such as by providing comfort, displaying empathy, and listening supportively to the patients.<sup>43</sup> If navigators are to serve as bridges, they must be able to connect to the patients. Empathy and an emphasis upon connecting to patients is a growing trend in medicine and is the subject of ongoing empirical research.<sup>44</sup> In fact, an early study looked at using the patient navigator role as a means to teach empathy and impart an understanding of the patients' subjective experiences to medical residents.<sup>45</sup>

The question is if patient navigation should be limited to clinical staff, non-clinical staff, or a mixture of the two. In an article written by Howard Freeman, he argues that the ideal situation is a "team" of patient navigators which is comprised of both clinical and non-clinical staff.<sup>46</sup> This composition theoretically allows the greatest flexibility with regards to patient interaction and care.<sup>47</sup> Navigators with clinical backgrounds are better at answering health related questions and predicting outcomes while non-clinical patient navigators tend to be cheaper and can focus more on extra-

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<sup>42</sup> Schwaderer, K.A. et al. 2007.

<sup>43</sup> Yosha, A. et al. 2011.

<sup>44</sup> Pedersen, R. 2009. pg. 307.

<sup>45</sup> Henry-Tillman, R. et al. 2002. pg. 660.

<sup>46</sup> Freeman, H.P. 2012. pg. 1616

<sup>47</sup> Meade, C. et al. 2014. Pg. 449.

clinical aspects of care such as compassion and empathy. Certainly, given the finding of the PNRP's cost-effectiveness study, it is important that navigators are as effective at improving outcomes as possible while remaining as inexpensive as possible. A major part of the PNRP's cost-effectiveness prediction is the fact that patient navigator oversight and administration amounts to more than \$15,000 per QALY.

This is where autonomy of the patient navigator becomes relevant. In order to maximize effectiveness, patient navigators need to be able to work autonomously without substantial oversight. Autonomy not only improves the cost-effectiveness of patient navigator programs but it also reduces the workload of other, clinical staff who are included in cancer care. A problem with autonomy, however, is that it means responsibility is also shifted away from the clinical staff and towards the patient navigator. There may be some resistance from clinical staff to shifting responsibility towards non-clinical lay health workers. Also, this may present an issue if patients expect answers to questions which are either beyond the expertise of the patient navigator or that the navigator does not feel comfortable answering. For instance, a patient may ask about prognosis after an abnormal screening result. Such a prognosis should be left to the clinical oncologist and not be answered by a non-clinical staff member. If the navigator is outside of the clinical setting and the oncologist or nurse is not available, however, the navigator may feel compelled to answer a question which he or she is not qualified to answer.

Finally, there is a lack of consensus about how the patient navigator should operate be it over-the-phone or face-to-face. Navigation over-the-phone is the easiest and most reliable means of establishing contact between the navigator and patient because it

usually does not require advanced scheduling of a meeting. Face-to-face, meanwhile, can only occur when the patient is in the navigator's place of employment or if the navigator travels to meet with the patient. Preliminary analysis shows that face-to-face navigation is the most effective form. However, face-to-face navigation tends to be more expensive, in that it costs more time and travel money. It does, however, improve patient satisfaction and seems to result in better outcomes. The most common means of navigation, however, is over-the-phone. While impersonal, over-the-phone communication is simpler and allows the navigator to work with multiple patients simultaneously. Over-the-phone navigation may decrease empathy and could potentially pose cultural issues for patients. Further, patients who lack a telephone number or who are generally unreachable may be more responsive to face-to-face visits.

### *The Gaps in the Data*

Through a comprehensive review of the literature, it has become apparent that there exist numerous gaps in our understanding of patient navigation. First, there is no set definition of what a patient navigator actually is. Stemming from this lack of a definition is the fact that there is no understanding of the core competencies or actions which a patient navigator must undertake. Finally, due to a lack of understanding of what core competencies are most important, there is no standardized way of training patient navigators. Overall, this lack of standardization means one thing – inefficiency. While navigation programs nationwide are quite varied and flexible, a lack of standardization means that there is no way to accurately gauge their effectiveness beyond recounting anecdotal outcomes and subjective claims at costs for specific programs which interact with even more specific populations.

