QUALITY OF LIFE IN PATIENTS WITH METASTATIC BREAST CANCER: A SOUTH AFRICAN PERSPECTIVE

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One of the wonderful characteristics of human existence is that we do not exist in isolation, but are all very dependent on one another. There is therefore no such thing as achievement that has been attained independently by one person. We inspire each other, learn from each other and support each other. It is often by means of the teamwork of ordinary people, that meaningful and valuable projects are conceived and executed.

There are a few wonderful people whom I would like to thank for their support and contribution to this study: Firstly my parents Robbie and Bella, who instilled in their children a culture of learning and a love of knowledge. Who supported us in our studies even when they didn't know how on earth it would be financed. Then the three PBs in my life: My husband Paul-Bolko who encouraged me every step of the way. My two statisticians Dr. Peter Braun and Dr. Piet Bekker without whose valuable input and seemingly endless hours of hard work this thesis certainly could not have seen the light. I would like to thank my promoter professor Carla Falkson.

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Our patients for the wonderful strength, dignity and courage that they bring to the fight with the cancer demon. I often wish that we could eradicate this dreadful adversary and take away all the suffering of our patients, but mostly in the metastatic setting, we can't. We can however improve the quality of our patients' lives very significantly and in this way lighten their burden and ease their way.

I do think that a revolution in the treatment of cancer will take place in the next ten to twenty years, given the great strides that are being made in our understanding of the molecular and genetic basis of the disease. But the psychosocial input that can be made

just by caring and taking time for another human being will always remain the foundation upon which our entire endeavor in this field will be built.

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INTRODUCTION

The advances made in medical science this century have completely transformed the practice of medicine. At the beginning of the century there were few efficacious treatments available and the primary role of doctors was to provide comfort. Nowadays the availability of sophisticated diagnostic procedures, therapies, drugs and surgical techniques have revolutionized the management of hitherto fatal conditions. Specialists today display a highly scientific and technical role. Unfortunately, the impressive list of advancements in the *science* of medicine has lead to a decline in the *art* of medicine. Patients complain increasingly that "high-tech" medicine dehumanizes them. There are actually states of life that are worse than death and few people accept the "life-at-any-cost" philosophy assumed by many doctors. We must consider both the quality as well as the quantity of life for any individual who requires medical treatment (Fallowfield 1990).

There has been a rapid increase in the interest of clinicians in the study of quality of life. Index Medicus citations about quality of life have increased as follows in the last few years:

- 20 in 1976
- 65 in 1984
- 1974 in 1996
- 2170 in 1997
- 1328 in 1998

Health-related quality of life has been defined as a concept for more than three decades. Despite the relative longevity of the quality of life concept, it's utility is often unclear. Quality of life data can be usefully employed in a multitude of ways:

- To improve clinical practice.
- As an integral tool for clinical trials.
- To help formulate health policy.

Unfortunately "Quality of Life" is not well conceptualized in the medical and health literature. Additionally clinical researchers are searching for a single best measure of quality of life and created a confusing multitude of measuring tools, most of which require sophisticated statistical analyses.

When one investigates the South African situation, the position becomes even more precarious. Up to date, no general studies have been published to reflect the quality of life of South African cancer patients. There are unique factors influencing the quality of life of this patient group:

- Huge cultural differences between black and white patients as well as between the different black racial groups (Pedi, Tswana and Zulu to name just the main groups). There is also a chasm in the way in which these different groups view the impact of diseases such as cancer on their lives.
- The political and social situation in the post-apartheid era.
- The dire financial position in which the health services find themselves currently. This is leading to the type of situation where decisions have to be made in a scientific way about whether to embark on costly medical interventions or not.

Breast cancer is the second most prevalent cancer among South African females and because advances in treatment have improved survival, it uses a sizeable part of the available health budget for cancer patients. It was therefore decided to investigate the quality of life of South African patients with breast cancer and to try and establish the utility of this measurement tool within the South African health service context. If some of these findings can be applied to more universal quality of life issues, then this discipline can also benefit from this current endeavor.

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SUMMARY

The purpose of my study was to establish norms and general trends of quality of life issues as they relate to South African breast cancer patients. The effect of race on quality of life was also of special interest.

