Sprituality in Adolescents and Young Adults With Cancer: The Need For Greater Research

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Abstract

Cancer is one of the leading causes of death worldwide. There are over 100 types of cancer that can affect anyone regardless of their gender, race, age and/or social status. Adolescents and young adults (AYA) 18-39 years old account for approximately 2% of the Canadian population with cancer. The AYA population is a new and upcoming population facing the physical, mental and emotional effects of the disease of cancer. It appears that insufficient research and resources exist for this understudied population. Cancer is a tragedy at any age but for the AYA population it occurs at a period that should be the one of most active stages of development, family and social life. The purpose of the proposed research is to reflect on how AYA cancer survivors can use spirituality to develop a better outcome and enhance life. A methodology and research design is provided for the further exploration of the population in the field.

Keywords: Spirituality, spiritual care, AYA with cancer, grieving, bereavement young adult cancer models, psychosocial development, healthcare, chemotherapy, radiation.

Backdrop

Cancer is anticipated to be the second leading cause of death and morbidity worldwide (WHO, 2018). Cancer is a nonspecific term for a large group of diseases that impact and attack any part of the body due to an uncontrolled and abnormal growth of cells (PHAC, 2015; WHO, 2016). This abnormality causes an attack against the body's natural defenses and it can last for long periods of time in the body (PHAC, 2015; WHO, 2016). During the period between 2012 and 2015, over 14 million new cases of cancer were diagnosed and 8.8 million deaths occurred worldwide from the disease (WHO, 2018). The incidence rate is estimated to increase by approximately 70% within the next 20 years (WHO, 2018). In 2017, it was projected that 206,200 Canadians would be diagnosed and 80,800 will die from the disease (Canadian Cancer Statistics, 2017). There are over one-hundred types of cancers that can affect anyone regardless of gender, race, age and/or social status (WHO, 2018). It is important to note that each of these cancer types requires a unique assessment, diagnosis and treatment plan. It is not uncommon to be left with life altering post treatment affects (WHO, 2018). This represents a tremendous burden and suffering that has, and will be, placed on the lives of many individuals, families and society.

Adolescents and young adults (AYA), between the ages of 18 and 39 years old, account for approximately 2% of the Canadian population with cancer (De, Ellison, Barr, Semenciw, Marrett, Weir, Dryer & Grunfeld, 2011). The number of newly diagnosed cases has tripled over the last ten years, reaching approximately 7,000 new cases per year (Canadian Cancer Society, 2015). The prevalence rates may appear to be relatively small in comparison to older adult cases but the major difference is the impact on life expectancy, the future quality of life and planning (De et al., 2011).

An Unique Cohort Within Psychosocial Development

The realization of having a life altering disease can be devastating at any age. The AYA encountering and coping with disease is unique in terms of their stage of psychosocial development. The AYA population has already transitioned, or is in the process of transitioning into adulthood by exploring intimate relationships, becoming more independent, setting goals towards the future, working at developing a sense of belonging and establishing a social life (Erikson, 1994). The AYA cancer experience has "a major impact on the future, quality of life and life expectancy, as well as disrupting normal trajectories of development (e.g. physical, psychological and social) and life goals related to family and career" (De et al., 2011, p. 187).

The Knowledge Gap

Unfortunately, a knowledge gap seems to exist in providing suitable care, information and treatment that caters to this population's unique needs. An intimate and in-depth investigation is needed to comprehend how the AYA population copes with these life changes that not only occurs within the body and mind, but also within their spirit. According to Richardson, "Facing a potentially incurable illness may elicit feelings of hopelessness, fear, anger and questions on the meaning of life and purpose" (2012, p.150). It can be speculated that having such an existential crisis may impact the AYA's level of faith and influence their current belief system.

