Faculty of Medicine and Health Sciences

Breast cancer and breast cancer screening in Niger, an epidemiological and public health prospect.

Borstkanker en borstkankerscreening in Niger, een epidemiologisch en volksgezondheidsperspectief.

Thesis submitted for the degree of Doctor of Medical Sciences at the University of Antwerp to be defended by

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Borstkanker (BK) is een wereldwijd probleem voor de volksgezondheid. Het vormt de belangrijkste morbiditeit en mortaliteit van kanker binnen de vrouwelijke bevolking met opmerkelijke geografische variaties. Borstkanker bij vrouwen heeft longkanker overtroffen als de meest gediagnosticeerde kanker, met naar schatting 2,3 miljoen nieuwe gevallen (Bray et al., 2021,'Global Cancer Statistics 2020/WHO, F Bray et al., 2018, Bray et al.; 2018). Er is gedocumenteerd dat BK-prevalentie en -mortaliteit toenemen in landen ten zuiden van de Sahara (Youlden DR et al.; 2012; Samuel NC et al.; 2017; Adeloye D et al.; 2018). Epidemiologische BK-literatuur is over het algemeen niet uitgebreid in Afrika bezuiden de Sahara en in het bijzonder in Niger. Veel studies wezen op de noodzaak voor Afrika, met name Afrika bezuiden de Sahara, om zijn plannen voor kankerbestrijding en preventiemaatregelen aan te passen aan zijn eigen realiteit, vooral wanneer men wordt geconfronteerd met algemene schaarste aan onderzoeksgegevens en wetenschappelijke evidentie (Black E en Richmond R 2019, Onyije et al.; 2010 Ifediora, 2019.). Er is daarom ruimte voor het heroverwegen van preventieve campagnes rond borstkanker in ontwikkelingslanden.

De Republiek Niger is een arm land van de Sahel in West-Afrika; het dankt zijn naam aan de rivier de Niger. Het land is het grootste in West-Afrika en beslaat een oppervlakte van 1.267.000 km2 en heeft ongeveer 24 miljoen inwoners (laatste volkstelling van 2012, decret nr. 2011-059/PCSRD/ME/F, 27 januari 2011). In Niger worden volgens de Wereldgezondheidsorganisatie (WHO) jaarlijks ongeveer 1.585 gevallen van borstkanker geschat. Deze schattingen zullen tegen 2040 naar verwachting 3.682 jaarlijkse gevallen bereiken (WHO, Niger Cancer country profile 2020). BK wordt ook geïdentificeerd als de eerste oorzaak van kankergerelateerde mortaliteit en is goed voor zevenentwintig procent (27,7%) van de totale kankersterfte binnen de vrouwelijke bevolking (WHO; Cancer Country Profiles 2014; Globocan; 2012, H.M. Zaki et al.; 2013, S. Mamoudou et al.; 2013). Het gemiddelde aantal kinderen per vrouw in het land is een van de hoogste ter wereld, met het huidige gemiddelde van 7,6 kinderen (UNICEF). De kennis over borstkanker bij vrouwen is over het algemeen niet hoog in Afrika bezuiden de Sahara en niet erg goed gedocumenteerd in Niger (Jennifer N. al.; 2017). Een lage leeftijd (gemiddeld 44 jaar) en late diagnose werden geïdentificeerd als enkele van de belangrijkste kenmerken van borstkankerpatiënten in Niger. Bijgewerkte onderzoekscijfers en referenties met betrekking tot BK in Niger blijven schaars. Het land heeft geen operationeel kankerbeleid/strategie/actieplan maar heeft sinds 1992 een kankerregistratie.

De grondgedachte van dit proefschrift was daarom om een leemte in de wetenschappelijke literatuur over borstkanker in de Republiek Niger te vullen. Na een literatuuronderzoek met behulp van het PRISMA-model (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) merkten we zelfs dat de literatuur over de epidemiologie en het onderzoek betreffende de volksgezondheid i.v.m. borstkanker over het algemeen zeer beperkt is. We hebben een eerste stap hierrond trachten te zetten door de validatie van de ‘Breast Cancer Awareness Measure’ (BCAM), specifiek voor Niger. De BCAM bleek een acceptabel, betrouwbaar en valide hulpmiddel wanneer het werd toegepast op vrouwen en verloskundigen in Niger. Desalniettemin vereist het enige verfijning om beter te passen bij een aantal sociale en contextuele

factoren. We publiceerden over Kennis, attitude en gedrag van vrouwen gerelateerd aan borstkanker in Niger. We hebben gedocumenteerd dat in Niger de kennis van vrouwen over borstkanker over het algemeen laag is. Als ze al enige kennis hadden van de symptomen en waarschuwingssignalen van borstkanker, blijft de kennis van vrouwen over het risico op borstkanker en beschermende factoren slecht. Vrouwen uit Niger rapporteerden dat ze klinisch borstonderzoek doen bij een huisarts, voornamelijk een vrouwelijke. Verder analyseerden we 27 jaar kankerregistratie in Niger van 1992 tot 2018. Het bleek dat BK de meest voorkomende kanker is die is geregistreerd in Niger, gevolgd door gynaecologische kankers (baarmoederhals- en eierstokkanker), gevolgd door lever-, huid- en colon-/rectumkanker . Ondanks een trage start, vertoonde de registratie van kankergevallen in Niger een significante toename. Dit is in lijn met andere onderzoeken die een stijgende trend voor BK in sub-Sahara Afrika hebben vastgesteld (Azubuike, Samuel O et al.; 2018, Brinton L A et al. al.; 2014, Sighoko D et al.; 2013, F. Bray et al.; 2018). De overleving voor BK bleek laag te zijn, net als in andere sub-Sahara Afrikaanse landen (McCormack V al.; 2013; Joko-F, W Y et al.; 2020). Follow-up van sterftegevallen blijft een bekende uitdaging in het land.

In Niger moeten inspanningen worden geleverd om de studies over de haalbaarheid en aanvaardbaarheid van alternatieve screeningsmethoden die zijn aangepast aan landen met weinig middelen, uit te breiden. We raden de ondersteuning aan van multicentrische kankerscreeningcentra en een systematische rapportage via een nationaal kankerregister voor een bredere dekking. Er zijn meer mensen en apparatuur nodig om monsters die naar het laboratorium worden gebracht snel te analyseren. Bij het uitvoeren van borstkankerscreening in Niger lijken vrouwelijke artsen/verloskundigen meer geschikt dan mannelijke artsen. Borstkankermodules zouden kunnen worden opgenomen in het opleidingscurriculum voor verloskundigen en artsen. Het opstarten van radiotherapie in combinatie met chemotherapie bij het National Center for the Fight Against Cancer moet worden versterkt, omdat het kan bijdragen aan een betere overleving van kanker. Het land heeft nu een gevalideerd BCAM-instrument dat kan worden gebruikt om de kennis, attitude en gedrag van vrouwen met betrekking tot BK te meten. Bewustmakingsprogramma’s moeten gericht zijn op oudere vrouwen met de nadruk op de verspreiding van risico- en beschermende factoren.

Dit onderzoek leverde informatie op die hopelijk gebruikt zal worden door beleidsmakers, clinici, patiënten (en hun familie, vrienden) en de ruime bevolking. Er werden suggesties gedaan voor het ontwikkelen van effectieve programma's om BK in Niger te bestrijden.

Breast cancer (BC) is a worldwide public health concern. It is the leading cancer morbidity and mortality within female population with outstanding geographical variations. Female breast cancer has surpassed lung cancer as the most diagnosed cancer, with an estimated 2.3 million new cases (Bray et al., 2021,'Global Cancer Statistics 2020/WHO, F Bray et al., 2018, Bray et al.; 2018). It has been documented that BC prevalence and mortality are increasing in sub-Saharan African countries (Youlden DR et al.; 2012; Samuel NC et al.; 2017; Adeloye D et al.; 2018). Epidemiological BC literature is not extensive in general in sub-Saharan Africa and in particular in Niger. Many studies pointed out the need for Africa especially sub-Saharan Africa to adapt its cancer control plans and prevention measures to its own reality, especially when facing general scarcity of research and evidence data (Black E and Richmond R 2019, Onyije et al.; 2010 Ifediora, 2019.). There is general space for rethinking breast cancer preventive campaigns in developing countries.

Niger Republic is a poor country of Sahel west Africa; it took its name from The Niger river. The country is the largest one in west Africa covering a land of 1.267.000 km^2 and about 24 million population (latest 2012 population Census, décret N° 2011-059/PCSRD/ME/F, 27 January 2011). In Niger, according to the World Health Organization (WHO), some 1.585 BC cases are estimated yearly. These estimates are forecasted to reach 3.682 yearly cases by 2040 (WHO, Niger Cancer country profile 2020). BC is also identified as the first cause of cancer related mortality standing for twenty-seven percent (27.7%) of the overall cancer mortality within the female population, (WHO; Cancer Country Profiles 2014; Globocan; 2012, H. M. Zaki et al.; 2013, S Mamoudou et al.; 2013). The average ratio of children per women in the country is one of the highest of the world with the current average standing at 7.6 children (UNICEF). Knowledge of breast cancer among women is not generally high in sub–Saharan Africa and not very well documented in Niger (Jennifer N. al.; 2017). younger age (patient of average age 44) and late diagnosis were identified as some of the main features of breast cancer patients in Niger. Updated research figures and references in relation to BC in Niger remain scanty the country does not have an operational cancer policy/strategy/action plan but has established a cancer registry since 1992.

The rationale of this thesis was therefore to address a research hole in the breast cancer scientific literature in Niger Republic. In fact, following a literature review using The PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) model, we noticed that overall, literature on the epidemiology and public health scrutiny of breast cancer is very limited. We established the first milestone of the validation of Breast cancer awareness Measure (BCAM) in the country, the BCAM was an acceptable, reliable and valid tool when applied to women and midwives in Niger. Nevertheless, it requires some refining to better suit some social and contextual factors. We published on Knowledge, attitude and practice of women related to breast cancer in Niger. We documented that in Niger, overall, women's knowledge of breast cancer is low. If they had some knowledge of breast cancer symptoms and warning signs, Women's knowledge of breast cancer risk and protective factors remains poor. Niger women have reported practicing clinical breast examination with a general practitioner, mainly female one. Furthermore, we analysed 27 years of cancer

registry in Niger from 1992 to 2018. It came out that BC is the most common cancer recorded in Niger, followed by gynecological cancers with cervical and ovarian, then followed by liver, skin and colon/rectum cancer. Despite a slow start-up, cancer cases registration in Niger showed a significant increase, This is in line with other researches that established an increasing trend for BC in sub-Saharan Africa (Azubuike, Samuel O et al.; 2018, Brinton L A et al.; 2014, Sighoko D et al.; 2013, F. Bray et al.; 2018). BC survival was found to be low as in other sub-Saharan African countries (McCormack V al.; (2013) Joko-F, W Y et al.; (2020). Follow up of mortality cases remains a recognized challenge in the country, .

In Niger, efforts should be made to extend studies on the feasibility and acceptability of alternative screening methods adapted to low-resource countries. We recommend the support of multicentric cancer screening centers and systematic reporting to a national cancer registry for a wider coverage. More human resources and equipment are needed to promptly analyze samples brought to the laboratory. When conducting breast cancer screening in Niger, female doctors/midwives would be more suitable than male doctors. Breast cancer modules could be inserted into the training curriculum for midwives and medical doctors. The startup of radiotherapy combined with chemotherapy at the National Center for the Fight Against Cancer should be strengthened as it could contribute to better cancer survival. The country now has a valid BCAM tool that can be used to measure women's knowledge, attitudes and practice in relation to BC. Awareness program should target older women with focus on dissemination of risk and protective factors.

This research provided information that will hopefully be used by policy makers, clinicians, patients (family, friends) and public. Suggestions were made on how to develop effective programs to fight BC in Niger.

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List of abbreviations

APC: Annual Percentage Change
BC: Breast Cancer
BCAM: Breast Cancer Awareness Measure
BCAS: Breast Cancer Awareness Scale
CI: Confidence Interval (95% by default)
CA: Cronbach alpha
DEP: ‘’Direction des Etudes et de la planification‘’
DER: ‘’Direction des Etudes et Recherches‘’
DF: Degree of Freedom
GEE : Generalized Estimating Equations
GLM : Generalized Linear Model
HDI: Human Development Index
HR: Hazard Ratio
IARC : International Agency for Research on Cancer
IACR: International Association of Cancer Registries
ICD-O: International Classification of Disease -Oncology
KAP : Knowledge, Attitudes and Practice
LIC : Low Income Country
MOH: Ministry of health
NA nor DA: Neither Agree nor Disagree
OLR: Ordinary Logistic Regression
OR: Odds Ration
PRISMA : Preferred Reporting Items for Systematic Reviews and Meta-Analyses
REM-Africa : Références Etudes de Marchés en Afrique
SG: ‘’Secrétariat Général‘’
SPSS: Statistical Package for Social Sciences
WAHO: West African Health Organization
WHO : Word Health Organization

Chapter one

General introduction

Breast cancer (BC) is a worldwide public health concern. It is the leading cancer morbidity and mortality within female population with extensive geographical variations. In a recent study by Bray et al., 2021, titled' 'Global Cancer Statistics 2020: GLOBOCAN Estimates of Incidence and Mortality Worldwide for 36 Cancers in 185 Countries'', it was stated that ''Female breast cancer has surpassed lung cancer as the most commonly diagnosed cancer, with an estimated 2.3 million new cases (11.7%). Trends differ from Sub-Saharan Africa to rest of the world. According to the World Health Organization, (WHO) fact sheets (Bray et al., 2018, Globocan 2018), North American, European and high-income Asian/Oceanian countries have the highest BC figures. The figures confirm higher incidence in the more-developed regions of the world. In the African region, Northern Africa has the higher estimates while lowest figures were observed in the middle Africa. It should be noted that estimates are rising in Western Africa (to whom Niger belongs) with 37.3 incidence and 17.8 mortality (F. Bray et al.; 2018). It has been documented that BC prevalence and mortality are increasing in sub-Saharan African countries (Youlden DR et al.; 2012; Samuel NC et al.; 2017). Adeloye D et al.; 2018 reported that the overall pooled African crude incidence of BC from population-based registries was 24.5 per 100, 000. Some neighboring countries of Niger specifically in west (Nigeria, Burkina) and north Africa (Algeria, Tunisia) have archived BC burden, nevertheless epidemiological BC literature is not extensive in Niger itself. Burkina Faso has 12.3 and 9.1 age standardized incidence and mortality rates while Algeria has 22.3 and 11.4. In Nigeria, according to the latest WHO data, Breast Cancer Deaths reached 14.9 with an age adjusted Death Rate of 30.08 per 100,000 of population. Nigeria has by far the best documented BC data as compared to other Niger neighboring countries (Samuel O et al. 2018, Pelumi E al. 2017, Ojewusi, A et al. 2016, Azubuike, Onyije et al., 2010, Okobia MN et al.; 2006, Anyanwu SN; 2000; Adebamowo CA and Ajayi OO. 2000, Nigeria National Cancer Control Plan, NCCP, 2018-2022).