An Afrikaans translation of the FACT-B was developed and found to be reliable. The previously translated versions of the FACT-B into the South African ethnic languages were re-assessed for reliability. Low reliability for the social/family well being scale was found.

The advantages of the Zulu, Pedi and Tswana translations were that the quality of life of these patients could be assessed in their own language for the first time. An added advantage was that the QOL of illiterate black patients could be assessed by means of the interview method, in their own language. We learnt a lot about the cultural differences between the black and white South African patients.

The interim analysis showed prominent differences in the quality of life of black and white patients. The multivariate analysis however, corrected for the factors that influenced the quality of life of the patients. These factors were baseline quality of life scores, performance status, race, disease stage, treatment time, marital status and educational status. The factors that were found to be significant predictors of the change of quality of life over time, were performance status, disease stage and total FACT-B score. Marital status, educational status and race showed a tendency towards significance.

Analysis of the patient demographics yielded interesting and useful information. The management of breast cancer in the black population needs to be improved. Concerted efforts should be made to educate the black population about breast cancer and about the benefits of early intervention.

A bimodal distribution for the age-related incidence of breast cancer in the black population was found for our patients in this area. This is unusual, because it is not found in other parts of South Africa. The reasons for this finding are unclear at the moment.

A previous analysis of the first two hundred patients showed that twelve percent of these patients had complained of pain at their first visit, but that no pain medication had been prescribed. During the course of the study, it became clear that specific problems or needs of patients were in fact identified by means of the quality of life questionnaire. An intervention program was then started.

A better understanding of the cancer patient and the impact of quality of life and related issues has been established. Quality of life norms for South African breast cancer patients have been established. Race-related issues have been explored and clarified.

The problems facing patients diagnosed with cancer are huge and very real. It is therefore imperative that we develop meaningful solutions to these problems and keep striving to improve patient care.

OPSOMMING

Lewenskwaliteit is 'n komplekse en veelkantige konstruk. Faktore so uiteenlopend as ouderdom en huweliksstatus kan dit beïnvloed. Ander faktore is die impak van slegte gesondheid, die kankersoort, die tipe behandeling, tyd sedert diagnose en stadium van die siekte. Die geskooldheid van pasiënte, of daar iemand met hulle saamwoon, geslag, verlies van rol, sosiale en familie verhoudings, vehoudings met mediese personeel en emosionele en geestelike faktore kan ook 'n rol speel. Die diagnose van 'n lewensbedreigende siekte as sulks, het sonder twyfel 'n geweldige impak op die lewenskwaliteit van 'n pasiënt. Swak gesondheid *per se* is 'n deursslaggewende faktor in die lewenskwaliteit van enige mens.

Die oomblik wanneer 'n pasiënt met kanker gediagnoseer word, verander haar lewe onherroeplik en moet sy die lang proses van aanpassing tot haar veranderde omstandighede aanpak. Sy moet woede, ontkenning en smart ervaar en uiteindelik die siekte en die impak daarvan op haar lewe aanvaar.Tydens hierdie proses moet sy vaardighede aanleer sodat sy haar fisiese swakheid en die onaangename aspekte van haar kanker en die behandeling daarvan kan baasraak.

Langs hierdie weg is daar 'n menigte terugslae wat sy mag ervaar. Sy moet die probleme wat in haar verhoudings met haar lewensmaat, haar familie en vriende kan ontwikkel, probeer oplos. Sy kan tydelike of permanente emosionele gebreke ervaar.

Vanuit die literatuurstudie het dit duidelik geword dat 'n verwarrende versameling van lewenskwaliteit instrumente tans beskikbaar is vir navorsing in hierdie veld. Dit is belangrik om tydens die beplanning van 'n studie oor die impak van bepaalde faktore op lewenskwaliteit, 'n instrument of instrumente te kies wat by die kankersoort onder bestudering pas. Enige studie-spesifieke aangeleenthed moet ook aangespreek word. Die instrument of instrumente moet psigometries aanvaarbaar wees, asook multidimensioneel. Twee voorbeelde van lewenskwaliteit instrumente wat geldig, betroubaar en multidimensioneel is, is die "Factual Assessment of Cancer Therapy" (FACT) skaal en die skaal wat deur die "European Organization for Research and Treatment of Cancer" (EORTC QLQ-C30) onwikkel is. Daar bestaan baie publikasies wat oor studies wat hierdie skale gebruik het, verslag lewer. Hierdie skale is gekonstrueer deur middel van die gebruik van 'n modulêre benadering. Dit beteken dat

die kern vraeboog vir die meet van lewenskwaliteit wat met enige soort kanker gepaardgaan, geskik is. Kanker spesifieke modules kan aangelas word, vir meer siekte-gerigte doeleindes.