Spirituality And Personal Connection

Spirituality can be defined as "that part of being human that seeks meaningfulness through intra-, inter-, and transpersonal connections" (Taylor, 2001, p. 198). The chronically ill patient tends to use spirituality, religious beliefs and practices as a means of coping with the life changes (O'Brien, 2008). The research indicates that a better quality of life and an ability to make more aggressive cancer care choices to extend life, is associated with spiritual well-being and religiosity (Balboni, Vanderwerker, Block, Paulk, Lathan, Peteet & Prigerson, 2007; Richardson, 2012). Due to the severity or life altering nature of cancer diagnoses, most adult patients have specific spiritual needs based on religious beliefs to provide them with a source of strength and comfort (Mosschella, Pressman, Pressman, & Weissman, 1997). Within a palliative care setting,

older adults use spirituality (i.e. prayer and meditation) and religiousness (i.e. God and church) as a strategy to better cope with the disease which also provides a positive impact on the experienced symptoms (i.e. emotional) (Paiva, Carvalho, Lucchetti, Barroso & Paiva, 2015). Older adult cancer survivors who embrace spirituality have lesser anxiety and develop less medical treatment complications (Cannon, Darrington, Reed & Loberiza, 2011). The research literature places a greater emphasis on the older or elderly adult experiences and use of spirituality and religion. As mentioned, spirituality is linked to many aspects of the cancer survivors' psychological and physical adjustment.

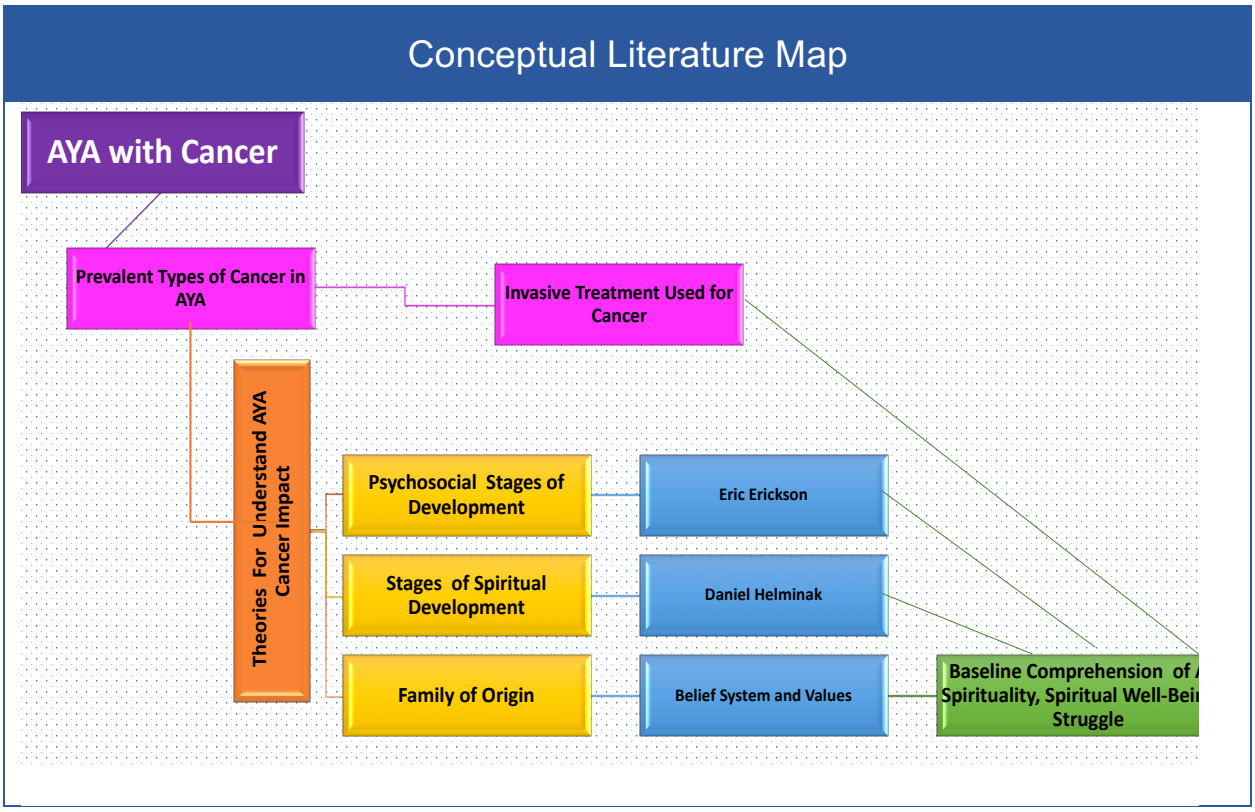
A Lack of Spirituality In AYA With Cancer