In order to truly grasp the effectiveness of patient navigation and to advance the science of a unique cancer disparity intervention, a comprehensive, qualitative analysis of the patient navigator experience should be conducted. Navigators themselves must be studied and interviewed so that an understanding may be gained of their roles and requirements. This capstone project seeks to serve as a pilot example of how information about patient navigation should be analyzed and then what conclusions may be gained from it. This capstone seeks, in a pilot effort, to answer what a patient navigator is, what role he or she serves in cancer care, and what competencies a patient navigation training program should emphasize. It will highlight discrepancies in experience between navigators, insights from those navigators, and attempt to tie the qualitative data back to existing literature on navigation.

## **Methods**

In 2010, a study was conducted by Mark Dignan and associates at the Markey Cancer Center. The study focused on the impact of patient navigator intervention on cervical cancer outcomes for female Appalachian patients. At the end of the study, all available navigator staff (N = 4) were interviewed as part of the study's summative evaluation activities. The 4 navigators were all female and from the two area development districts included in the study. These interviews were conducted face-to-face by a separate investigator in a semi-structured manner. The semi-structured interviews were designed to elicit the perceptions of the navigators with regards to what was successful and unsuccessful about their experiences with patient follow up care during the intervention. They were conducted in the office of the navigators at separate

time. Each interview lasted for approximately one hour and was audio recorded. The audio recordings were then transcribed verbatim into Word documents.

A separate investigator, the author, then obtained the tapes from the principle investigator. The interview transcripts were each read through twice in order to establish a flowing narrative. Once each interview's narrative was established, the interviews were coded. Coding was done line-by-line by the single researcher. This line-by-line coding resulted in the identification of key words and phrases. Attention was paid to words and phrases which were repeated throughout the interview and the literature. The results of the coding, keywords, and phrases were then interpreted for themes. Interpreted themes were then compared between interviews and analyzed. These overarching themes were related back to three categories described in the literature review – patient navigator effectiveness, the definition of what it means to be a patient navigator, and core competencies / actions / or skills which are important for patient navigators to possess.

## **Results**

Each interview followed a structure of beginning with targeted questions such as “what is a patient navigator?” to more open ended questions where the navigators would describe specific cases or instances encountered during the intervention. In the course of the interviews, keywords and themes which were explored followed the topics which became evident in the literature review. Hence, the themes which receive the most discussion are those of the definition of patient navigation, patient navigation efficiency

or effectiveness, and core competencies which are important for successful patient navigation.

### *Patient Navigator Definition*

When prompted to describe what, exactly, a patient navigator is, all four navigators stressed three key concepts. First, they reinforced the idea that the work they do is oriented towards the patient or is otherwise patient-centric. PN1 states that the role of the patient navigator is to "...help the patient just in whatever they need to do." PN2 states that patient navigators are there "just to make [patients] aware of what services are available..." Ginger PN3 when asked what patient navigation is immediately responds with "basically I look at it like I'm here for the patient..." Finally, according to PN4, patient navigation is "helping the patient with overcoming barriers... I think of [navigating] as trying to help people." While they recognize that their efforts help care providers, the navigators primarily identify their work as being for the good of the patient. Further, the language utilized in the responses indicates that the relationship between navigator and patient is a partnership. In this partnership, the patient is the primary actor who acts with navigator assistance rather than a service such as those carried out by physicians and nurses.

Being patient-centric in their focus, the navigators were particularly attentive to patients' concerns and fears. "But mostly I'm concerned about, with how they're feeling because it's kind of a traumatic moment for some people..." said PN3. PN2 makes it a point to help the patients feel better after they have received news of their abnormal Pap screening: "By the time we're basically done, you know I think they feel comfortable. Some of them's hugged me..." According to PN4, "...as soon as I get an abnormal Pap

referral, I want to get in contact with that patient and find out if they have any kinds of fears or barriers...” Finally, PN1 relates the story of a patient who took the Pap result particularly hard, saying “she was just really tore up because she had had cancer before she said... you just have to meet [with] her.”