Many studies pointed out the need for Africa especially sub-Saharan Africa to adapt its cancer control plans and prevention measures to its own reality, especially when facing general scarcity of research and evidence data in many African countries. For instance, mammography while established as an efficient early detection tool against breast cancer may not necessarily be the way forward in sub-Saharan African due to lack of financial and human resources and infrastructure (Black E and Richmond R 2019, Onyije et al.; 2010). There is general space for rethinking breast cancer preventive campaigns in developing countries as noted by Ifediora, 2019.A comprehensive study published by the American Institute for Cancer Research found that the most convincing preventive and protective measure against breast cancer is breast-feeding. Research from Mexico is consistent with this finding (World Cancer Research Fund, AICR, 2007; López L, et al., 1997). Felicia K et al; 2009 pointed out that recent research reviews, including the World Cancer Report (Stewart B, Kleihues P, WHO. WCR, IARC, 2003), suggest that after the genetic correlation with breast cancer, reproductive health-related risk factors, early age at menarche, late age at

menopause, and first, full-term pregnancy after age 30, as well as hormone replacement therapy (HRT)- are important factors associated with an increased risk of breast cancer.

Studies found that if women adopt early risk-reduction behaviours like physical activity, healthy diets, breastfeeding, non-extensive alcoholic beverage consumption to mention but a few, part of the breast cancer burden can be prevented through primary prevention (Colditz and Bohlke; 2014, Graham and Kari; 2015). It has been documented (Colditz and Bohlke; 2014, Graham and Kari; 2015) that "depending on when in her lifespan a woman integrates risk-reduction behaviours, part of BC can be prevented through primary prevention". In Sub-Saharan Africa, many breast cancers are not detected until they are advanced stage, (Islami et al.; 2015). There is reasonable ground to advocate for screening and its public health relevance in contrast with different treatment options.

The Niger context

Niger Republic is a country of west Africa; it took its name from The Niger river. The country is the largest one in west Africa covering a land of 1.267.000 km^2 and about 24 million population (latest 2012 population Census, décret N° 2011-059/PCSRD/ME/F, 27 January 2011). It's bordered by Libya and Algeria in northeast and northwest respectively, Chad (in the east,) Nigeria (in the south), Benin and Burkina Faso (in the southwest) and Mali in the west. About 80% of its land area lies in the Sahara Desert. The population is predominantly Muslim and lives in the far south and west of the country. Niger is one of the if not the poorest nation on earth, it is a ''Low Income/developing country which consistently ranks near the bottom in the United Nations' Human Development Index (HDI). It was ranked 187th of 188 countries for 2015 and 189th out of 189 countries in the 2018 and 2019 reports''. (*"Latest Human Development Index (HDI) Ranking (2018)". hdr.undp.org. united nations development programme, UNDP). The country is landlock mostly relying on Togo, Benin and Nigeria for its access to sea.*

The geography of the country is much more of a Sahel country with most of the non-desert portions of the country threatened by periodic drought and desertification. The raining season only lasts for few (3 to 4) months and recently the country has sustained asymmetric rainfall. Agriculture and breeding are the two-main components of the economy of the country.

In terms of export, Niger is exporting some uranium being extracted in the northern ''Agadez'' region, border with Libya and Algeria, this uranium has contributed for a long record to France nuclear capacity. SOMAIR and COMINAK are the compagnies historically working on Niger uranium exploration in collaboration with AREVA (now become ORANO). Areva worked on the ''Imouraren project'', a new mining project in northern Niger, that is the largest uranium mine in Africa. Preparations for mining were under way (construction of the mine, plants and infrastructures, etc.), with extraction of the first ore scheduled for 2015 but the project was postponed. At present, AREVA and its partners are operating two other mines, which produce more than 4,500 tons of uranium a year. AREVA is the operator and majority shareholder of the mining companies

in the Arlit region. The Group had interests of 63.6% in SOMAÏR (Société des Mines de l'Aïr), 34% in COMINAK (Compagnie Minière d'Akouta), and 66.65% in IMOURAREN SA.https://www.sa.areva.com/EN/news-9723/

One of the gaps on Breast cancer scientific literature in Niger is the hypothetical impact of ionized radiation on people living in the northern part of the country, specific breast cancer data from transversal studies are also lacking.

The country got its independence from France in august 1960. Since then, the population has lived under five constitutions and three periods of military rule. To date, the country is a democratic, multi-party state. Majority of the population lives in rural areas with little access to infrastructure, proper health facilities and advanced education.

In Niger, according to the World Health Organization (WHO), some 1.585 breast cancer cases are estimated yearly in this poor Sahel country. These estimates are forecasted to reach 3.682 yearly cases by 2040 (WHO, Niger Cancer country profile 2020, https://www.iccp-portal.org/who-cancer-country-profiles-niger-2020). Breast cancer is also identified as the first cause of cancer related mortality standing for twenty-seven percent (27.7%) of the overall cancer mortality within the female population, ((WHO; Cancer Country Profiles 2014; Globocan; 2012, H. M. Zaki et al.; 2013, S Mamoudou et al.; 2013). According to the latest 2012 Niger population Census (Décret N° 2011-059/PCSRD/ME/F, 27 January 2011), the country population is 17.138.707 inhabitants with 8.518.818 men (49.7%) and 8.619.889 women (50.3 %). The current population of Niger is 24.088.564, based on projections of the latest United Nations data *(https://worldpopulationreview.com/countries/niger-population/*). The 2020 population grew 3.84% over the 2019 population, adding about 896,000 people to the population. 69% of Niger population is rural while 31% is urban. Age groups of 0-4 years (21.6%), 5-9 years (17.5%) and 10-14 years (12.6%) have the highest proportions in Niger population age structure. Citizens aged from 15 years old have a cumulative proportion of 48.3%. People aged from 65 years old and above represent 3.1% of the population. Thus, Niger population is very young. Niger has one of the lowest literacy rates in the world. The preschool enrolment rate is just 7% and over 50% of children aged 7-16 are not in school. Literacy rate for 15 years and older is 39% for men and 22.5% for women, Gross graduation ratio (ISCED 6 and 7, First degrees) is 5.5% for men and 3.3% for women. (UNICEF, https://www.unicef.org/niger/education) and UNESCO (http://uis.unesco.org/en/country/ne). In Niger, malnutrition rates are established to be high, in fact, up to 16% of women are under the critical Body Mass Index, BMI threshold of 18.5kg/m^2 (EDSN-MICS IV, INS, 2012). Previous research (Pike et al.; 2015; Graham and Kari; 2015) has shown that women who eat a high-calorie, low-nutrient, few vegetables and fruits diet combined with lack of physical exercise are more likely to produce estrogen for breast cancer to develop and grow. Early marriage is still phenomenal in Niger and the average ratio of children per women is one of the highest of the world with the current average standing at 7.6 children (UNICEF, at a glance: Niger, 2012). In Niger, the weight of tradition is high and women with cancer are often seen as victim of an "evil spell", perception, behaviors, knowledge and

attitudes of women towards breast cancer is also not very well documented. In Niger, the social and economic fragmentation is high across different parts of the country which is far from its epidemiological transition.

Knowledge of breast cancer among women is not generally high in sub–Saharan Africa and not very well documented in Niger (Jennifer N. al.; 2017). Breast cancer awareness can significantly contribute to early diagnosis and disease mortality reduction (Anderson B & Jakesz R 2008). In Niger, mammographic screening facilities are not widely available and research literature on breast cancer epidemiology and awareness is not extensive.

Soliman et al.; 2015 outlined younger age (patient of average age 44) and late diagnosis as some of the main features of breast cancer patients in Niger. Research data and references related to breast cancer in Niger remain scanty, certain studies, (Zaki et al.; 2013; Rachid et al.; 2009, Nouhou H et al.; 1994) and theses from medical students have contributed sketching histopathologic, demographic and epidemiologic peculiarities of breast cancer. Nevertheless, no novel studies have addressed advanced epidemiological analyses and conceptual framework appraisal of breast cancer in Niger. Actually, the country does not have an operational cancer policy/strategy/action plan but has established a cancer registry since 1992. Recently, Niger has strengthened the fight against breast cancer by using screening and awareness campaigns. A radiation therapy centre is under construction supported by the International Atomic Energy Agency, IAEA in this country ranked world's fourth uranium producer (UIC Ltd.; 2007).

Even though clinical and histopathological features of breast cancer have been documented in Niger (Zaki et al.; 2013; Rachid et al.; 2009, Nouhou H et al.; 1994, M Nayama, et al. 2006, Salamatou et al., 2013), a research hole lies in the epidemiological analysis of breast cancer data in Niger and its public health exploration. There is no recent update on retrospective analysis of breast cancer data in the country using cancer registry. Knowledge, attitudes and practices of women in relation to BC have not been established. To the best of our knowledge, no recent studies were conducted in the analysis of knowledge, attitudes and practices of women in relation to breast cancer in Niger. No validation of a Breast Cancer Awareness Measure, (BCAM) tool has been done in the country.

The rationale of this research is therefore to address this research hole in the breast cancer scientific literature in Niger Republic. We conducted an update analysis of breast cancer data using cancer registry, a novel validation of Breast Cancer Awareness Measure (BCAM) tool in the country. Following a literature review, we published on Knowledge, attitude and practice of women related to breast cancer in Niger. This research provided information that will hopefully be used by policy makers, clinicians, patients (family, friends) and public. Suggestions were made on how to develop effective programs to fight BC in Niger.

In **chapter one**, we provided a general introduction on the breast cancer with an outlook on African region and Niger context. We presented the documented growing trend of breast cancer incidence and mortality in relation to the latest WHO Globocan estimates (2018) and Niger Cancer Country profile (2020).
The Niger context with its specificities was portraited. A specific demographic profile of the country characterized with the highest word fertility rate, a very young population and poor resources/health infrastructures was introduced.

In **chapter two,** we presented an updated literature review on the epidemiology of female breast cancer in Niger. Series of articles were scanned, discussed to identify published evidence concerning the epidemiology of female breast cancer in Niger using The PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) model. The idea was to know how much is available on the topic and what are the gaps in a prospective public health approach. The output of the review pointed out sustainable gaps in the field of epidemiology and public health research on BC in Niger. The country does not yet have a national screening program and an updated analysis of cancer registry data. There is need to conduct research on feasibility and acceptability of alternative screening methods adapted to low-income countries, such as Niger.

In **chapter three**, we reported the published article on the validation of BCAM (Breast Cancer awareness Measure) tool in Niger. Item analysis was used to assess acceptability and needed adaptations, 'known group method'' was used to assess construct validity and internal consistency was assessed using Cronbach's alpha. We found that the BCAM was an acceptable, reliable and valid tool when applied to women and midwives in Niger. Nevertheless, it requires some refining to better suit some social and contextual factors.

In **chapter four**, we presented main findings of a published paper on knowledge, attitudes and practice of women towards BC in Niger. We documented that, overall women's knowledge of breast cancer is low, from a cross sectional study conducted in Niamey and Zinder regions. Women's knowledge of breast cancer risk and protective factors remains specifically poor whereas their knowledge of symptoms remain acceptable.

In **chapter five**, we produced an updated analysis of BC registry data from 1992 to 2018. It was observed that despite a slow startup, cancer cases registration in Niger showed a significant increase from 1992 to 2018. It also came out that breast cancer is the most common cancer recorded in Niger, followed by gynecological cancers with cervical and ovarian. Then followed by liver, skin and colon/rectum cancer. Overall Breast cancer mortality was found to be low.

In **chapter six**, we summarized the main findings and general discussion of this thesis.

In **chapter seven**, we presented the conclusion and practical enjoinders for a better BC care and prospective public health research in Niger.

MAP of Niger republic with neighboring countries

NB : Zinder and Niamey regions were selected for data collection

Chapter two

Epidemiology of female breast cancer in Niger: a literature review

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Epidemiology of female breast cancer in Niger: A literature review

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Breast cancer (BC) is a public health concern in sub-Saharan Africa with rising incidence and mortality. In Niger, BC is identified as the leading cancer morbidity and mortality within female population. Its epidemiological literature remains limited or not structured. The aim of this work was to summarize evidence in relation to epidemiology of female breast cancer in Niger. The idea was to know how much was published and available on the topic and what the gaps are. This review was conducted by considering all articles published on the epidemiology of breast cancer in Niger using The PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) model. A comprehensive search of material was performed using PubMed/Medline, African Journals Online, (AJOL), Web of Science, Google Scholar and Scopus/Elsevier. In total, 16 articles were initially screened, 14 full text articles were accessed for eligibility and 6 were included in the final review. None of the screened papers had clinical trial methodology or survival analysis. Moreover, no peer reviewed paper was found on breast cancer screening. The output of this review pointed out sustainable gaps in the field of epidemiology and public health research on BC in Niger. The country should have a national screening program and an updated analysis of cancer registry data. Effort is to be done on studies about cancer survival, feasibility and acceptability of alternative screening methods adapted to low-income countries, such as Niger.