The research indicates that younger adults tend not to practice spirituality or religiousness as older adults do when encountered with cancer (Peterson & Potter, 1997; Salsman, Fitchett, Merluzzi, Sherman & Park, 2015). Park & Cho (2017) indicate that while spirituality is not important to all AYA survivors, both spiritual well-being and struggle have important associations with adjustments. The need for further research is instrumental for comprehending the role of adjustment in spirituality for AYA survivors, their coping strategies and heath related outcomes (McNeil, 2016; Park & Cho, 2017; Taylor, Petersen, Oyedele & Haase, 2015). Therefore, one may question why there is a limited amount of knowledge in this domain for the AYA survivor population (Park & Cho, 2017). Furthermore, one may question how the AYA's encounter with a life-threatening disease uses spirituality to lead towards a new meaning of the situation to better their outcome and to extend life.

A Review Of The Literature

As stated, spirituality in the AYA population has been met with complexity and a lack of clarity in terms of its definition, purpose and usage for extending life and improving outcomes with cancer. There is also a limited amount of research for understanding AYA encounters with spirituality. Therefore, an integrative thematic literature review is an important starting point in the development of any research design. This should allow for the generation of different categories and subcategories experienced in AYA with a cancer diagnosis. The integrative review is dived into four major themes below.

1. Common AYA cancer types and invasive treatments used;
2. AYA psychosocial stages of development;
3. Stages of spiritual development; and
4. Family of origin.



Common AYA Cancer Types and Invasive Treatments Used

The distribution of cancer types differs among AYA males and females. Young male statistics have been on the rise by 0.9 % per year and 1.7% per year for females. In the USA and Canada, young women are more likely to be diagnosed with cancer than young men, but young men and women are equally likely to die of cancer (American Cancer Society, 2015; Canadian Cancer Society, 2015). A few of the most common types of cancer in the AYA population include: blood cancers, brain tumors, breast, ovarian, cervical, testicular, melanoma and thyroid (Canadian Cancer Statistics, 2009) (see Appendix B). The listed examples of cancers in AYA have a tremendous impact on self-image and gender identity by creating body image issues and fertility problems which may elicit feelings of isolation. Other factors that seem to have an impact are the person's age, the location and extent of the cancer, and how well the cancer responds to treatment (Canadian Cancer Statistics, 2009) (see Appendix C).

The common types of treatments used for cancer are: surgery to remove tumors and body parts/organs, chemotherapy and radiation therapy (Canadian Cancer Society, 2015). These invasive treatments must require some psychological and physical adjustment as the body is no longer functioning in the same way but may appear to be the same. Moreover, these treatments are not without side effects and if no support is provided, it may lead towards a cycle of negative behavioral changes from the harsh and traumatic experience. There is a need to develop and incorporate creative ways for AYA to express their needs and cope positively with the cancer experience (Phillips &

Davis, 2015).

Cancer is usually detected late in the AYA because they tend to seek medical advice late and they do not have consistent medical care or advice where symptoms can be identified and therefore symptoms are often missed (Donovan, Knight & Quinn, 2015). End of life care for AYA patients also lacks standardization and this reveals a need to collaborate earlier with palliative care specialists to control symptoms and relieve suffering within this vulnerable population (Donovan, Knight & Quinn, 2015). Delayed diagnosis, frequently misdiagnosis, and lack of clinical trials lead to slower gains in overcoming the experience (Clark & Fasciano, 2015). AYA are not served well by the traditional dichotomy of the health care system: a model based on and primarily split between pediatric and older adult segments (Clark &Fasciano, 2015).