Omdat die meeste behandelings teen kanker 'n geweldige impak op lewenskwaliteit veroorsaak, het die bestudering van lewenskwaliteit 'n belangrike studierigting geword. Dit is 'n onomwonde feit dat geen fase III studie sonder die insluiting van 'n lewenskwaliteit module aangepak behoort te word nie. Die waarde van die bestudering van lewenskwaliteit tydens fase II studies is ook al goed gedokumenteer.

Ongelukkig is die probleme wat met die bestudering van lewenskwaliteit gepaard gaan 'n werklikheid. Die insluiting van die assessering van lewenskwaliteit vergroot die werkslading van die kliniek personeel. As lewenskwaliteit assessering gedoen gaan word, moet dit op 'n gekontroleerde manier gedoen word. Al die korrekte tegnieke om te verseker dat data van 'n hoogstaande gehalte versamel word, moet toegepas word. Die pasiënte se samewerking is ook nodig, omdat verlore data 'n kritieke uitvloeisel in hierdie navorsingsveld geword het. Die statistiese analises kan ook duur en tydrowend word. Vereenvoudiging in hierdie veld sal die bestudering van lewenskwaliteit meer aantreklik vir navorsers maak.

Die nuttigheid van die bestudering van lewenskwaliteit kan as volg opgesom word:

- As 'n addisionele parameter in kliniese proewe, waar die lewenskwaliteit data dikwels die vernaamste faktor in die uitkoms van die navorsing kan wees.
- Die resultate van lewenskwaliteit studies kan 'n direkte impak hê op die hantering en behandeling van kankerpasiënte wat sjirurgie en/of radioterapie en/of chemoterapie ontvang.
- As 'n prognostiese faktor kan lewenskwaliteit data as 'n voorspelling van oorlewing gebruik word.
- Om standaarde van sorg en pasiënt funksionering te verbeter.
- As 'n hulpmiddel in die diagnose van emosionele en ander probleme.
- Om ingeligte besluite betreffende die risiko-voordeel ruiltransaksies ("risk-benefit trade-offs") te maak en as 'n hulpmiddel in kliniese besluitneming.
- As 'n hulpmiddel by die formulering van gesondheidsbeleid.

Psigososiale evaluasie word as een van die basislyn ondersoeke in 'n standaard onkologie teksboek beskryf, reg tussen die volbloedtelling, borskas x-straal en die beenskandering. Dit bly die ideaal waarna ons moet strewe en sal effektiewelik 'n baie betekenisvolle bydrae tot optimale pasiëntsorg maak.

Die doel van my studie was om norme en algemene neigings vir lewenskwaliteit aangeleenthede, soos wat dit van toepassing op Suid Afrikaanse borskanker pasiënte is, daar te stel. Die effek van ras op lewenskaliteit was ook van spesiale belang.

'n Afrikaanse vertaling van die FACT-B is ontwikkel en betroubaar bewys. Beskikbare vertalings van die FACT-B in die Suid Afrikaanse etniese tale is ge-hervalideer deur middel van Chronbach se aplha. Probleme met die betroubaarheid van die sosiale/familie welstand skaal was tot 'n groter mate gevind as wat Mullin (1999) bevind het. Redes vir die onvoldoende betroubaarheid en moontlike oplossings om betroubaarheid to verbeter, word verskaf. Hierdie area is definitief 'n veld vir verdere navorsing.

Die voordeel van die Zulu, Pedi en Tswana vertalings was dat die lewenskwaliteit van hierdie pasiënte vir die eerste maal in hulle eie taal bepaal kon word. 'n Bykomende voordeel was dat die lewenskwaliteit van ongeletterde pasiënte in hulle eie taal bepaal kon word, deur middel van 'n onderhoud. Ons het baie geleer betreffende die kultuurverskille tussen swart en blanke Suid Afrikaanse pasiënte.