Key words: Niger, breast cancer, public health, screening.

INTRODUCTION

Breast cancer (BC) stands as a public health concern in sub-Saharan Africa (Bray et al., 2018; Brinton et al., 2014; Bray et al., 2008, Azubuike et al., 2018). It remains the leading cancer in morbidity and mortality statistics especially in female population with prevailing geographical variations. On a wider perspective, according to the World Health Organization, (WHO) latest fact sheets Globocan, 2018), North American, European and high-income Asian/Oceanian countries have the highest BC figures, sustaining higher incidence in the more-developed regions of the world. BC incidence and mortality (Age-Standardized Rates per 100,000 females) were reported to be the highest in Australia/New Zealand with 94.2 incidence and 12.6 mortality. Western Europe (Belgium, the Netherlands, and France) accounts for 92.6 and 15.5 incidence and mortality respectively. Northern

European countries (Sweden, Finland, United Kingdom, and Denmark) have 90.1 incidences and 14.1 mortality. Elsewhere, northern American countries stands for 84.8 and 12.6 respectively. Estimates reached 56.8 and 13.4 in South American countries. Western Asia has 45.3 incidences and 13.6 mortality. Moreover, BC is the most frequently diagnosed cancer in women living in Gulf Cooperation Council countries (GCCCs). In the six GCCCs (Bahrain, Saudi Arabia, Kuwait, Oman, Qatar and the United Arab Emirates), BC is the greatest cause of cancer incidence and mortality, Tanner and Cheung (2020).

In the African region, Northern Africa has the highest estimates with 48.9 incidences and 18.4 mortality. (Bray et al., 2018), outlined that Western Africa to which Niger Republic belongs has 37.3 and 17.8 incidence and mortality respectively. It should be noted that lowest figures were observed in the middle Africa (27.9 and 15.8) and south-central Asia (25.9 and 13.6) regions. According to the latest 2012 Niger population Census (Décret N° 2011-059/PCSRD/ME/F DU 27 Janvier 2011), the country population is 17.138.707 inhabitants with 8.518.818 men (49.7%) and 8.619.889 women (50.3 %). The current population of Niger is 24.088.564, based on projections of the latest United Nations data (https://worldpopulationreview.com/countries/niger-population/). Niger is also the largest country in West Africa. The 2020 population size grew up by 3.84% over the 2019 population, adding about 896,000 people to the population. About 69% of Niger population is rural while around 31% is urban. Age groups of 0-4 years (21.6%), 5-9 years (17.5%) and 10-14 years (12.6%) have the highest proportions in Niger population age structure. Citizens aged from 15 years old have a cumulative proportion of 48.3%. People aged from 65 years old and above represent 3.1% of the population. Thus, Niger population is very young.

LITERATURE REVIEW

In Niger, BC has been identified as the first cause of cancer related incidence and mortality standing respectively for 18.3 and 14.6% of the overall cancer burden in the country (WHO; Cancer Country Profiles, 2020). The country does not yet have an operational ‘’Cancer management guidelines’’ nor ‘’Palliative care included in their operational, integrated NCD plan’’. Besides, there is no national ‘’breast cancer screening program’’. The heath system capacity is yet to be strengthened. As an example, according to the latest WHO Cancer Country Profiles (2020), there is no availability of ‘’PET or PET/CT scanners’’ nor ‘’MRI scanners’’ in Niger. There is 2.3 ‘’radiologists’’ and 1.2 ‘’Public cancer centres’’ per 10,000 cancer patients in the country. Pathology services and Palliative care are rated as ‘’ generally not available’’ in the country by WHO.

Some studies (Zaki et al., 2013, Nayama et al., 2006) sketched basic description of cancer patients in the country without engaging into a deep epidemiological analysis of cancer disease. (Zouladeny et al., 2015) outlined younger age and late diagnosis as common features of breast cancer in Niger. Studies established that if women adopt early risk-reduction behaviors like physical activity, healthy diets, breastfeeding, non-extensive alcoholic beverage consumption to mention but a few, significant part of the breast cancer burden can be prevented through primary prevention Colditz and Bohlke (2014), Graham and Kari, (2015). This is even more important in countries like Niger where sophisticated material like mammographic screening facilities are not widely available. According to WHO cancer country profile (2020), there was about 10.4 mammographs for 10 .000 cancer patients on Niger Republic.

Various studies (Youlden et al., 2012; Samuel et al., 2017) have documented that BC prevalence and mortality are increasing in sub-Saharan African countries. In a paper by (Adeloye et al., 2018), it was stated that the overall pooled African crude incidence of BC from population-based registries was 24.5 per 100, 000. Whereas some neighboring countries of Niger such as Nigeria, Algeria and Burkina have archived BC burden, researchers in the country itself did not established extensive epidemiological BC literature. Burkina Faso has 12.3 and 9.1 age standardized incidence and mortality rates while Algeria has 22.3 and 11.4. In Nigeria, according to the latest WHO data, Breast Cancer Deaths reached 14,932 with an age adjusted Death Rate of 30.08 per 100,000 of population. Spell neighboring Niger Republic and sharing many socio demographic features, Nigeria is currently the most populated country in Africa and is projected to be the world’s third most populous country (behind China and India) by the year 2050, according to a report released by the UN Department of Economic and Social Affairs. Niger remained the country with the word highest fertility rate with an outstanding growing population also.

The aim of this study trajectory work was to summarize evidence in relation to epidemiology of female breast cancer in Niger by scanning all

published papers in the past. The idea was to know how much is available on the topic and what are the gaps in a prospective public health approach.

METHODOLOGY

This review has been conducted by considering all articles published in the past in Niger on epidemiology of breast cancer. The main search keywords used were ‘’Breast cancer, women, public health, epidemiology, breast self-examination, maternity, screening, cancer de sein, dépistage, revue littéraire, and Niger ‘’. The authors used various combinations supported by Boolean expressions AND/OR in the search engines. This comprehensive search of material was performed using PubMed/Medline, African

Journals Online, (AJOL), Web of Science, Google Scholar and Scopus/Elsevier. We also conducted a general search scanning in Google and the online ‘’catalogue collectif réseau bibliothèques du Niger‘’. Moreover, the WHO (Globocan) website and discussion with cancer specialists in Niger was done to track relevant material. The research and scanning methodology thus involved online search using the material described above, physical material tracking in libraries and discussions with cancer specialists in Niger.

Eligibility criteria

Published papers and articles that went through peer review were included in the final section. The authors considered articles published both in English and French without filtering by the publication date. The articles included needed to have an abstract and full text available before being selected. Articles that were not published or did not undergo a peer review process were not included in the final selection. Moreover, papers whose methodology is not well described or not scientifically sound was not included. Some studies were considered methodologically not sound because the method section if it exists is not well described when reviewing them. Most of them were reports written by students from faculty of medicine, university of Niamey as one requirement to the fulfilment of their bachelor’s degree in medicine. They did not go a peer review process nor are they published. They were mainly found in the ‘’catalogue collectif réseau bibliothèques du Niger‘’.

RESULTS AND DISCUSSION

The first result of this work is shown on Figure 1 with the summary of articles selection based on PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) model.

Globally, few articles were found published on the epidemiology of breast cancer in Niger. In total, 24 articles were initially scanned at identification stage; they subsequently proceeded by eliminating duplicates and remained with 14 articles. Other sources included authors’ referrals on some articles and faculty of medicine students’ referrals in their assignments or theses. In total, 14 full text articles were accessed for eligibility and 6 were specific to breast cancer including one on male breast cancer.

Table 1 shows scanned papers, both included and excluded, with reasons behind their exclusion. (Zaki et al., 2013) and (Nayama et al., 2006) reported a retrospective analysis of cancer registry data in Niger. The first article aim to identify the epidemiological and histological aspects of gynecological and breast cancer for the best care of patients while the second determined the various epidemiological characteristics of cancers (broadly) in Niger from 1992 to 2009. Both were retrospective descriptive approaches of breast cancer data.

(Nayama et al., 2006) explored 9 years (from 1992 to 2000) of Niger cancer registry data. They found out that gynecological and breast cancer represented 54.3% of women cancer and 33.1% of diagnosed cancer of both

sexes. Patients mean age was 36.5 years. The most frequent site was breast (40.4%) followed by cervix (26%). On a more clinical/ histological profiling, the study stated that epithelial tumors represented 87%, sarcoma 7.9% of cases while the other histological types 5.1%.

(Zaki et al., 2013) explored 17 years (from 1992 to 2009) of cancer trends in Niger; broadly, they found an average age of 43 ± 17.53 years for breast cancer patients. Breast cancer was the most frequent female cancer; it represented 27.4% of all cancer cases followed by cervical cancer (13.4%) and ovarian cancer (8.83%). Approximately 7% of the registered cases are due to childhood cancers. This is not broadly in line with the well-known representative percentage of childhood cancer of all cancers which is about 1%. Different reasons could explain this, one of them in Niger context is the exactitude of patient’s age as reported by parents during cancer registration. Sometimes, patients do not have official data birth certificate and data registry rely on oral information given by parents. Nevertheless, (Peko et al, 2004) reported

a child average year of 7,9 in a study in Congo-Brazaville.

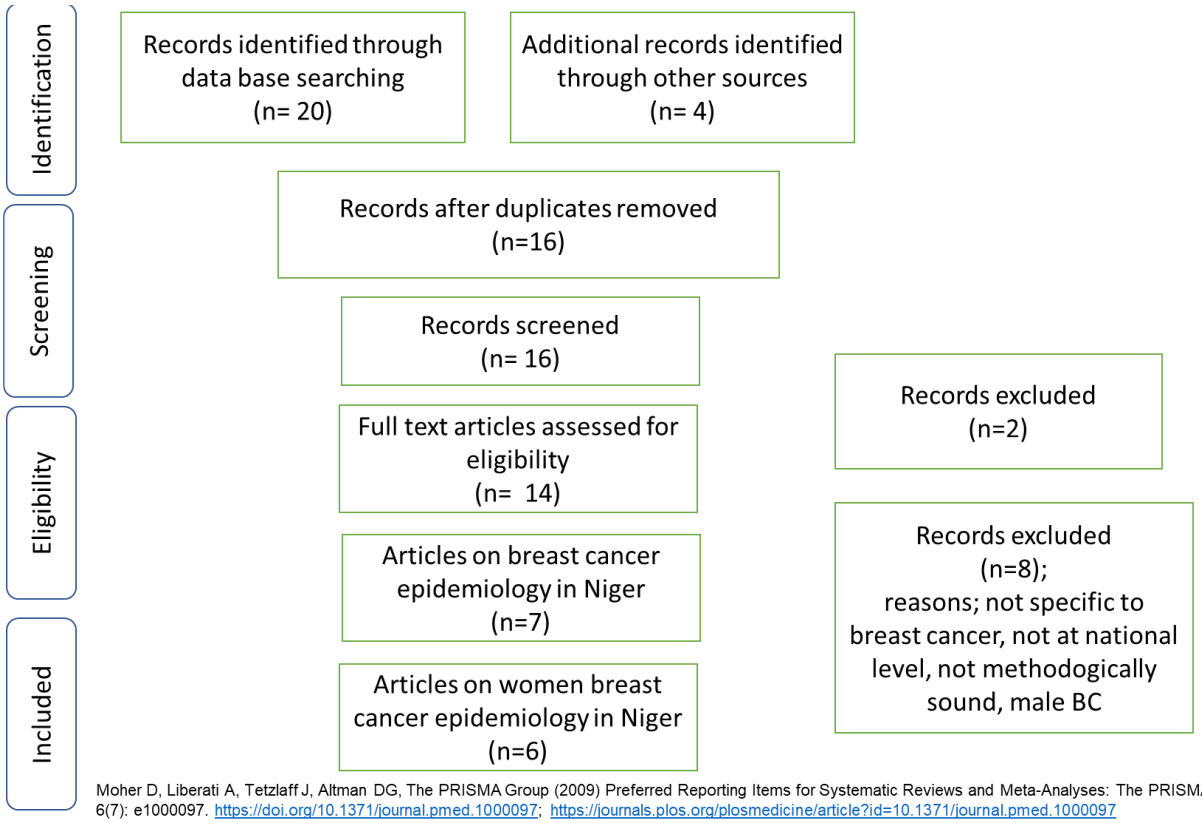
Forty- two percent of the cancers had cytological and histological confirmation. The carcinomas constituted 27.0%, the most frequent histological type. (Zaki et al., 2013), consider the same period (from 1992 to 2009) and reported that BC represents 16.5% of all cancers collected over the study period and 27.4% of female cancers. It is diagnosed at an average age of 44.1 years in women. The 40–49 age group is the majority of women affected by this pathology. Approximately Forty- seven percent (47.3%) of reported breast cancer cases had cytological and histological confirmation.

Zouladeny et al. (2015) outlined epidemiological and clinical profiles of breast diseases in Niger during the period of 2010–2013 at the National Hospital of Niamey. They identified 245 breast cancers with patients mean age of 45.4 (±13.26 years). Their paper reported younger age of breast cancer with 1/3 of cancers under age 44. While only 37.1% of cancers had histopathological confirmation, 90% of cancer patients presented at advanced stages and mastectomy was performed for 66% of breast cancers.