Psychosocial Stages of Development – Erik Erikson

The psychosocial stages of AYA can be studied from the perspective of Erik Erickson. In his perspective, psychosocial development occurs when crises arise. The term crises denotes a turning point that creates an increase of susceptibility and increased potential (Erickson, 1994). Crises revolve and involve establishing a sense of trust in others and developing a sense of identity in society (Erickson, 1994). Each psychosocial stage has both an effective and ineffective outcome that impacts how resolutions are formed later in life (Sokol, 2009). This can prove to be useful for understanding the developmental stages of 18-40 year olds prior to the cancer experience.

AYA are placed into Erikson's stages 5 and 6 of development (identity versus role confusion) (McAdams, 2008). The 18-year-old (or younger) is within the "identity versus role confusion stage", they are transitioning from childhood into adulthood (McAdams, 2008). There are many changes occurring both cognitively and physically. The AYA is seeking independence, creating ideologies, career planning and forming interpersonal relationships (Sokol, 2009). During the 'intimacy versus isolation' stage, young adults begin to share themselves more intimately with others and aim to form long-term interpersonal relationships (McAdams, 2008). Issues of AYA identity fall into three categories: body image, cognition and society. Therefore, it is important to note that uninterrupted completion of these stages should lead to comfortable relationships, a sense of commitment, healthy identity and care. Equally, interruption with life threatening or altering disease, like cancer, can lead to an unhealthy personality, poor relationships and a poor sense of self. Therefore, a strong sense of identity is a concern for AYA and is imperative for future life adjustments.

Stages of Spiritual Development – Daniel A. Helminiak

A separation view of spirituality has been taken in terms of it not being the same or equal to religion but understands and acknowledges that religious beliefs can incorporate spirituality and spiritual practices. Spirituality can be viewed as independent to religion or inherent in all individuals. According to Daniel Helminiak:

> "*Spirituality entails lived-out commitment to a set of meanings and values -- credo and commitments, vision and virtues, beliefs and ethics, cognitions and evaluations -- and traditionally, organized religions carry and foster these. Religion tells us what life is about and how we are to live it. This vision and its implementation in individual lives is spirituality; religion is the social vehicle that, at its best, proclaims and supports spirituality", (Helminiak, 2001, p. 164).*

The premise of Daniel A. Helminiak's work is that the stages of psychosocial development catalyze the stages of spiritual development. Helminiak (1987) takes the position that spiritual development is based on the growth of authentic self-transcendence that results from the individual taking responsibility for his or herself. It is important to note that spiritual development is viewed as a process of consciousness and self-awareness (Helminiak, 1987). The person is motivated by an ongoing personal commitment to openness, questioning, goodwill and honesty (Love, 2002). Spiritual development requires openness to the dynamism of the human spirit (Helminiak, 1987). The AYA would fall into three stages: conscientious, compassionate, and cosmic.

Helminiak Stages	
Conscientious	This is the first stage of true spiritual development. It is characterized by a sense of achievement felt due to structuring life according to a personal understanding of things. Optimistic and accepting of a new sense of self responsibility and committed to personal principles.
Compassionate	Learning to surrender some of the world that has been constructed for them. Ability to make realistic commitments that are internally supported through deep and complex emotions. Personality becomes gentler.
Cosmic	The final stage based on habitual patterns of perception, cognition and interrelations are becoming more authentic. The person becomes more open and willing to change and adjust to demands of circumstance or situations. In touch on a deeper level about self and a possible merging of spirit and self.
Source: Helminiak, 1987	

The following section will explore family of origin, which is instrumental in comprehending how beliefs, values and meaning make experiences that are first learned and encountered. Furthermore, the family of origin is where AYA may learn ways of coping with illness, life and death.