While the navigators’ actions are patient-centric, they report directly to a nurse manager. The patients interact with the nurses before being forwarded to the navigators and is who the navigators usually consult with questions. “I don’t really give them a packet,” says PN2, “that comes from the nurse case manager who they see first.” When asked about their relationships with the nurses and other staff, the navigators all replied that they hadn’t had any issues and that they felt comfortable approaching the nurses to ask questions on behalf of the patients. “[The patients] have questions...” says PN1, “but I don’t answer them.” “I go find out the answer for them.” PN3 often tells patients “I might look like a nurse but I’m not and if you have any questions, I’ll get the answers for you somehow.” According to PN4, “a lot of women in this area have a problem with still communicating.” The Appalachian women PN4 interacted with tended to defer to their husbands and, as a result, didn’t get their own concerns and questions answered by the nurses and physicians. As “an advocate for patients,” PN4 was able to aid these women in voicing their own concerns. Despite constantly relaying questions and information back to the case nurses, the navigators tend to view themselves as being autonomous. PN2, for example, says that it is important to be flexible and disciplined as a patient navigator “since there’s no one over my shoulder you know.” The autonomy is important because it allows the navigators to be flexible in how they interact with patients and it also allows for nurses to be able to focus on clinical duties rather than logistical barriers.

Unlike nurses, patient navigators are extremely limited in their capacity to answer direct, clinical questions or solve issues for the patients by themselves. All four of the navigators stressed that they try to help the patient in overcoming issues preventing them from getting proper care, and the emphasis is on the word “try.” “I should be there to help them,” says PN1. “I may not be successful at it but yes, I mean I would try.” The emphasis on the attempt demonstrates the limited capacity within which patient navigators operate. In contrast with nurses, the success of the navigator intervention largely depends on the efforts of the patient as well as the navigator. As PN3 says, navigators “help [patients] get from one point to the other.” They cannot force the patient to get the proper follow-up care but instead serve as a “resource person” or “liaison.”

In the course of the interviews, the precise definition of what it meant to be a navigator hinged on three important themes: Navigators are non-clinical, patient-oriented, and primarily deal with barriers to proper follow-up care. Further, their utilization in the care of cervical cancer – a serious and chronic disease, as well as their focus on patients who are in poverty is an important defining characteristic of the work which navigators do. Finally, they mention their capacities as patient advocates, specifically for patients who either do not know what questions to ask or how to voice concerns.

### *Significant Barriers*

Perhaps the most prominent theme which became apparent in analyzing navigator responses regarding their role in the health care continuum is that they are focused on helping patients overcome barriers to proper follow-up care. To quote PN4, “I think of patient navigation as helping the patient with overcoming barriers that they feel that

hinder them from getting services...” The perceived barriers, however, varied among the navigators. Navigators PN1 and PN4, for example, highlighted transportation and keeping appointments as major barriers. PN4 uses the analogy of a broken leg to explain why she thinks many women don’t keep their appointments. Many patients don’t realize the seriousness of an abnormal Pap result because cervical cancer, unlike a broken leg, doesn’t “have any difficulties or anything.” Instead, it is up to the navigator and nurse to drive home the seriousness of the patient’s situation and how important scheduling follow-up appointments and then making those appointments is. Says PN1, “the thing that probably aggravates me the worst is so many of these people, you know I want Friday at 10:00 o’clock... and you do everything you can to get exactly when you want, then they cancel.” If a patient misses a follow-up appointment, it is up to that patient to reschedule.

The navigators often have to prompt the patient to reschedule and assist them in doing so. When asked why patients often miss appointments, PN1 stated that there could be schedule conflicts with work or child care, or that transportation could be an issue. “My job I think is just getting them to where the treatment can begin...” says PN1. This sentiment is shared by PN4 who also stated that “lack of transportation” is a barrier. In fact, if a patient’s family only has one car, often the husband will have to miss work on that day so his wife can make an appointment. Meanwhile, PN2 says that transportation “hasn’t been an issue for me.” She says “you just mention what public transportation’s available. It hasn’t been a problem for me.”