Laurent et al. (2019) conducted a case control study in women aged 15 to 49 from January 1st, 2012 to December in Niamey region, they identified 144 cases and 144 controls in medical records of ''Maternité Issaka Gozobi'' admission records and cancer registry of the Anatomopathological Laboratory of the Faculty of Health Sciences. They found that BC was associated with: age ≥ 35 years OR=1.97 (1.16-3.35), oral contraceptive use OR=2.29 (1.31-4.01) and breastfeeding OR=0.43 (0.23-0.46).

Mamane et al. (2012) described the knowledge, attitudes and practices (KAP) of non-medical health professionals related to BC in different health care structures in Niamey. They included 112 health

Figure 1. Article selection flowchart (based on PRISMA Model).



Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009) Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLOS Medicine 6(7): e1000097. https://doi.org/10.1371/journal.pmed.1000097; https://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1000097

professionals (non-physicians) from 10 health centers in Niamey and found that they were mostly insufficiently informed about BC and diagnostic methods. They recommended continuing education for non-medical health professionals on BC and involvement of midwives in the management of BC in order to improve the early detection.

Globally, the authors could not find extensive literature on epidemiology of breast cancer or its public health determinants in Niger. Some of the published papers we found (Nayama et al., 2006; Zaki et al., 2013; Zouladeny et al., 2015) framed descriptive retrospective analysis of breast cancer features in Niger. Useful characteristics and basic description of cancer profiles was done but the papers did not explore in depth epidemiological analysis of breast cancer or its public health ramifications. It should be noted that no paper was found on breast cancer clinical trials in Niger. No peer reviewed paper was found on screening even if some activities of screening are organized in the country.

While Mamane et al. (2012), presented the knowledge, attitudes and practices (KAP) of non-medical health professionals related to breast cancer in different health care structures in Niamey. (Aissami et al., 2020) analyzed the KAP of women in Niamey and Zinder. Both studies pointed to an insufficient level of awareness of women and health professionals on breast cancer especially knowledge of risk factors. Both articles identified midwives as an essential link in the chain of breast cancer management. (Aissami et al., 2020) recommended that awareness programs should promote clinical breast examination as mammography is not common and promote early detection procedures. Mamane et al. (2012) recommended continuing education for non-medical health professionals on breast cancer and involvement of midwives in the management of breast cancer in order to improve the early detection. (Aissami et al., 2020) found that age, clinical breast examination, breastfeeding, history of participation in breast cancer screening and areas of residence were associated with awareness of breast cancer. They reported an awareness level of 41.2% (37.5–45.0) in Niger women.

Guthega et al. (2019) using the PRISMA model found two papers on validation of the Breast Cancer Awareness Measure tool in Kenya (Wachira, 2017; Violet et al., 2015). (Aissami et al., 2020) performed a validation of Breast cancer awareness Measure, BCAM tool in Niger. They found that the BCAM was an acceptable, reliable and valid tool when applied to women and midwives in Niger. Nevertheless, it requires some refining to better suit some social and contextual factors. (Azubuike et al., 2018) published a review titled “Rising global burden of breast cancer: the case of sub-Saharan Africa (with emphasis on Nigeria) and implications for regional development”. Nigeria shares some socio-economic features with Niger, the two countries being neighbors whereas this could have relevance for Niger context, we could not find in depth analysis and review of this type done in Niger. It comes out from this study that globally, about 25% and 15% of all new cancer cases and cancer deaths respectively among females were due to breast cancer and Africa currently had the highest age-standardized breast cancer mortality rate globally, with the highest incidence rates being recorded within the sub-Saharan African sub-region. Certain factors such as westernized diet, urbanization and possibly increasing awareness had been implicated, though their specific contributions were yet to be fully established.

Ojewusi et al. (2016) conducted a systematic review on breast cancer awareness, attitude and screening practices in Nigeria, and found up to 40 articles that were included. They found that the majority of the respondents were aware of breast cancer as a disease entity. Electronic media and television (TV) were the leading sources of information on breast cancer in Nigeria, while use of leaflets and internet were unpopular in this regard. Moreover, their results pointed out deficiency in screening practices even among those who were aware of the screening methods. They stated that ‘’campaigns that couple information with other services are more likely to bring sustained changes in behavior.’’ Mammography and other sophisticated diagnostic tests are not that much available in Niger, as of the moment this paper is being written, no single mammography device is available in public health structures in Niger. A national center on Cancer (Centre National de Lutte contre le Cancer, CNLC) is created; it has chemotherapy service but does not yet have radiotherapy or mammography services. In the absence of mammography in low income countries like Niger alternative screening options like clinical breast examination or breast self-examination if well performed are suggested (Black and Richmond, 2019; Onyije et al., 2010).

Laurent et al.2019 recommended an awareness program on breast cancer towards women. Specifically, regarding the importance of breastfeeding as it was found to lower the risk of breast cancer. Studies on factors associated to BC in Niger are limited. Laurent et al.2019 ound that BC was associated with: age ≥ 35 years OR=1.97 (1.16-3.35) and breastfeeding OR=0.43 (0.23-0.46). (Aissami et al., 2020) found that age (OR = breastfeeding 3.34 (2.12–5.26) were associated with BC awareness.

They could not find studies on feasibility and acceptability of alternative screening methods adapted to low resources countries. Given the rising of cancer incidence in the region (Azubuike et al., 2018; Sambo et al., 2012), this would, however, be very welcome.

Conclusion

6 papers were included in the final stage of this review following the PRISMA model (Table 1). No paper was found on BC clinical trials from Niger out of this review. No evidence of published paper was found on breast cancer screening in Niger. While Screening of breast and cervical cancer is conducted in Niger, its structured documentation is yet to be done given its importance in cancer prevention in this Low-Income Country which does not yet have a national ‘’breast cancer screening program’’. One important hole in breast cancer epidemiology literature review is ‘Breast cancer survival’’ in Niger, no studies was

found on survival analysis and information on ''Quality of mortality registration'' is not is not well known in Niger.
It was reported from retrospective descriptive review of BC data in Niger from 1992 to 2009 that gynecological and breast cancers represented 54.3% of women cancer with BC representing 16.51% of all cancers. Patients mean age was 43 years. Some studies pointed younger age and late presentation as main features of BC cases in Niger. Elsewhere, BC was found to be associated with age, oral contraceptive use and inversely with breastfeeding. Knowledge, attitudes and practices (KAP) of women and non-medical health professionals related to BC were mostly insufficient. Mammography and other sophisticated diagnostic tests are not that much available in Niger. An article on validation of a Breast Cancer Awareness Measure, BCAM for women and midwives' tool was reviewed.
The output of this review pointed out sustainable gaps in the field of epidemiology and public health research on BC in Niger. While records and milestones are available on some clinical features of the disease, its epidemiological exploitation using advanced biostatistical or epidemiological methods are very limited.

RECOMMENDATION

1) Research should be conducted on survival of breast cancer in Niger as no material was found in this review an 'Quality of mortality registration'' is not well known in Niger
2) In Niger, effort is to be done on studies about feasibility and acceptability of alternative screening methods adapted to low resources countries.
3) Given the specific profile of the country (highest fertility rate of the world, one of the youngest populations, one of the largest countries in Africa, poor workforce in public health), national and international research in public health in Niger should be enhanced and supported, the country could be included in multicentric BC clinical trials on occasion. Investment in research on cancer in general and BC could bring clarity and inform clinicians both on prevention and management of cancer in the country still struggling for its epidemiological transition.
4) The latest epidemiological description of breast cancer registry data that we found concerned data from 1992 to 2009 and was published in 2013, about a decade ago, there is need to produce updated analyses of cancer registry data in Niger.

LIMITATION

The limitation of this work as literature review included its potential for selection bias from scanning and analysis of articles. The paper focused on female BC and did not explore papers on clinical features of breast cancer in Niger. Although it is possible that we omitted some articles, the paper was written considering the methodology described and the availability of materials. The study meets ethical requirements on literature review; it did not include collection on persons or any authorization from third parties concerned.

CONFLICTS OF INTERESTS

The authors have not declared any conflicts of interests.

Table 1. Papers included and excluded in the review.

n	Author(s)	Year	Journal/Source	Methods	Objectives	Title	Included/excluded reason
1	Laurent et al.	2019	Vol. 42 No. 2 (2019) ajol. eISSN: print ISSN: 1011-6028	Case control study	Identify factors associated with breast cancer in women aged 15 to 49 years and contribute to reduce its incidence.	Facteurs associés au cancer du sein chez les femmes âgées de 15 à 49 ans de la Maternité Issaka Gazobi de la région de Niamey, janvier 2012 à décembre 2016	Included
2	Mamata AA	2019	106203064 ALI Memoire/Thèse 03. FSS	Restrospective descriptive study	Analyze epidemiological, clinical, therapeutic and prognostic characteristics of breast cancer in postmenopausal women	Quelques aspects du cancer du sein de la femme ménopausée au Niger : étude prospective à propos de 31 cas	Excluded/ not peer reviewed or methodologically not sound
3	Ousmane AI	2019	106203147 ABO Memoire/Thèse 03. FSS	Restrospective descriptive study	Write the epidemiology of the different types of cancer recorded in the anatomy and cytology laboratory of Niamey	Registre des cancers : Fréquence relative des cancers au Niger de 2008 à 2017 Etude rétrospective à propos de 5529 cas	Excluded /not peer reviewed or methodologically not sound
4	Aminata HH	2019	06203104 HAM Memoire/Thèse 03. FSS	Case study and literature review	Observation of the first case of breast carcinosarcoma diagnosed at the Issaka Gazoby Maternity Hospital in Niamey with a literature review.	Carcinosarcome du sein au Niger à propos d'un cas et revue de la littérature	Excluded /not peer reviewed or methodologically not sound
5	Jacob dit Yacouba PO	2016	106202624 PHI Memoire/Thèse 03. FSS	Cross sectional descriptive study	Assess knowledge, attitudes and perception of women of childbearing age towards breast cancer in the urban community of Niamey	Connaissances, attitudes et perception des femmes en âge de procréer vis-à-vis du cancer du sein dans la communauté urbaine de Niamey en 2016 Etude transversale à propos de 192 femmes enquêtées dans la ville de Niamey en 2016	Excluded /not peer reviewed or methodologically not sound
6	Zouladeny H et al.	2015	Intl J Cancer Oncol 2(2): 1-6. doi:10.15436/2377-0902.15.015	Mixed methods	Characterizing epidemiological and clinical profiles of breast diseases in Niger during the period of 2010–2013	Epidemiologic and Clinical Profiles of Breast Diseases in Niger	Included
7	Salamatou et al.,	2013	Bulletin du Cancer Volume 100, Issue 2, February 2013, Pages 127-133	Retrospective ; descriptive study	Determine the various epidemiological characteristics of cancers in Niger from 1992 to 2009.	Épidémiologie des cancers au Niger, 1992 à 2009	Included
8	Zaki H, et al.	2013	Journal Africain du Cancer /10.1007/s12558-013-0274-9.	Retrospective ; descriptive study	Present epidemiological profile of breast cancer in Niger	Profil épidémiologique et anatomopathologique du cancer du sein au Niger.	Included
9	Mamane, A et al.	2012	Journal Africain du Cancer / African Journal of Cancer volume 4, pages156–163 (2012)	Cross sectional study	Describe the knowledge, attitudes and practices (KAP) of non-medical health professionals related to breast cancer in different health care structures in Niamey	La prise en charge du cancer du sein au Niger : connaissances, attitudes et pratiques des professionnels de santé non médecins de Niamey, Niger, 2010	Included

10	Nafissatou BC	2012	06201982 BOU Memoire/Thèse 03. FSS	Cross sectional study	assess the knowledge, attitudes and practices of health care professionals towards breast cancer	Connaissances, attitudes et pratiques du personnel soignant du Centre Hospitalier Régional de Maradi sur le cancer du sein	Excluded /not peer reviewed or methodologically not sound	

Table 1.contd.

11	Omar GB	2011	06201836GAR Memoire/Thèse 03.FSS	Restrospective descriptive study	Describe the epidemiological and histopathological aspects of breast cancer	Cancer du sein au Niger : aspects épidémiologiques et histopathologiques, étude rétrospective de 1992 à 2009 à propos de 1157 cas recensés au niveau du laboratoire d'anatomie pathologique de l'hôpital national lamorde.	Excluded/ not peer reviewed or methodologically not sound
12	Ramatou SB	2009	106201692SEY Memoire/Thèse 03. FSS	Cross sectional study	Attract the attention of all stakeholders to strengthen awareness and improve the prognosis of breast cancer	Effets de la sensibilisation sur le cancer du sein chez les femmes dans la ville de Tillabéry	Excluded /not peer reviewed or methodologically not sound
13	Sani R et al.	2009	The Pan African medical journal 10.4314/pamj.v3i1.52454	unclear	Report clinicopathological characteristics, treatment patterns, and outcomes of male breast cancer	Male breast cancer: 22 case reports at the National Hospital of Niamey-Niger (West Africa)	Excluded/paper rather on male breast cancer, methods not well described
14	Nayama et al.	2006	Mali Med. 2006; 21 (3):43-9. French. PMID: 19435008.	Retrospective; descriptive study	Identify the epidemiological and histological aspects of gynecological and breast cancer for a best care of patients.	Epidemiological and histological aspects of gynecologic and breast cancer in the pathology department of Niamey's Health Faculty, Niger	Included

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Chapter three

Validation of a BCAM (Breast Cancer Awareness Measure) tool for Women and Midwives in Niger

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ABSTRACT

Background: Breast cancer is the first cause of cancer mortality in Niger. The objective of this study was to assess the internal consistency, validity and acceptability of the Breast Cancer Awareness Measure (BCAM) among women and midwives.