Family of Origin

The family system or origin is where an individual may first encounter religion or spirituality. According to Rolland (2005), “Illness, disability, and death are universal experiences within families” (p. 2584). The diagnosis of cancer has a ripple effect that reverberates throughout the family system, leaving no one untouched (Rolland, 2005). It is important to note that the experience of cancer deteriorates the quality of life for some families, whereas others are resilient and thrive (Rolland, 2005). One question that may arise is what may lead a family to select a particular direction over another (deteriorate versus strive).

Belief and Value system

A belief system is made up of cultural orientation and the individual and family experiences and that the levels of meaning is dictated by the correct belief system (Rolland, 1998). A person’s belief system during existential crises establishes meaning of the experience which is critical because it protects the person from disconnection of meaning and relationship (Rolland, 1998). The beliefs of the family as to what is normal, or abnormal, is key to understanding the implications of adapting to chronic disorders (Walsh, Scheinkman, Tolan & Cohler, 1993). Family values that allow for a problem without self-regulation is at a distinct advantage because they can maintain positive identity in the face of chronic conditions (Walsh et al., 1993).

It appears that the primary challenge for a family is to create meaning for the experience of illness that promotes a sense of competency and mastery (Rolland, 1998). Families who view seeking help as being weak and shameful undercut this kind of resilience and can add insult to the pre-existing injury (Walsh et al., 1993). Therefore, the human experience of the disease process seems to be influenced by their belief system. The belief system appears to have an internal influence on the disease process and an external process on how society can assist AYA in the healing process.

Discussion

The AYA’s are within a distinctive life stage that is meet with differences in how disease, illnesses and behaviors are experienced (Grinyer& Thomas, 2004). It would be expected that there is specialized expertise for the AYA population but this is not the case, and therefore, it creates a complexity of issues that contribute to the low survival rates in comparison to younger patients and older adults with cancer (Fernandez, & Barr, 2006; Donovan et al., 2015).

As mentioned, AYA’s are within a crucial stage of development and self-identity and the diagnosis of cancer changes their direction or halts puts life events until solutions are found. The literature points out that the demands of AYA cancer survivors and their treatments are often directly counter to the developmental needs of this age group and

often alter those life course experiences that contribute to resilience, thriving, and flourishing. The importance and implications of research in this area would help upcoming counsellors in spirituality and spiritual care in terms of ethical practice.

Future Developments

To ensure ethical practice it is important for new counselors in the area of marriage and family therapy, couple's and individual therapy to develop a level of competency within this understudied, unavoidable and increasing growing population. More training, course work and possibly supervised experiential learning, needs to be offered at the graduate level to ensure a base level comprehension of the pending issues and to be able to address the unique needs associated with this population.

Counselors and other healthcare professionals seem to lack ethical orientation for these cases because of their lack of competency within this area. Counselors, and other health care professionals, seem to lack the knowledge, skills and attitudes to integrate competent care in the area of spirituality for the AYA with cancer. Hence, the possible reason for a lack of research. The former is needed to effectively implement competent counseling services. Universities need to take a lead in educating their graduates through a new diploma programs based on spirituality, grief and palliative care. Such advances will ameliorate the level of care and the types of treatments plans utilized to help clients and their families to find meaning in their experiences and to better cope with death and dying.

Furthermore, the therapist may have undergone the experience of cancer, either directly or indirectly, and may develop psychological distress and a level of discomfort if they have not dealt with their own issues. This may impede their ability to provide ethical services being offered to AYA with cancer. The field of spirituality and counseling takes pride in its appearance as a multicultural profession but it would not truly attain its goal if the profession is not educated on the culture of life altering diseases like cancer.

Possible Phenomenological Research Design

In facing the lack of research towards AYA with cancer and the link with spirituality it is useful to put forward a possible research design that researchers may employ to address the issue and improve understanding and education. As mentioned, there appears to be limited research pertaining to AYA perspectives and practices in terms of spirituality throughout the trajectory of the disease. Thus, a potential research question may be as follows:

Continued…

Possible Phenomenological Research Design

Potential Research Question:

> "How do AYA with cancer define and use the principles and practices of spirituality to obtain better outcomes from initial diagnosis to the end of treatment?"