Another barrier to proper follow-up care mentioned in the interviews is issues with payment. For low-income patients, initial screening at the health department is free.

However, according to PN1, “I still get questions about the payment but I always refer them back to [the case manager].” While the patients may not have questions about the exact cost, they are often concerned about what procedures they will be receiving and how that will affect their insurance if they have it. The navigators themselves are unable to address issues stemming from payment or insurance, but they know who to direct the patient to. Without this direction, they say that patients would be less likely to seek the care they need.

Ultimately, the navigators stress that the biggest barrier to proper follow-up care for patients is their general lack of knowledge regarding the area resources and procedures. According to PN4, “a lot of the women that I talk to, they just don’t realize what this area offers.” If patients were more aware of the resources available where they lived and why certain procedures are important, then they would be better equipped to deal with logistical barriers to proper care. The ability for navigators to connect the patients to these needed services is what makes their intervention so effective.

#### *Patient Navigator Background*

According to the navigators, being from the area was important because it familiarized them with available resources in the region. Says PN2, “You need to know what is out there in those counties... Obviously I know more; I mean I’m from Somerset, I know what’s available here but I certainly didn’t know, and I used to work in Russell County or in Clinton.” In this statement, PN2 is saying that she is acutely aware of services which can help patients in Somerset County which is where she is from, but she is less aware of services in other counties where she used to work. This sentiment is corroborated by PN1 who says “I’m not from these counties; I don’t know what these

counties have. You know if it was Green County I might know...” When she didn’t know what resources were available in the counties she was assigned, PN1 reached out to the head nurse and then started making phone calls to local groups and programs.

The navigators reported knowing the patients and being familiar with the local communities as being major reasons why the patients were comfortable working with them. According to PN3, “Usually I know them actually. If I don’t know them, they know me or we have mutual [acquaintances].” While she admitted she doesn’t know all of her patients, PN3 says that she can usually connect with them on a personal level by engaging them in conversation about where they are from, if they have kids, or some other personal details. PN2, meanwhile, related the story of a lady who seemed “paranoid” and resisted her attempts to help. “She didn’t know me; that might’ve been the thing... It was a smaller, rural county.” The response from PN2 highlights an important facet of interacting with patients who are from small, rural Appalachian counties. They may be reluctant to engage or open up to navigators who they are not acquainted with. Despite the fact that PN2 was from “the next county over,” that short distance meant that she was an “outsider” to the patient.

Finally, the navigators were asked about their educational attainment levels and previous work experiences. While education was deemed to be “not important” whether a navigator had completed her G.E.D. or actually completed college, past work experiences were significant. PN4, for instance, has an EMT degree and had worked as an EMT in the past. This past work experience gave her a “fair amount of medical knowledge” and helped her become interested in patient care. Similarly, PN1 had worked for 10 years in a hospital in administration and then did medical transcription for

2 years. According to her, “I know how to spell the word but I don’t have a clue what it means.” While her actual medical knowledge is limited, her work fostered interest in patient care much like with PN4. Both PN2 and PN3 worked outside of healthcare. PN2 worked in the unemployment office while PN3 worked as an administrative secretary. Those jobs did not provide exposure to medical terms but they are important for navigators as navigators must be able to keep track of appointments, patients, and contacts.

In the course of the interviews, the navigators identified three main themes in their background experiences which have had an impact upon their work as patient navigators. These themes are where they are from, who they know, and in what jobs they used to hold. It was apparent from the interviews that knowledge of the county and available resources within it were integral to patient navigation. Further, familiarity with patients seemed to make the patients more comfortable and made it easier for the navigators to relate to those patients. Finally, past work experience, according to the navigators, was more important than their formal education background. All three of these themes are significant and cannot be necessarily trained for, instead they must be considered when hiring a patient navigator.

### *Core Competencies*

Throughout the interviews, the patient navigators repeatedly identified core skills or traits which are important to properly carrying out the work of patient navigation. The skills which were identified most often were interpersonal skills and motivational skills. The navigators also identified skills which they wished they had better training in. The

core competencies detailed in the patient navigator interviews can be used to inform future patient navigator training programs.