Methods: We conducted the study in the Niamey and Zinder regions of Niger. Multistage random sampling was used to select the women. All midwives working in the selected health districts were interviewed. Item analysis was used to assess acceptability and needed adaptations, the 'known group method' was used to assess construct validity, and internal consistency was assessed using Cronbach's alpha.

Results: In total, 675 women, 93 midwives and 25 specialists (gynaecologists, surgeons, and oncologists) participated in the survey. The average age of the women respondents is 39.2 years, the average age of the midwives is 38.6 years, and that of the specialists is 44.1 years; 72 % (62.2−80.1 %) of midwives who partici- pated in the survey are clinical midwives, while 8.6 % (4.4−16.1 %) are heads of service. The average number of working years is 13.6 (11.7−15.6). The women and midwives found the questionnaire to be acceptable. Cron- bach's alpha has shown an admissible level of internal consistency. It ranges from 0.67 (0.63−0.71) to 0.85 (0.83−0.86) for women but is lower for midwives 0.63 (0.51−0.73). We found a significant knowledge gap among the women, who know significantly less than the midwives, who know less than the specialists, supporting the construct validity of the BCAM.

Conclusion: The BCAM was found to be an acceptable, reliable and valid tool when applied to women and midwives in Niger. Nevertheless, it requires some refining to better suit some social and contextual factors.

1. Background

Breast cancer is a significant public health concern worldwide, including sub-Saharan African countries ([1,2]). In Niger, breast cancer has been identified as the first cause of cancer-related morbidity andmortality, accounting for 28 % (27.7 %) of the overall cancer mortality within the female population [3–6]. Studies have found that if women adopt early risk-reduction behaviours—such as physical activity, healthy diet, breastfeeding, non-extensive alcohol consumption, to mention but a few—part of the breast cancer burden could be prevented [7,20]. This is even more important in countries like Niger where mammographic screening facilities are not widely available and research literature on breast cancer epidemiology and awareness is not extensive. Knowledge of breast cancer among women is not generally high in sub-Saharan Africa and is not very well documented for Niger [21]. To the best of our knowledge, the Breast Cancer Awareness Mea- surement (BCAM) tool has not previously been tested and validated in the context of Niger, and the country does not yet have an operational cancer policy/strategy/action plan [3].

In this study we tested, adapted and validated the BCAM in the context of Niger, to contribute to the literature on measuring breast cancer awareness both in women and in health professionals (midwives especially). The BCAM consists of items related to 'knowledge of breast cancer risk factors', 'knowledge of breast cancer protective factors', and

Abbreviations: BCAM, Breast Cancer Awareness Measure; BCAS, Breast Cancer Awareness Scale; CI, confidence interval; CA, Cronbach alpha; DF, degree of freedom; MOH, ministry of health; SPSS, Statistical Package for Social Sciences; SG, 'Secrétariat Général'; DER, 'Direction des études et Recherches'; DEP, 'Direction des études et de la planification'; REM-Africa, Références Etudes de Marches en Afrique; WHO, Word Health Organization.

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'knowledge of breast cancer symptoms or warning signs'; there are also items dealing with age-related risk knowledge, attitudes of women towards breast cancer, frequency of breast checking, treatment options and behaviours towards breast cancer.

2.Materials and methods

2.1. Acceptability and item analysis

In this study the BCAM [8] was used and adapted to the context of Niger. To achieve this, a complementary literature search and a discussion with a group of Niger health professionals involved in cancer were performed; the aim was to adapt the items to be more in accor- dance with the general Niger female population. Items were organized into four categories: knowledge of *risk factors* with four items (alcohol consumption, smoking, sedentary lifestyle obesity, nulliparity/late ma- ternity) for women and six (the first four followed by family history and genetics and hormone replacement therapy) for midwives, knowledge of *protective factors* with three items (breastfeeding, early maternity, balanced diet and lifestyle), knowledge of *warning signs* with 11 items (change in the position of the nipple, pulling in of the nipple, pain in oneof the breasts or armpits, puckering or dimpling of the breast skin, discharge or bleeding from the nipple, a lump or thickening in the breast, nipple rash, 'redness' of the breast skin, a lump or thickening under the armpit, change in the size of the breast or nipple, change in the shape of the breast or nipple) and knowledge of breast cancer *best practice* with three items (breast self-examination, clinical examination, mammography). The following random warning signs with no relation to breast cancer were introduced into the questionnaire to avoid the'halo effect': blurred vision, hunger and strong appetite, neurological disorders and memory loss, chest pain or discomfort (see questionnaire in the Appendix).

Age, survival after treatment, and breast examination (self, clinical, mammography) were also used in the questionnaire. Items are reflected in Table 2.

Item analysis is usually conducted to investigate potential problematic items [9,10]. Generally, a high proportion of missing values (35 %) and an obvious level of skewness (85 %) are used to identify problematic items [11]. Very often, low item response rates indicate items referringto a difficult question which respondents do not want to answer or that shocks them. Highly skewed items refer to questions yielding little in- formation. In this report, items having a proportion of missing values >35 %, or >85 % of the responses on the same side of the response scale (especially on a five-item Likert scale) are considered problematic.

2.2 Internal reliability

The internal consistency was assessed using Cronbach's alpha. Usually, the higher Cronbach's alpha, the more reliable the test. A cut-off of ≥0.7 is acceptable [9]. It is a common misconception that if the alpha is low, it must be a bad test. Actually, the test may measure several latent dimensions rather than one, and in this case the Cronbach's alpha will be deflated. It should be noticed that alpha is a lower boundary of the true reliability of a test under general conditions, and that it only equals the true reliability if the items satisfy a property known as essential equivalence [12], which requires that items must be measuring the same thing. Reliability, being the reproducibility of an empirical measure, has several dimensions; in this report, the focus will be on internal consistency rather than external reliability.

2.3 Validity

We accessed the construct validity of the questionnaire on breast cancer awareness using the 'known group' method. In fact, if a test is 'valid', one criterion could be that test scores must discriminate among groups that are known to differ [13]. A procedure is outlined to assess the discrimination among groups that uses information from means. The validity of the measure is supported if the scores of two groups known to differ in levels of cancer awareness are significantly different in the expected direction. We administered the questionnaire to a general population of women, midwives and a small sample of medical specialists, and compared their responses. Chi-squared tests were used—as suggested by Campbell [14] and Richardson [15]—to compare the proportions.

2.4. Sampling method

We conducted the study in the Niamey and Zinder regions of Niger. Niamey is the capital city of the country, located in the south west, and is home to the national reference hospital where many cancer cases are reported. Zinder is the most populated region of the country and lies at the crossroads of the main east–west road and the north–south route from the desert to Nigeria. The region also has a regional reference hospital.

The study targeted women aged 25≥in the Niamey and Zinder re- gions for participation in the survey. The sampling frame was made up of a list of villages in the health districts and the number of households in the two regions with a population of women of this age. A two-stage clustered random sampling was used to select first villages in healthdistricts, and then households within villages, using a random walk technique. Finally, women were randomly selected in these households. After a random selection of health districts, all midwives working in the selected health districts were interviewed. The specialists were inter-viewed during a national symposium in Niamey. The questionnaire was administered through face-to-face interviews. Oral consent was compulsory before the data were collected. The required sample sizewas calculated based on a 95 % confidence interval (about 630 women), which we adjusted with a 5% increase as a security margin to account forpossible non-response. The collected data were analysed using R version Epidata analysis v2.2.2.183 and IBM SPSS Statistics 24.

3.Results

3.1 Description of the sample

The questionnaire was carried out in 675 women, 93 midwives and 25 specialized medical doctors in the two regions historically home to national reference hospitals, Niamey and Zinder. Households were selected within health districts in 'commune 2', 'commune 3' and 'commune 4' in the Niamey region and Goure, Miriah and Zinder in the Zinder region (see list in Appendices).

Table 1

	General women n=675	Midwives n=935	Medical Specialists n=25
Age at menarche	14.1 years (13.9–14.3)	14.7 years (14.3–15.0)	13 years (12.6–13.8)*
Breastfeeding practice	75.6 % (72.2–78.6)	63 % (52.2–72.8)	43.8 % (32.1–66.8)
Exclusively breastfeeding	31 % (26.9–55.2)	60 % (47.3–72.7)	42.9 % (14.3–85.7)
Had abortion history	28.3 (25–31.8)	31.2 % (22.7–41.2)	38.9 % (16.7–61.1)
Average age	39.2 years (38.2–40.2)	38.6 years (36.8–40.3)	44.1 years (41.–47.1)
Smoking	0.4 % (0.2–1.3)	1.1 % (0.2–5.8)	4% (0.7–19.5)
Drinking	0.7 % (0.3–1.7)	1.1 % (0.2–5.8)	4% (0.7–19.5)
Average number of children	4.6 children (4.3–4.8)	3.2 children (2.9–3.6)	2.6 children (2.0–3.2)
Average working experience		13.6 years (11.7–15.6).	8.4 years (5.4–11.4)

The first four items for specialists in table were computed on n=16 specialists

Table 2
Women: missing values-skewness and mean values with 95 %CI for women.

	Women			Midwives	
Knowledge of risk and protective factors:	Skewness 95 %CI	Mean 95 %CI	Missing values	Skewness 95 %CI	Mean 95 %CI
Alcohol	−0.03 (−0.14 to −0.07)	3.09 (2.99–3.20)	0.1 % (0–0.8)	−0.39 (−0.81 to −0.26)	3.27 (3.09–3.45)
Smoking	−0.53 (−0.64 to −0.42)	3.50 (3.40–3.60)	–	−0.86 (−1.30 to −0.49)	3.66 (3.46–3.84)
Sedentary lifestyle-obesity	0.19 (0.11–0.29)	2.85 (2.76–2.94)	0.1 % (0–0.8)	0.46 (0.08–0.85)	2.77 (2.58–2.96)
Nulliparity/late maternity	0.15 (0.05–0.25)	2.78 (2.67–2.88)	–	−0.25 (−0.63–0.10)	3.20 (2.98–3.41)
Breastfeeding	−1.28 (−1.78 to −0.88)	3.26 (3.16–3.36)	–	−1.28 (−1.73 to −0.87)	3.76 (3.56–3.96)
Early maternity	0.12 (−0.22–0.48)	3.12 (3.03–3.22)	–	0.12 (−0.25–0.45)	2.86 (2.65–3.07)
Balanced diet and lifestyle	−1.2 (−0.52–0.21)	3.16 (3.06–3.27)	–	−0.14 (−0.51–0.21)	3.04 (2.83–3.25)
Family history and genetics				−0.60 (−1.02 to −0.20)	3.48 (3.26–3.69)
Hormone replacement therapy				−0.35 (−0.73–0.78)	3.29 (3.10–3.46)
Knowledge of warning signs:					
Change in the position of your nipple	1.18 (1.02–1.33)	1.44 (1.39–1.49)	–	0.36 (0.12–0.62)	176 (1.63–1.90)
Pulling in of your nipple	0.60 (0.48–0.71)	1.63 (1.58–1.68)	–	0.14 (−0.01–0.34)	1.88 (1.74–2.01)
Pain in one of your breasts or armpit	1.27 (1.10–1.43)	1.42(1.37–1.47)	0.1 % (0–0.8)	2.59 (1.82–3.739	1.19 (1.10–1.31)
Puckering or dimpling of your breast skin	0.55 (0.44–0.66)	1.67 (1.62–1.73)	0.4 % (0.2–1.3)	0.73 (0.41–1.09)	1.62 (1.47–1.77)
Discharge or bleeding from your nipple	1.08 (0.94–1.24)	1.47 (1.42–1.52)	0.6 % (0.2–1.5)	1.39 (0.93–1.90)	1.39 (1.26–1.53)
A lump or thickening in your breast	0.96 (0.81–1.11)	1.53 (1.48–1.59)	–	2.70 (1.66–3.98)	1.14 (1.06–1.22)
Nipple rash	0.71 (0.60–0.84)	1.62 (1.56–1.67)	0.3 % (0.1–1.1)	0.86 (0.53–1.23)	1.55 (1.42–1.69)
'Redness' of your breast skin	1.07 (0.93–1.23)	1.48 (1.43–1.53)	0.6 % (0.2–1.5)	1.62 (1.14–2.24)	1.33 (1.22–1.46)
A lump or thickening under your armpit	1.18 (0.02–1.34)	1.44 (1.39–1.49)	0.6 % (0.2–1.5)	1.94 (1.26–2.69)	1.25 (1.15–1.35)
Change in the size of your breast or nipple	0.93 (0.79–1.07)	1.53 (1.48–1.58)	0.7 % (0.3–1.7)	1.47 (1.03–2.13)	1.39 (1.25–1.53)
Change in the shape of your breast or nipple	0.90 (0.77–1.03)	1.54 (1.49–1.60)	0.4 % (0.2–1.3)	1.65 (1.17–2.25)	1.34 (1.23–1.47)

NB: Knowledge of risk and protective factors has a five-item Likert scale while knowledge of warning signs has a three-item scale.

Of the women who participated in the survey, 79.1 % (75.9–82.0 %) are married, 46.5 % (42.8–50.3 %) are from rural areas, and 48.4 % (44.7–52.2 %) are not educated. Hausa remains the main ethnic group(53 %), followed by Djerma (17 %); 42.2 % (38.6–46.0 %) of the women take oral contraception and 35.5 % (32.2–39.4 %) do not practice contraception at all. Of the midwives who participated in the survey, 72% (62.2–80.1 %) are clinical midwives while 8.6 % (4.4–16.1 %) are heads of service; 86 % (77.5–91.6 %) of the midwives are married; 40.9% (31.4–51.0 %) are from the Hausa ethnic group and 30.1 % (21.7–40.1 %) are Djerma; 31.2 % (22.7–41.2 %) of the interviewed midwives use oral contraception methods, 19.2 % (12.6–28.5 %) use injectable contraceptives, while 43 % (33.4–53.2 %) use no contraception methods at all. The sample of specialists comprised 21 doctors specialized in gynecology, three PhD holders (surgery) and one professor. It should be noted that 16 out of the 25 specialists (64 %) were women. Table 1 shows the description of the sample.