Purpose of the Research

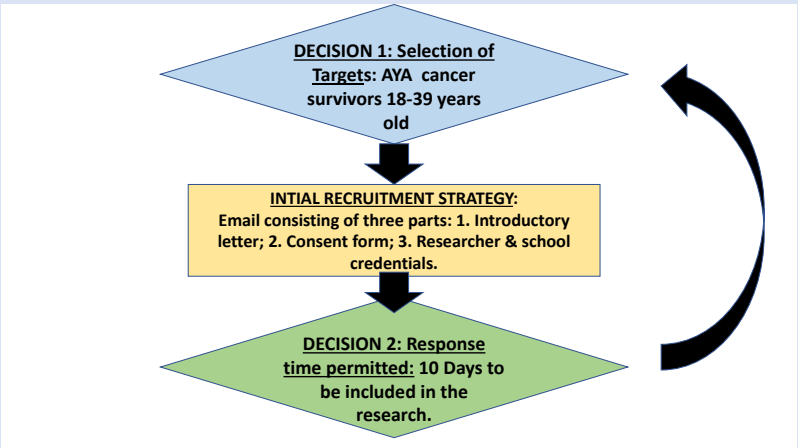
The purpose of the proposed research is to comprehend how AYA cancer survivors define and use spirituality to better their outcome and enhance life. On the provision of AYA with cancer, their unique psychosocial needs and the connectivity to spirituality in developing a better outcome and enhancing life while formulating to choose life and to keep fighting would be studied.

Research Methodology

A qualitative phenomenological research method is used to uncover meaning, and articulated essences of meaning in the AYA cancer survivor. Using the lens of AYA cancer survivors will also aide in breaking through the limited amount of research in this understudied area. Each participant is able to give a voice to the silence surrounding their experiences. Phenomenological methodology is considered most appropriate for capturing subtle meanings and personally held beliefs without imposing external thought complexes on the participants (Creswell & Creswell, 2018; Moustakas, 1994). Furthermore, phenomenology allows for exploratory linkages to be developed between the theoretical concepts and the data collected from direct experiences (Creswell & Creswell, 2018).

Research Design

The recruitment of the AYA survivors (18-39 years old) is based on introductory letters and emails to general and specialized care hospitals in a major metropolitan area.



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Possible Phenomenological Research Design

From: dr.york@umonarch-email.ch Sent: Mon 01/04/18 19:10

To: <xxxxx@xxxxxxxx.org> Priority: High

Subject: Assistance with Post-doctoral Research

Dear xxx xxxxx,

I have received your contact information from Executive Director xxxxxxxxx concerning my research. My topic of interest is "*the experience of adolescents and young adults survivors with cancer"*. I have selected your organization because it has an area of expertise and have facilitated my participants within the research subject. It would consist of an anonymous volunteer interview of approximately 30 minutes in duration (via telephone) to respond to approximately 15 questions pertaining to the trajectory of the cancer experience from diagnosis until end of treatment. Please let me know if this would be of interest to you and we could then proceed to discuss the next steps. I have attached an introductory package pertaining to the intended research. Thank you very much for your time.

Yours truly,

Prof. Dr. Oxford York
Monarch Business School Switzerland

For illustrative purposes the city of Ottawa, Canada is used identifying several large hospital centers: Montfort Hospital, The Ottawa Hospital and Ottawa Integrative Cancer Centre. The target sample is selected by way of purposive sampling. The aim is to conduct a minimum of twenty mixed gendered open-ended interviews with AYA cancer survivors within the Ottawa area.