Die interim analise het prominenete verskille in die lewenskwaliteit van swart en blanke pasiënte aangetoon. Die meerverandelike analise ewenwel, het vir die faktore wat die lewenskwaliteit van pasiënte beïnvloed, gekorrigeer. Hierdie faktore was die basislyn lewenskwaliteit telling, werkverrigtings status ("performance status"), ras, stadium van siekte, behandelingstyd, huweliksstatus en opvoekundige peil. Die faktore wat as betekenisvolle voorspellers van die verandering in lewenskwaliteit oor tyd gevind is, was werkverrigtings status, stadium van siekte en die totale FACT-B punt. Huweliksstatus, opvoedkundige peil en ras het 'n neiging tot betekenisvolheid getoon.

Analise van die pasiënt demografiese gegewens het interessante en nuttige informasie getoon. Die hantering van borskanker onder die swart bevolking moet verbeter word. Gesamentlike optrede om die swart bevolking oor borskanker en die voordele van vroeë ingryping in te lig, moet gemaak word. Die waarskynlikheid dat swart pasiënte adjuvante chemoterapie sal ontvang is baie klein, meestal omrede hulle geografiese onbereikbaarheid. In my studie was daar nie een enkele swart pasiënt wat adjuvante chemoterapie gehad het nie.

'n Bimodale distribisie vir die ouderdoms-verwante insidensie van borskanker is vir ons pasiënte in die swart populasie gevind. Dit is ongewoon, omdat dit nie in die ander dele van Suid Afrika die geval is nie. Die redes vir hierdie bevinding is tans onbekend.

'n Vorige analise van die eerste tweehonderd pasiënte het aangetoon dat twaalf persent van hierdie pasiënte tydens hulle eerste besoek oor pyn gekla het sonder dat daar vir hulle enige pynmedikasie voorgeskryf is. Gedurende die verloop van die studie het dit duidelik geword dat spesifieke probleme of behoeftes van die pasiënte deur middel van die lewenskwaliteit vraeboog geïdentifiseer word. 'n Intervensie program is gevolglik begin. Sommige van die belangrikste intervensies was: die verskaffing van addisionele informasie, identifikasie en fasilitasie van die behandeling van depressie en slapeloosheid, raadgewing oor medisynegebruik, ongeskikheidspensioene, behandelings newe effekte en praktiese aspekte soos pruike en prosteses.

'n Beter begrip vir die kankerpasiënt en die impak van lewenskwaliteit en verwante uitkomste is daar gestel. Norme vir lewenskwaliteit vir Suid Afrikaanse borskanker pasiënte is bepaal. Ras-verwante aangeleenthede is verken en verklaar.

Ek het probeer om vir ander navorsers in die veld 'n omvattende oorsig oor die huidige lewenskwaliteit instrumente te gee. Sommige van hierdie instrumente is as addenda aan hoofstukke twee en vier aangeheg. Duidelikheidshalwe is die lewenskwaliteit instrumente in tabel nege van hoofstuk twee opgesom. Hierdie tabel lys die lewenskwaliteit instrumente en die spesifieke weergawe daarvan, watter domeine die instrument aanspreek, en die voordele en nadele van die instrument. Ek het probeer om my taalgebuik eenvoudig te hou sodat die tesis tot die breë publiek kan spreek. Ek het lyste met nuttige inligting spesifiek vir gebruik deur pasiënte ingesluit as addenda.

Alle huidige lewenskwaliteit instrumente het sekere tekortkomings. Bestaande instrumente is tans nog maar growwe benaderings van wat dit behoort te wees. Ons is beslis nog vêr weg van die verfynde meting van al die faktore wat 'n impak op die lewenskwaliteit van ons pasiënte kan hê. Bestaande lewenskwaliteit instrumente spreek geensins die meting van subtiele persoonlikheids- en houdings-verskille van pasiënte aan nie. Laasgenoemde is dalk nog belangriker as al die huidiglik bekende faktore. Maar elke bydrae in hierdie veld bring ons uiteindelik 'n klein stappie nader aan die ideaal. Die probleme wat kanker pasiënte ondervind is enorm en baie werklik. Daarom is dit noodsaaklik dat ons sinvolle oplossings vir hierdie probleme ontwikkel en aanhou om daarna te streef om pasiëntsorg te verbeter.