3.2. *Acceptability and item analysis*

No problematic items with extreme levels of missing values or skewness were found (see Table 2). In fact, none of the items reached 5%of missing values. The highest level of skewness was observed on the items 'Breastfeeding' −1.28 (−1.78 to −0.88) and 'Pain in one of yourbreasts or armpit' 1.27 (1.10–1.43), and the highest levels of missing values were found on 'Change in the size of your breast or nipple' 0.7 % (0.3–1.7), 'Discharge or bleeding from your nipple', 'Redness' of your breast skin' and 'A lump or thickening under your armpit', with all of them having 0.6 % (0.2–1.5 %) missing values. Regarding the midwives' data, the highest level of missing values is 2.7 % (1.66–3.98 %) observed those with low levels of education and from rural areas. It may be that future surveys in Niger women could disregard the questions on smoking and alcohol intake in the general female population.

3.3. *Internal consistency*

The Cronbach's alpha values are shown in Table 3. When we consider women's data, knowledge of risk factors (alcohol, smoking, sedentary lifestyle obesity, nulliparity) items have a value of 0.77 (0.74–.79), which denotes good internal consistency. Knowledge of protective factors (breastfeeding, early maternity, balanced diet and life style) has an alpha of 0.67 (0.63–0.71) and knowledge of warning signs (nine non-lump warning signals) an alpha value of 0.81 (0.78–0.83), which also denotes good internal consistency. When we consider all 11 symptoms (including two lump items), we see an alpha value of 0.85 (0.83–0.86), which is the highest value of alpha observed in our study. In view of these figures, we can confirm the fact that the BCAM questionnaire has a good internal consistency and is reliable when applied to Niger women.

Cronbach's alpha values for midwives' data are lower than those for women, but generally acceptable; the highest alpha is related to the 11 warning signs, at 0.63 (0.51–0.73). The alpha value for nine warning signs is 0.60 (0.47–0.71), and knowledge of protective factors also hasan alpha value of 0.60 (0.47–0.71); items related to knowledge of risk factors have a Cronbach's alpha of 0.40, which is questionable (see table 3 below).

***Table 3: Women and midwives* Cronbach's-Alpha**

	Items	**Cronbach's-Alpha 95% CI**	
		Women	**Midwives**
Knowledge of risk factors	(alcohol, smoking, sedentarity-obesity, nulliparity)	0.77 (0.74-0.79)	0.40 (0.17-0.57)
	Nine items -non-lump warning signals	0.81 (0.78-0.83)	0.60 (0.47-0.71)
Knowledge of warning signs	Eleven items - including lump warning signals	0.85 (0.83-0.86)	0.63 (0.51-0.73)
Knowledge of protective factors	(breastfeeding, early maternity, balanced diet and life style)- (hormone replacement, genetics and family history were added for midwives)	0.67 (0.63-0.71)	0.60 (0.47-0.72)

3.4. Validity

The following table (Table 4) compares the results of women, midwives and medical specialists for the main warning signs. For instance, as per the question on *''Change in the size of your breast or nipple''* as a breast cancer warning sign, general women population average answers of 'yes' is 57.8% (54.1-61.6), midwives' answer is 74.2% (64.5-82.0) which differs with statistical significance (x^2=9.13, df=1 and p<0.0025) from women. If we consider the question on *'A lump or thickening under your armpit'*, as a potential breast cancer symptom, general women population average answers of 'yes' is 64.5% (61-68.4) while midwives' answer is 78.5% (69.1-85.6) which differs with statistical significance from women (x^2=7.15, df=1 and p<0.007). On the item, ''*A lump or thickening under your armpit*'' Specialist proportion of 'yes' is 96% (80.5-99.3) as compared to women (x^2=10.5, df=1 and p<0.001) and as compared to midwives (x^2=4.09, df=1 and p<0.04). When we consider the questions *'Puckering or dimpling of your breast skin'* and *'Nipple rash*'' as a warning sign of breast cancer, there is no significant difference between women and midwives. It should be noted that some items were weighed to account for their relative importance as risk/ protective factors and warning signs for breast cancer. So, factors like breastfeeding, late maternity and nulliparity and age were weighed as important risk factors. So also, symptoms like change in the size of your breast or nipple, change in the shape of your breast or nipple, a lump or thickening in your breast, a lump or thickening under your armpit, were weighed as important warning sings.

Table 4: Knowledge of warning signs: Answer is ''Yes''-Proportions

Breast cancer warning signs	Women (n=675)	Midwives (n=93)	Specialist (n=25)
Change in the position of your nipple	65.8% (62.2-69.6)	38.7% (29.4-48.9)	50 % (29.2-70.8)
Pulling in off your nipple	48.9% (44.7-52.4)	29.0 % (20.8-38.9)	25% (8.3-45.7)
Pain in one of your breasts or armpits	66.3% (62.8-70.2)	84.9% (76.3-90.8)	84% (65.3-93.6)
Puckering or dimpling of your breast skin	46.4% (42.6-50.3)	52.7% (42.6-62.5)	48% (30.0-66.5)
Discharge or bleeding from your nipple:	61.8% (58.1-65.6)	68.8 % (59.1-77.3)	25% (8.3-41.7)
A lump or thickening in your breast	60.1% (56.2-64.1)	87.1% (78.8-92.5)	96% (80.5-99.3)
Nipple rash	52.2% (48.1-55.7)	55.9 v(45.8-65.6)	88% (70.0-95.8)
Redness of your breast skin	62.1% (58.1-65.6)	73.1% (63.3-81.1)	92% (75.0-97.8)
A lump or thickening under your armpit	64.5% (61.0-68.4)	78.5% (69.1-85.6)	96% (80.5-99.3)
Change in the size of your breast or nipple	58.1% (54.4-62.2)	71.0% (61.1-79.2)	84% (65.3-93.6)
Change in the shape of your breast or nipple	57.8% (54.1-61.6)	74.2% (64.5-82.0)	76% (56.6-88.5)

From Table 5, we can see that based on weighed important risk factors and warning signs, knowledge of midwives is significantly higher than this of general women and the knowledge of specialists is far higher than the knowledge of women, and higher than this of midwives. For instance, 14.7% (12.0-17.4) of women consider alcohol intake as a risk factor for breast cancer, while this proportion is 28% (18.3-36.6) for midwives, which is significantly higher (x^2=10.5, df=1 and p<0.001) showing an expected discrepancy in knowledge. Moreover, 40% (20.0-60.0) of specialists consider alcohol intake as a risk factor which is higher than midwives and significantly higher than women. When we consider early maternity as a protective factor, we can see that while 14.4% (12.0-17.3) of women agree, 30.1% (21.7-40.1) of midwives consider early maternity as a protective factor (x^2=14.74, df=1 and p<0.0001). As far as specialists are concerned, 48% (28.1-68.0) of them consider early maternity as a protective factor.

When we look at nulliparity-late maternity as risk factor, proportion of women's that agree is 29.7% while that of midwives' is 48.4% whereas that of specialist is up to 72%. Considering family history-Genetics as a risk factor, the proportion of midwives that agree is 65,6% while all specialist reached 100%. Considering breast awareness, we can see that while 16.3% (11.8–21.7) of women declare to practice breast self-examination every month, up to 44.9% (31.9-56.5) of midwives (x^2=42.10, df=1, p<0.0001) are doing so and 61.1% (38.9-83.3) of female specialists, Hormone replacement therapy and family history and genetics were restricted to the midwives' and specialists' questionnaire. The observed knowledge gap supports the construct validity of the questionnaire because women know less than midwives who know less than specialists

Table 5: Knowledge of risk, protective factors, good practice on breast cancer, Answer is ''Strongly agree and agree''

Breast cancer risk factors	Answer	Women	midwives	Specialists
Alcohol intake	Strongly agree	25.5% (22.4-29.2)	28 % (18.3-36.6)	32% (12-52)
	Agree	14.7% (12-17.4)	28% (18.3-36.6)	40% (20-60)
Smoking	Strongly agree	29.8% (26.4-33.3)	11.8 % (6.7-20.0)	40% (20-60)
	Agree	26.2% (23.1-29.3)	61.3 %(51.1-70.6)	44% (24-64)
Nulliparity-late maternity	Strongly agree	11.6% (9.3-14.1)	7.5% (2.2-14.0)	12% (0-24)
	Agree	18.1% (15.3-21)	40.9% (30.1-51.6)	60% (40-80)
Physical inactivity and obesity	Strongly agree	13.8% (11.1-16.5)	3.2% (1.1-9.1)	48% (28-68)
	Agree	13.5% (11-16)	20.4% (13.5-29.7)	40% (20-60)
Hormone replacement therapy	Strongly agree		6.5% (3.0-13.4)	12% (0-24)
	Agree		37.6% (28.5-47.8)	60% (40-80)
Family history and genetics	Strongly agree		12.9% (7.5-21.2)	60% (40-80)
	Agree		52.7% (42.6-62.5)	40%(20-60)
Knowledge of Age as a risk factor				
	50 years	13.3% (10.8-16)	25.8% (17.2-34.4)	12% (0-24)
	70 years	7.1% (5.2-9)	0%	24% (8-40)
Breast cancer protective factors				
Breastfeeding	Strongly agree	23.9% (20.7-27.4)	16.1% (10.0-24.9)	48.0% (28.0-68.0)
	Agree	20.9% (17.9-24.1)	64.5% (54.4-73.5)	44.0% (24.0-64.0)
Early maternity	Strongly agree	21.2% (18.1-24.3)	4.3% (1.7-10.5)	24.0% (8.0-40.0)
	Agree	14.4% (12-17.3)	30.1%(21.7-40.1)	48.0% (28.1-68.0)
Balanced diet and lifestyle	Strongly agree	25.2% (21.9-28.4)	4.3% (1.7-10.5)	36.0% (16.0-56.0)
	Agree	17% (14.2-20.0)	38.7% (29.4-48.9)	32.0% (16.0-52.0)
Breast cancer good practice				
Breast self-examination	Once a week	6.3% (3.2 – 9.5)	17.4 % (8.7– 27.5)	16.7% (9.1-33.3)
	Once a month	16.3% (11.8 – 1.7)	44.9% (31.9-56.5)	61.1% (38.9-83.3)
Clinical examination		27% (23.8-30.4)	26.9%(18.9-36.7)	12.0% (0-28.0)
Mammography		20.1% (17.3-23.3)	21.5%(14.4-30.9)	48.0% (28.0-680)

4 Discussion

4.1 : Item analysis and acceptability

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We did not find any items with extreme levels of missing values or skewness that should be labelled as problematic following the results of this study. Women and midwives found the questionnaire to be acceptable, welcomed the data collectors, and the response rate was very high. Niger women—especially those with low levels of educa- tion—are somehow shocked to discuss alcohol intake and smoking.

4.2. Internal consistency

The BCAM applied to Niger women and midwives has shown good internal consistency. When applied to midwives, the BCAM showed less, but still acceptable, internal consistency. In view of the figures discussed earlier, we can confirm that the BCAM questionnaire has good internal consistency when applied to Niger women especially, but also for mid-wives in the Niger context. Wachira et al. [16] found Cronbach's alpha
ranging from 0.60 to 0.80, supporting good internal consistency of the BCAM refined and applied to Kenyan women. Linsell et al. [8] foundgood to moderate internal consistency when the BCAM was originally applied to a population of British women.

4.3. Validity

When using the BCAM in Niger women and midwives, we found a significant knowledge gap in the expected direction.

In general, mid- wives scored higher than women who scored much lower than special- ists, which supports the construct validity of the questionnaire. Linsell et al. [8] demonstrated good construct validity of the BCAM when it was applied to British women. Age as a risk factor doesn't seem to be a discriminatory knowledge item. In fact, [17] found that the average ageof Niger women cancer patients is 45.4 (13.26 years), and [5] stated that Niger women present with breast cancer about 10 years earlier on average than Arab and European women. Some items—like 'redness of the skin', smoking and alcohol drinking—could be attributed to socio-anthropological and cultural differences in Niger. As only 6.4 % (4.8–8.5 %) of the survey population is of a white race, the 'redness of the skin' could be considered an inconvenient wording for a black race population. Wachira et al. [16] suggested also an adaptation for Kenyan women when translated into Swahili. We adapted it to 'change in color aspect of the skin'.

The study could contain bias in terms of reproducibility for the whole country. Results need to be interpreted within the regions of the Niamey and Zinder framework. Lack of wide access to equipment formammography could introduce a bias for the proportion of women reporting on mammography, as at the time of the survey (January 2018), only one mammography machine was available in the whole country and was in the capital city.

5 Conclusion

In view of the above results, we can see that the findings of this study demonstrate that the BCAM questionnaire is reliable (internal reli- ability) and valid when applied to Niger women, midwives, and even a sample of specialized medical doctors. Moreover, it has adequate acceptability. Nevertheless, given that the original tool was developed and tested on a population of UK women, some adaptations need to be
made to account for sociocultural variability. For instance, since most Niger women don't smoke or drink, rephrasing or leaving out questions on smoking and drinking could be considered. As no study on the vali- dation of the BCAM had been done in Niger, this could be a modest step
towards increasing the knowledge of this disease in a country that does not yet have a national operational cancer policy, strategy or action plan, struggling to handle epidemiological transition.