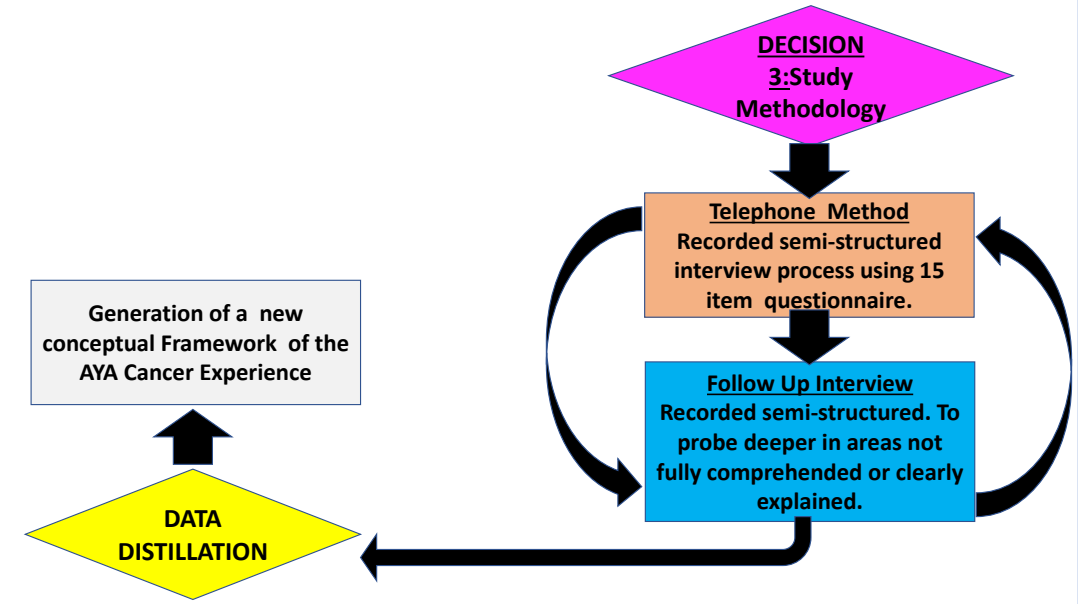
Data Collection

An original 15 item open-ended research questionnaire is based on the identified research gap discussed throughout findings and analysis of the literature issues and critique (see Appendix F). Telephone interviews are the primary method for collecting qualitative data for the research. The data is collected using a speakerphone, digital tape recorder with USB port and laptop computer. The data collection instruments are used to initiate direct entry of information while the interview is taking place.

Data Analysis

Additionally, by using this methodology, the attitudes of the participants towards the subject matter can be meticulously analyzed and theories can thus be extracted through the grounded theory approach. Using MAXQDA 2018, the audio file generated from the recorded interview may be transcribed into document format. This method also allows for the verification of the information being transcribed. The software creates code categorizations to be formed from the data and analysis to occur on its significance. Finally, the transcribed information is then sent back via email to the participants for verification and approval. Continued..

Possible Phenomenological Research Design



Validity and Reliability

Multiple strategies are used to test for validity and reliability of the research (Creswell & Creswell, 2018). In terms of qualitative validity of the findings, two approaches are used:

1. Member Checking: through follow-up interviews, the accuracy of the descriptions are determined and provide an opportunity to make comments;
2. External Auditor: is used to review the study in order to question and enhance the overall validity of the research.

Two approaches are be used to test for qualitative reliability:

1. All transcripts are checked by the researcher, participants (their own data) and the external auditor to eliminate any obvious mistakes made during transcription;
2. A qualitative code book is used to organize a list of predetermined codes that are used for coding the data. One column will be organized by names of codes with another column for definitions and where the code is found in the transcript.

Continued..

Young Adult and Adolescent Qualitative Cancer Interview Questionnaire

Part A- Participant Profile Questions:

Code name: (Ex. P1)
Age:
Gender:
Ethnicity:
Level of education:
Religious beliefs or philosophical upbringing:
Age at diagnosis :
Time frame taken to be diagnosed:
Cancer type:
Cancer site:
Type of primary treatment:
Time since diagnosis (year):
Time since primary treatment ended(year):

Part B- Experience:

1. Definitions:
    a. Spirituality:
    b. Spiritual:
    c. Spiritual well-being:
    d. Spiritual pain:
    e. Physical health:
    f. Emotional health:
    g. Mental health:
    h. Social health:
    i. Maintaining life balance:
    j. Stress management:
    k. Stressors:
    l. Coping tools:
    m. Relaxation methods:
2. Did you sense something was wrong or was changing inside your body? What did you tell yourself was happening as these changes occurred?
3. Describe your initial symptoms/feelings prior to your cancer diagnosis that caused you to seek professional help?
4. What did you perceive these symptoms/feelings to be?
5. How were your symptoms perceived by the health care workers?
6. How many health professionals were seen until you were sent for specific cancer testing?
7. Were you coached, mentored or provided with information to prepare you for the many possibilities about your feelings/ symptoms while you waited for test results to be returned for your possible outcome/diagnosis?
8. Describe the feelings experienced when you were told about your diagnosis? What happened next?

Continued..

Young Adult and Adolescent Qualitative Cancer Interview Questionnaire

9. Were you, and your family, given detailed information about your next steps and treatment options for the type of cancer?
10. How well were the next steps and treatment regime tolerated?
11. Did you have, or chose, to seek support from family, friends and/or partners to accompany you to appointments?
12. During treatment, please described the felt experience?
13. At the end of treatment, please describe the felt experience and your re-integration process?
14. What type of support services exist for your age group to help you through this experience and to re-integrate?
15. How has this experience shaped your outlook and current thinking about life?

From Coding to New Model and/or Actionable Framework Generation

The research can follow a qualitative coding process by systematically categorizing excerpts from the in-depth interview responses. This will allow for the creation of themes and the highlighting of various new patterns for analysis that will ultimately lead towards the creation of a unique model and/or actionable framework.

The research will abide by four essential phenomenological steps to code and distillation of the data involved:

1. Bracketing: This is the part of the process where preconceived opinons, usage and beliefs concerning AYA and spirituality are identified and then held in postponement;
2. Intuiting: Focus is then placed on attributing meaning of AYA spiritual definitions, beilefs, opinons, and meanings through the preceeeded research. This section will only be completed when a common meaning of the data variance is truly met;
3. Analyzing: This step willl require taking all of the coding and categorizing then making sense of the significant meaning of spirituality in this target population. This is also where the emergence of universal themes and true essence of the data results will appear; and
4. Describing:This is final and crucial step in the comprehension of spiriruality and its use towards better outcomes of AYA with the experience of cancer. What will begin to surface is a given shape to a model and/or actionable framework. In other words, this is where the comprehension and definition for where critical decriptions are listed in both written form and illustrated graphicaly for practitioner application.

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Young Adult and Adolescent Qualitative Cancer Interview Questionnaire

An important point to highlight is that once the understanding behind the data is clear it may be contrasted with the generally accepted or dominant models in the literature in order to point-out any difference of understanding or incongruities in insight. This is refered to as the Praxis Gap : the delta between the academic models and the practice in the field.

Three resulting avenues will present themselves for the researchers at this point between lying between congruity and incongruity of the data to the existing models.

1. Congruity : where there is congruity with the academic models no further modification of the existing models is required;
2. Similarity : where there is similarity with existing models yet partial incongruity the existing academic models may be modified to better reflect praxis, new aspects are added or removed from the existing models;
3. Incongruity : in some cases praxis may be very different from the acadmic models for a number of reasons, ie : missing aspects such as gender, or simply the passage of time which has rendered existing models obsolete. In this case an entirely new model may need to be fashioned to better illustrate the underlying dynamics found in the field.

In the case of point #2 and #3 above the reserchers should revise the academic models by authoring their research for the benefit of the academic and professional communities.

Note To The Reader

The interested reader is encouraged to further explore the methodological aspects of the above in a companion article presented in this issue and co-authored by Prof. Miray Barsoum and Dr. Henderson. The article elaborates the philosophical underpinnings and methodology of qualitative research used at Monarch Business School. It is entitled: “The Monarch Standard Research Method: Perfecting Business Research From Methodology to Praxis.”

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