The most important skill, as identified by all four of the navigators, was having good interpersonal skills. Navigators need to be empathetic, open-minded, and willing to take an interest in the well-being of the patients. If navigators did not have good interpersonal skills, they could potentially alienate the patients or become indifferent to their outcomes. According to PN1, “I think you have to have the personality before you even want to get on this job anyway... You want [patients] to call you, you want them if they have questions you want them to [ask you].” PN3, meanwhile, says of future navigators; “I would want them to be a people person and to relate... not make somebody feel inferior.” The most important quality of a patient navigator, according to the interviews, is that navigators possess the ability to be empathetic as well as non-judgemental. This is represented by the fact that the navigators often use the terms “friends,” “kind,” “good listener,” and “approachable.”

Secondary to interpersonal skills, navigators identified self-motivation as being a key trait of successful navigators. According to PN4, the ideal navigator would be “someone that’s friendly and outgoing, someone that could, that’s a self-starter.” The need to be a “self-starter” is reiterated by PN1 when she says a navigator needs to be “somebody dedicated and that’s going to show up.” Being tenacious, according to the navigators, is important because patients will miss appointments and it is often up to the navigator to stay on top of them in order to improve patient outcomes. Says PN2, “The important thing is just not to go stick your head in the sand you know and think it’s going to go away.” Because part of the role of the navigator is to take some of the work load

off of the nurses, the nurses aren't always looking over the navigators' shoulders. Instead, the navigators often have to work independently and without supervision. Much like being a good people person, being self-motivated is something that the navigators say cannot be taught but instead must be innate. Hence, it must be something which is looked for when considering who to hire as a navigator.

In addition to interpersonal skills and self-motivation, the navigators identified key areas in which they wished they had been better trained. These areas, unlike interpersonal and self-motivation skills, can be trained after a person is hired. The navigators identified better understanding of cervical cancer as one of these areas. PN2, for instance said she would like to know more about “cervical cancer, about HPV, about just the guidelines of how the follow up goes.” Similarly, PN3 says “I do have a lot of patients that ask me exactly, they want to know exactly what is going on with their body and what is HPV... I try to educate myself on it and it's not enough.” While patient navigators are non-clinical workers, they are still faced with questions from patients which they feel obligated to answer. Despite the fact that navigators usually refer the question back to the head nurse, educating them about the specific disease they are working with may be helpful so they can answer rudimentary questions or in case the nurse is not available. Finally, the navigators stated that they would be interested in spending a day in an OB/GYN's office so they could better understand what happens to patients during their appointments.

While burnout was not specifically mentioned in the interviews, the fact that the navigators did not tend to have direct contact with patients was an issue. If navigators do not receive validation for their work – after they are done with a patient they do not

usually hear from that patient again – may make them prone to burnout. While the navigators initially said that they did not know of too many success stories first hand, they insisted that they knew they were making a difference in the outcomes of the patients. Further, they would be able to elaborate on success stories at the insistence of the interviewer. According to the navigators, most interaction with patients occurred over the phone. The amount which navigators traveled to meet with patients face-to-face varied with some regularly conducting home meetings and others rarely doing so. Further, while some of the navigators used a lot of mail in order to contact patients, others did not. It remains to be seen whether face-to-face contact can provide better outcomes and better validation for the navigators rather than talking over the phone. Preliminary research indicates that it does not make a significant difference for the patient outcomes themselves.<sup>48</sup> While no direct conclusions can be drawn about burnout from the interviews, perception of success and having identifiable success stories is something to consider going forward.