6 Policy recommendations

- When conducting breast cancer screening in Niger, female doctors would be more suitable than male doctors as 8.5 % (5.1–11.9 %) of women see a male doctor as a 'barrier'.
- In Niger, midwives could be used as ambassadors for breast cancer awareness as they are champions of practicing 'exclusive breastfeeding' (60 % (47.3–72.7 %)) and are more in contact with women through prenatal and postnatal consultations.
- While the knowledge gap between women and midwives was substantial, that between midwives and specialists was not that wide. In Niger, a breast cancer awareness programme could target both midwives and medical doctors.
- A Breast Cancer Awareness Scale—Niger (BCAS-N) accounting for socio-anthropological specificities of Niger could be con- structed and adapted for the Niger context, just as Solikhah et al., 2017 developed a BCAS-I for Indonesia.
- The development of a national cancer policy could be strengthened, as 86.7 % (80.0–93.3 %) of interviewed mid- wives thought that the country had a national cancer policy while this was not the case.
- Breast cancer awareness programmes with a tailored tool could be strengthened in the country as this can prevent late diagnosis and contribute to mortality reduction through earlier presentation.
- Breast cancer modules could be inserted into the training cur-riculum for midwives and medical doctors.

Ethics approval and consent to participate

The study was approved by the Niger Republic Ministry of Health by authorization of the directorate of Research and Studies, DER (Direction des etudes et Recherche), reference letter: 04712/MSP/SG/DEP/DER on 21-12-2017). The results are expected to contribute to strengthening the disease knowledge and scientific literature in the country. Each respondent was asked to decide whether she wanted to participate in the survey after an explanation, and oral informed consent was obtained before proceeding.

Availability of data and materials

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

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Author contributions

AA analyzed the data, reported the figures and drafted the first study materials (questionnaire, methods, data plan). He participated in the field on data collection.

GH advise on the questionnaire and study design. He gave significant guidance on the state of current scientific literature on the topic globally.

ID advised on the knowledge score construction in the Niger context and supported with the current state of existing scientific literature onthe topic at local level. She also advised on the questionnaire design.

All authors read and approved the final manuscript.

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Appendix A. Supplementary data

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Chapter four:

Awareness, Attitudes and Practices of women in relation to breast cancer in Niger

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Research article

Awareness, attitudes and practices of women in relation to breast cancerin Niger

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ABSTRACT

Introduction: In Niger, breast cancer is the first cancer related morbidity and mortality within female population. While awareness can contribute to early diagnosis and disease mortality reduction, Niger women's knowledge of breast cancer is not well documented. In this study, we assessed the awareness, attitudes and practices of womenin relation to breast cancer and identify the factors associated with it.

Methods: The study was conducted through a cross sectional survey in Zinder and Niamey regions. A random sampling was used to select women in households within health districts. We defined a breast cancer knowledge score and used a generalized linear model to assess factors associated with it.

Results: Overall women's knowledge of breast cancer was found to be low, only 41.2% (37.5–45.0) were aware of breast cancer. 65.0% (61.3–68.7) of women demonstrated an awareness of symptoms. Insufficient level of knowledge was observed on knowledge of risk and protection factors with 27.4 % (24.0–31.0), breast cancer good practice with 16.9% (14.2–19.7). Age OR ¼ 0.98 (0.96–0.99), practicing clinical breast examination OR ¼ 2.25(1.31–3.16), breastfeeding 3.34 (2.12–5.26), not having a history of participation in breast cancer screening and living in rural and peri-urban areas were found to be associated with awareness of breast cancer.

Conclusion: Niger women were found to have a relatively low level of breast cancer awareness. While not acquainted with self and clinical breast examination, Niger women knowledge of breast cancer symptoms was acceptable. Awareness programs can promote clinical breast examination as mammography is not common and promote early detection procedures.

1.Introduction

Breast cancer (BC) is a worldwide public health concern. It remains the leading cancer morbidity and mortality within female population with outstanding geographical variations. According to the World Health Organization, (WHO) latest fact sheets (Globocan, 2018), North Amer- ican, European and high-income Asian/Oceanian countries have the highest BC figures, confirming higher incidence in the more-developed regions of the world. In fact, BC incidence and mortality (Age-Standar-dized Rates per 100,000 females) are highest in Australia/New Zealand with 94.2 incidence and 12.6 mortality. Western Europe (Belgium, the Netherlands, and France) accounts for 92.6 and 15.5 incidence and mortality respectively. Northern European countries (Sweden, Finland, United Kingdom, Denmark) have 90.1 incidence and 14.1 mortality. Northern America countries stands for 84.8 and 12.6. respectively.

Estimates reached 56.8 and 13.4 in South American countries. Western Asia has 45.3 incidence and 13.6 mortality.BC is the most frequently diagnosed cancer in women living in Gulf Cooperation Council countries (GCCCs). In the six GCCCs (Bahrain, SaudiArabia, Kuwait, Oman, Qatar and the United Arab Emirates), BC is the greatest cause of cancer incidence and mortality (Tanner and Cheung, 2020). In the African region, Northern Africa has the higher estimateswith 48.9 incidence and 18.4 mortality. Western Africa has 37.3 and 17.8incidence and mortality respectively. Lowest figures were observed in themiddle Africa (27.9 and 15.8) and south-central Asia (25.9 and 13.6) regions (Bray et al., 2018). It has been documented that BC prevalence and mortality are increasing in sub-Saharan African countries (Youldenet al., 2012; Samuel et al., 2017). (Adeloye et al., 2018) stated that the overall pooled African crude incidence of BC from population-based registries was 24.5 per 100, 000. Some neighboring countries of Niger such as Nigeria, Algeria and Burkina have archived BC burden,

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nevertheless epidemiological BC literature is not extensive in Niger itself. Burkina Faso has 12.3 and 9.1 age standardized incidence and mortality rates while Algeria has 22.3 and 11.4. In Nigeria, according to the latest WHO data Breast Cancer Deaths reached 14,932 with an age adjusted Death Rate of 30.08 per 100,000 of population.

Breast cancer remains a public health concern worldwide including sub-Saharan African countries (Brinton et al., 2014; Ferlay et al., 2010).In Niger, breast cancer is identified as the first cause of cancer related morbidity and mortality standing for twenty-eight percent (27.7%) of the overall cancer mortality within the female population (WHO CancerCountry Profiles, 2014; Zaki et al., 2013; Mamoudou et al., 2013). Studies found that if women adopt early risk-reduction behaviours like physical activity, healthy diets, breastfeeding, non-extensive alcoholic beverage consumption to mention but a few, part of the breast cancer burden can be prevented through primary prevention (Colditz and Bohlke, 2014; Graham and Kari, 2015). This is even more important in countries like Niger where mammographic screening facilities are not widely available and research literature on breast cancer epidemiology and awareness is not extensive. Soliman et al., 2015 outlined younger age and late diagnosis are common features of breast cancer in Niger.

Knowledge of breast cancer among women is not generally high in sub Saharan Africa and not very well documented in Niger (Githaiga et al., 2017). Breast cancer awareness can significantly contribute to early diagnosis and disease mortality reduction (Anderson & Jakesz 2008).

According to the latest 2012 Niger population Census (Decret N° 2011-059/PCSRD/ME/F DU 27 Janvier, 2011), the country population is 17,138,707 inhabitants with 8,518,818 men (49.7%) and 8,619,889 women (50.3 %). The current population of Niger is 24,088,564, based on projections of the latest United Nations data (*https://worldpopulationreview.com/countries/niger-population/*). Niger is also the largest country in West Africa. The 2020 population grew 3.84% over the 2019 population, adding about 896,000 people to the popu- lation. 69% of Niger population is rural while 31% is urban. Age groups of 0–4 years (21.6%), 5–9 years (17.5%) and 10–14 years (12.6%) have the highest proportions in Niger population age struc- ture. Citizens aged from 15 years old have a cumulative proportion of 48.3%. People aged from 65 years old and above represent 3.1% of the population. Thus, Niger population is very young. Niger has one of the lowest literacy rates in the world. The preschool enrolment rate is just 7% and over 50% of children aged 7–16 are not in school. Literacy rate for 15 years and older is 39% for men and 22.5% for women, Gross graduation ratio (ISCED 6 and 7, First degrees) is 5.5% for men and 3.3% for women. (UNICEF, https://www.unicef.org/niger/education) and UNESCO (http://uis.unesco.org/en/country/ne).

To the best of our knowledge, no recent studies were conducted in the analysis of knowledge, attitudes and practices of women in relation to breast cancer in Niger. The country does not yet have an operational cancer policy/strategy/action plan (WHO, Cancer Country Profiles,2014). In this paper, we used and adapted Breast Cancer Awareness Measure, (BCAM) to assess knowledge, practices and attitudes of women in Niamey and Zinder.

2.Methods

2.1.Study design, sampling and data collection

This study was conducted in Niamey and Zinder regions of Niger.Niamey is the capital city of the country, located in the south west, andhosting the national reference hospital, where the majority of cancercases are diagnosed and treated. Zinder is the most populated region ofthe country (3,539,764 inhabitants (20.7 %), it lies at the crossroads ofthe main east-west road and the north-south route from the desert toNigeria. The region is also hosting a second national reference hospital. The study targeted women aged from 25 and above to participate to the survey. The lower limit age of 25 was set because the incidence of BCbelow that age is documented to be extremely low. In fact, this is the category of women that would be more likely to be concerned with breast cancer as compared to more younger women. Niger women average age is 20 years, the population is young with proportion of people less than15 years old reaching 51.7% and women being 50.3 % of the overall population (National Census data, RGPN, 2012 INS). The sampling frame was composed by a list of villages from the health districts and the number of households in the two regions with population of women 25 years and older. A two-stage clustered random sampling was used to select women participating to the study. Commune in Niger adminis- trative division refers to a municipality, it's a settlement either urban or rural, it's composed of quarters/wards and small townships. A group of'communes', form a department and group of departments form a region. The country now has 10 regions, 36 departments and 265 communes. Firstly, villages/quarters were randomly selected out of the list of health districts. Secondly, households were randomly selected within the village using random walk technique. The interviewer started from the house ofthe head of village (usually centre of the village (for rural area) or the quarter (for urban area), throwed a pen in the air and started the selec- tion of the households from the direction indicated by the pen. The first house was selected and women within the household were asked to participate to the survey, this was done until the end of the street. Finally, women were randomly selected within these households as primary sampling units. The required sample size was calculated based on a 95% confidence interval, assuming that 50% of women know the basics of BC with a correction of design effect for cluster. We assumed an average number of 7 persons per household (National Institute of Statistics reference from the last 2012 population census). The collected data was analysed using R version 3.4.0 Epidata analysis v2.2.2.183 and IBM SPSS Statistics 24. All confidence intervals were computed with 5% error margin. The questionnaires were conducted using face to face interviews.The questionnaire was orally administered using Haussa (Maradi) and Djerma (Niamey) languages. The original questionnaire in English was translated by certified language translation and data collection institute (http://www.rem-africa.com/) prior to data collection. Data collectors speak both Haussa and Djerma, it should be noted that majority of women in Niger Speak Haussa. Two teams (one for each region) of two data collectors were used for this survey, moreover each team had a supervisor. The teams used 4*4 cars for field works and were paid at local rate as daily workers. A two-day training was organised in ReM-Africacabinet in Niamey to familiarize the team with the survey protocol. The first author supervised the data collectors to ensure the compliance with the survey protocol.

The study was approved by directorate of research and studies board, (Direction des etudes et Recherche), DER, Niger republic ministry health, by authorization letter (04712/MSP/SG/DEP/DER on 21-12-2017). Informed consent was obtained for each respondent participating in the study.

The aim of the study was to assess women's knowledge, attitudes and practices related to BC and identify the factors associated with this knowledge.

2.2Knowledge score construction

We constructed a knowledge score variable for each respondent woman to assess an overall answer and estimate her level of knowledge and breast cancer awareness. This was done using the WHO breast cancer rating scale (https://www.ncbi.nlm.nih.gov/pmc/articles/PM C1514477/). We selected main factors associated with breast cancer like family history, maternity, breastfeeding and age. A scan of risk fac-tors, protective factors, symptoms and warning signs was conducted to complete the BCAM items on symptoms and risk/protective factors. A 5- point Likert scale was used for assessing knowledge of women related to BC.

A Weighting of the knowledge factors was done to substantiate and allow some leverage for important risk factors generally accepted (WHO) but also accounting for context specific factors. Globally, correct answers

were given points (see Table 1 below) and a wrong answer was givenzero. Mammography is not that much common in Niger context (as ofJanuary 2018, the data collection period, only one mammography ma-chine was available for the whole country and it was located in Niamey).It is accessible only to few high income women or women referred underspecific conditions. In Niger, screening is often done using clinical breastexamination. Hormone replacement therapy is also not common. Asshowed in the descriptive results, only 0.4% (0.2–1.3) of Niger Womensmoke and 0.7% (0.3–1.7) of them drink alcohol, so even if these areknown established risk factors, they do not seem to be very relevant inNiger context, so we did not weigh them. Breastfeeding, maternity,physical activity, breast self-examination, clinical breast examinationand age-related factors were weighted to account for their relativeimportance. Some important potential BC symptoms were also weighted.In general, women should have minimum half of the overall knowledge score (18 total points) to be labelled as aware of breast cancer.

In this study, "higher education" refers to educational level above secondary school. By "rural", we mean areas (township, quarters, com- munes) that are officially declared rural by administrative authorities, would this be next to urban areas, as this is the case in Niamey. "Breast feeding attitude" refers to women that use to breastfeed their children months after birthhood.

2.3.Generalized Linear Model

A Generalized Linear Model was built where knowledge score was used as a response variable to assess its relationship with other predictors related to socio demographic, practice and attitude features. The response variable, knowledge score, was used to classify women based on their answers into those aware of breast cancer (was coded as response variable 1) and those not aware (was coded as response variable 0).A generalized linear model through Ordinary Logistic Regression, OLR (ignoring clustering) and through Generalized Estimating Equations (GEE) (Molenberghs and Verbeke, 2005), accounting for clustering at health centre levels were used to model the odds of being aware of BC accounting for predictors.