## **Conclusion**

The results of the four interviews shed light on issues presented in the literature. The first issue is the lack of a clear definition of a patient navigator. The navigators themselves did not relate a textbook-style definition, but instead discussed important themes of their work which should be incorporated into the role of the navigator itself. Incorporating these themes into a cohesive definition means, according to the interviews,

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<sup>48</sup> Dignan, M.B. et al. 2005. Pg. 6.

a patient navigator is a “non-clinical, patient-oriented health worker who advocates and helps medically underserved patients overcome barriers to timely and quality follow-up care for a specific chronic disease.” This definition is in line with that of the literature but is more specific in that it identifies patient navigation as a non-clinical role, it highlights the unique relationship which navigators have to underserved patients as both advocates and helpers, and ties navigation to the treatment of specific chronic diseases. If patient navigation is to become embraced nationally, it must be standardized. Central to standardization is the adoption of a formal definition of what it means to be a patient navigator. While navigators tend to vary with regards to function, population, and disease on a program-to-program basis, the aforementioned definition is broad enough that it incorporates this flexibility while still identifying patient navigation as a unique health care service.

All four of the navigators interviewed were non-clinical workers. This means that it was not feasible to compare their subjective experiences to that of patient navigators with clinical backgrounds. As mentioned in the literature, Dr. Harold Freeman suggested that teams of patient navigators incorporate both clinical and non-clinical workers so that they may address a wide range of patient issues and barriers.<sup>49</sup> However, employing nurses as patient navigators may be more expensive and may not be any more efficient. Further study is needed in order to gauge the efficiency and cost of patient navigators with clinical backgrounds versus non-clinical patient navigators.

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<sup>49</sup> Freeman, H.P. 2012. Pg. 1616.

While interpersonal skills and self-motivation may be trained to a small degree, they must be strongly considered when hiring new patient navigators. However, as the literature identified, formal patient navigator training programs currently do not exist. The existence of a formal navigator training program is important if patient navigation is to become standardized so that it may be adequately studied and regulated. The navigator interviews highlighted a few topics which would be important to navigator training programs. First, disease specific education is needed so that navigators have a working knowledge of the chronic disease they are helping patients overcome. By educating patient navigators about specific diseases, they are better able to answer patient questions when they are in a one-on-one situation and cannot resort to the nurse. This does not mean navigators should answer specific questions about outcomes or diagnoses, they should be equipped to discuss the disease with the patient to a moderate degree. Such an analysis is similar to the one found by Cohen et al when they analyzed these same four navigator interviews.<sup>50</sup> Further, navigators need to be able to read charts because that is where patient information is given to them by the nurses. This is a skill which can be easily taught. Finally, how to look for and find local resources is a vital skill which patient navigators need to possess. While familiarity with the people and local resources can readily come from experience living in the same county as a patient, the ability to network and contact local resources can be taught

Shortcomings of this paper are that only four navigators total were interviewed. While four is a relatively small number, it is representative of the navigator program in 2010 from which these interviews were taken as that intervention only featured a total of

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<sup>50</sup> Cohen, E.L. et al. 2013. Pg.89.

six navigators. Another shortcoming is that the reviewer of the interviews did not design or conduct the interviews, instead they were taken from study tapes. Ideally, following the qualitative method of grounded theory, the investigator would be the one to design and conduct the interview, allowing their framework and the themes that are presented to influence the interview itself. This is what separates the qualitative method from the quantitative – the study instrument should reflect the framework from within which the interview was conducted. Also, there was only one reviewer who analyzed the tapes and, ideally, two or more people should analyze the interviews and then compare what they found with regards to keywords and themes. Further, these navigators only interacted with rural, Appalachian cervical cancer patients. Themes found in the interviews may not apply to urban patients or patients who suffer from a different chronic disease or other form of cancer. Instead, this qualitative analysis does shed some light onto the experiences of navigators, better inform the patient navigator definition, and help identify core competencies. This study, however, needs to serve primarily as a pilot example of other, qualitative studies which should be carried out on a national scale and incorporate many navigator programs.

In summary, there are many areas which require further research with regards to patient navigation. The results of the PNRP indicating that patient navigation is not inherently cost-effective means that proper standardization and instruction is in order. In order to maximize patient navigator efficiency, they must be targeted towards specific, underserved populations which have an identifiable need for better chronic disease care. This means that a community health needs assessment should be utilized prior to the consideration of implementing a patient navigator program. By standardizing patient

navigation and better identifying core competencies for a training program, we may better understand the impact which navigators have upon patient outcomes at a national level.

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## **Biography**

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