3.Results

3.1.Description of the sample

The questionnaire was basically administered to 675 women in thetwo regions historically hosting national reference hospitals, Niamey and Zinder. Niamey is the capital city and Zinder the most populated region in Niger. Households were selected within health districts in 'commune 2', 'commune 3' and 'commune 4' in Niamey region and Goure, Miriahand Zinder in Zinder region.

The average age of women that participated to the survey was 39.2years (38.2–40.3), 79.1% (75.9–82.0) of them were married and 46.5% (42.8–50.3) from rural areas. Moreover, 48.4% (44.7–52.2) were not educated, only 5.5% (4.0–7.5) had higher education. The average num- ber of children per woman was 4.6 (4.3–4.8). The average age of menarche was 14.1 years (13.9–14.3). Hausa remains the main ethnic group (53%) followed by Djerma (17%). 96.9% were Muslim, and 2.7% Christian. 43% (39.7–47.2) of the survey participants were 'housewomen' or unemployed while 20% (17.2–23.2) were vendors. Only 0.4%(0.2–1.3) of the responders smoke and 0.7% (0.3–1.7) drink alcohol. 75.6% (72.2–78.6) of the interviewed women had a breastfeeding atti-tude with 31% (26.9–55.2) doing exclusive breastfeeding. 42.2% (38.6–46.0) of women took oral contraception and 35.5% (32.2–39.4)

Table 1. Knowledge score construction: KAP Survey Breast Cancer – Niger 2018, Women.

Knowledge of symptoms	Yes	I dont know-no	weighting	Score
- Change in the position of your nipple	1	0	no	1
- Pulling in off your nipple	1	0	no	1
- Pain in one of your breasts or armpits	1	0	yes	2
- Puckering or dimpling of your breast skin	1	0	no	1
- Discharge or bleeding from your nipple	1	0	no	1
- Nipple rash	1	0	no	1
- Redness of your breast skin	1	0	no	1
- Change in the size of your breast or nipple	1	0	yes	2
- Change in the shape of your breast or nipple	1	0	yes	2
- A lump or thickening in your breast	1	0	yes	2
- A lump or thickening under your armpit	1	0	yes	2
maximum weighted score for symptoms				16
Knowledge of risk and protective factors				
- Alcohol intake	1	0	no	1
- Smoking (chewing tobacco)	1	0	no	1
- Nulliparity and late maternity	1	0	yes	3
- Physical inactivity and obesity	1	0	yes	2
- Breastfeeding	1	0	yes	3
- Early maternity	1	0	yes	2
- Balanced diet and lifestyle	1	0	no	1
- Age	1	0	yes	2
maximum weighted score for risk and protective factors				15
Knowledge of Breast cancer good practice				
Breast self-exam (once a week or a month)	1	0	yes	2
Clinical examination (Yes or No)	1	0	yes	2
Mammography (Yes or No)	1	0	no	1
maximum weighted score good practice				5
Overall maximum knowledge score (symptoms þ risk and protective factors þ good practice)				36

did not practice contraception at all. Finally, 28.3 % (24.9–31.9) had anabortion history.

3.2. Overall knowledge of breast cancer

Table 2 shows that overall women's knowledge of breast cancer is low, only 41.6% (37.8–45.4) were aware of breast cancer following the retained definition (cf. knowledge score construction in methodology section). In the paragraphs below, we further discuss each dimension of breast cancer knowledge.

3.3. Women's knowledge of breast risk and protective factors

Overall women's knowledge of breast cancer risk and protective fac- tors remains poor, it only reached 27.4 % (24.0–31.0). Table 3 and Table 4 summarize women's appraisal of breast risk and protectivefactors.

Only 36.2% of the interviewed women were convinced that long termsurvival (longer than 5 years) is common when BC is treated in an early stage.

3.4. Women's knowledge of breast cancer warning signs

It could be seen from Table 5 that most of Niger women considered change of size 58.1% (54.4–62.2) and shape 57.8 % (54.1–61.6) of their breast as a warning sign for BC. Change in the position of the nipple was considered as a warning sign by 65.8 % (62.2–69.6) of women. Pain inone of your breasts or armpit was considered a symptom by 66.3% (62.8–70.2), discharge or bleeding from your nipple by 61.8% (61.8–65.6). "Redness" of your breast skin (adapted in this context as "Change in the colour aspect of the skin") was considered as a symptom by 62.1 % (58.1–65.6) and 'A lump or thickening under your armpit' by64.5 % (61–68.4). Pulling in of your nipple 48.9% (44.7–52.4), puck- ering or dimpling of your breast skin 46.4 % (42.6–50.3) and 'nipple rash' 52.2% (48.1–55.7) were not considered by a (borderline) majorityof women as breast cancer warnings signs.

In general, women had an overall acceptable level of knowledge of breast cancer symptoms 65% (61.3–68.7), anyhow, a higher level of knowledge was demonstrated here compared to the one regarding risk and protective factors.

Breast examination, mammography and history of screeningparticipation

The proportion of women who did not have any history of partici-pation in BC screening is relatively high as indicated in Table 6. The main reasons for not participating in breast cancer screening include the lack of facilities or hospital in the area 20.9% (15.3–26.4) and lack of money (transport) 34.9% (28.5–47.1). Nevertheless 8.5% (5.1–11.9) of the interviewed women declared not to participate in breast cancer screening because the doctor is a man. In Niger, very often screening is done through clinical breast examination. The extreme majority of women declared to go to the doctor once facing BC symptoms. Nevertheless, a minority expressed the attitude of going to a traditional healer. Some women declared family consultation as first reaction when confronted with BC symptoms. The majority intend to participate in BC screening in future. Some of them participated in cervical cancer and HIV screening in the past, but manifested more enthusiasm to breast cancer screening.

If we consider the knowledge of BC good practice as defined earlier, a pooled combination of (breast self-examination, clinical breast exami- nation and mammography), only 16.9% (14.2–19.7) of women can be classified as being aware of breast cancer good practice.

3.5.Factors associated with knowledge of breast cancer

Table 7 shows the results of modelling of odds of being "breast cancer aware" given socio demographic and specific predictors. We fitted bothOLR and GEE models.

Considering OLR, we found the odds of being aware of breast cancer associated with age, breastfeeding practice, clinical breast examination, area, and participation to BC screening. In fact, the odds of being aware of BC is 3 times higher for a woman doing exclusive breastfeeding as compared to one who does not. The odds of being aware of BC of women doing clinical breast examination is twice that of a woman who is not doing clinical breast examination. Women that have participated in breast cancer screening are half as likely to be aware of breast cancer compared to those who don't participate. Younger women are more likely to be aware of breast cancer compared to older ones. Women in the capital city were less aware than women in the most populous township, even though administratively this is considered rural. This is more likely due to administrative classification, in fact, according to the latest General Population Census (Décret N° 2011-059/PCSRD/ME/F DU 27 Janvier, 2011), Niamey the capital city had a 95.2% rate of urbanization and many townships are classified rural while they have quite an urban profile, with growing population and middle income.

Considering GEE results, thus accounting for within health centre clustering, we found the following results. In fact, Niger women that consult in the same health centre are more likely to see the same health professionals and receive the same awareness programs. Clinical breast examination, age and area of residence were found to be associated with breast cancer knowledge. The odds of a woman that practices clinical breast examination is 2.25 higher than of one who is not. Urban women were less likely to be aware of breast cancer as compared to rural women. Younger women were more likely to be aware of breast cancer. We observed an association between knowledge of breast cancer good practice and number of children, women with more children were more likely to be aware of breast cancer good practice.

4.Discussion

Although the knowledge score was constructed somehow like acomposite multidimensional score, overall women's knowledge of breast cancer in Niger was found to be low. Dimensions where women showed specific low levels are knowledge of breast cancer risk/protective factors and knowledge of "good practice". The majority of women did not agree that smoking and alcohol are breast cancer risk factors. This could be explained by the insignificant proportion of women who smoke or drinkin the survey sample, which is representative of the Niger community in general due to religious and personal beliefs. Smoking and alcohol use were documented historically to be low in Niger. Fewer women smoke inNiger than on average in low-HDI countries, adult women smoking (% using tobacco daily for above 15 years old) in 2015 is only 0.1%. Ac- cording to the latest WHO data published in 2017, alcohol deaths in Niger stands only for 0.11% of total deaths. The age adjusted death rate is 1.80 per 100,000 of population. Alcohol morbidity prevalence estimates for men are 0.09 and 0.01 for women. Niger women also did not recognize physical inactivity and nulliparity as a breast cancer risk factor.

Table 2. Women's overall knowledge of breast cancer.

Women's knowledge of breast cancer	Overall knowledge % – (95% CI)	Knowledge of symptoms	Knowledge of risk and protection factors	Knowledge of good practice
Aware	41.6 (37.8–45.4)	65.0 (61.3–68.7)	27.4 (24.0–31.0)	16.9 (14.2–19.7)
Not aware	58.4 (54.6–62.2)	35.0 (31.3–38.7)	72.6 (69.0–76.0)	83.1 (80.3–85.8)

Table 3. Breast cancer risk factors.

Risk factors	Disagree	NAD	Agree
Alcohol intake	37.8 %	22 %	40.2 %
Smoking	23.6 %	20.4 %	56 %
Nulliparity and late maternity	42.2 %	28.1 %	29.7 %
Physical inactivity and obesity	39.3 %	33.4 %	27.3 %

NAD: Neither agree nor Disagree.

Table 4. Breast cancer protective factors.

Protective factors	Disagree	NAD	Agree
Breastfeeding	31.9 %	23.4 %	44.7 %
Early maternity	34 %	30.4 %	35.6 %
Balanced diet and lifestyle	35.9%	21.9 %	42.2%

Table 5. Breast cancer warning signs.

Breast cancer warning signs	Yes		No		I don't know
Change in the position of your nipple:	65.8	(62.2–69.6)	25.9	(22.5–29.5)	8.3 (6.2–10.4)
Pulling in off your nipple	48.9	(44.7–52.4)	39.9	(36.4–44.0)	11.3 (9.0–13.8)
Pain in one of your breasts or armpit	66.3	(62.8–70.2)	24.3	(21.1–27.6)	9.3 (7.1–11.6)
Puckering or dimpling of your breast skin	46.4	(42.6–50.3)	39.1	(35.6–42.9)	14.4 (11.8–17.3)
Discharge or bleeding from your nipple:	61.8	(61.8–65.6)	28.0	(28.0–31.4)	10.2 (10.2–12.6)
A lump or thickening in your breast	60.1	(56.2–64.1)	27.1	(23.4–30.4)	12.8 (10.3–15.6)
Nipple rash	52.2	(48.1–55.7)	33.9	(30.6–37.7)	14.0 (11.4–16.9)
"Redness" of your breast skin	62.1	(58.1–65.6)	27.7	(24.4–31.3)	10.1 (7.7–12.5)
A lump or thickening under your armpit	64.5	(61–68.4)	26.7	(23–30.4)	8.8 (6.7–11)
Change in the size of your breast or nipple	58.1	(54.4–62.2)	30.2	(26.8–33.8)	11.7 (9.3–14.3)
Change in the shape of your breast or nipple	57.8	(54.1–61.6)	29.4	(26.3–32.9)	12.7 (10.3–15.4)

Table 6. Screening, intention, attitudes and practice of women related to BC.

Screening, attitudes and practice of women	Yes - % (95% CI)	No - % (95% CI)		
Did you participate in BC screening in the past?	25.2 (22.1–28.6)	74.7 (71.3–77.8)		
Do you intend to participate to BC screening?	65.2 (61.5–68.7)	34.8 (31.3–38.5)		
Did you already undergo a mammography?	20.1 (17.3–23.3)	79.6 (76.3–82.4)		
Did you practice BSE?	32.7 (29.3–36.4)	67.1 (63.5–70.5)		
How often do you practice BSE?			% (95% CI)	
		Rarely	53.4	(48–60.6)
		A least once in 6 months	23.1	(17.6–29)
		At least once a month	16.3	(11.8–21.7)
		At least once a week	6.3	(3.2–9.5)
What do you do if you have BC symptoms?		Go to doctor	93.8	(91.7–95.4)
		Consult my family	3.3	(2.2–4.9)
		Traditional healer	2.2	(1.4–3.6)
		Buy drugs myself	0.7	(0.3–1.7)

These findings correspond with those of Azubuike SO, 2017 who recently found a generally poor knowledge of BC among women in Benin city, Nigeria, whose knowledge concerning breast cancer risk factors was also worse than concerning signs and symptoms. Okobia et al., 2006 in a study in Nigeria also found participants to have a poor knowledge of breast cancer with a mean knowledge score of only 42.3%. Moreover, Kohler et al., 2017a, b in a study in Malawi also found that women know more about breast cancer symptoms than about breast cancer risk factors, like in our study findings. Opeku, 2012 observed a low level of breast cancer knowledge within the women population in Ghana. A recent literature review on "Symptom awareness measures for breast and cervical cancer in Sub-Saharan Africa" conducted by Githaiga et al., 2017 summarized studies all reporting a generally low level of breast cancer awareness in the women population in sub-Saharan Africa. Only 27.0% (23.8–30.4) of Niger women have reported to practice clinical breast examination with a general practitioner, it should be noted that this was found to be associated with breast cancer knowledge. In fact, BC in Niger is done using clinical breast examination rather than mammography which is not available or widely accessible in the country. 32.7% (29.3–36.4) of women reported to practice breast self-exam. While breast self-examination is important, the meta-analysis conduct- ed by Hackshaw and Paul, 2003 in Russia and China showed its low

Table 7. Generalized linear model results: Being aware of breast cancer (OLR and GEE).

Risk factors	OLR					
	B coef- (P-value)	Adjusted OLR – (95% CI)		Adjusted OLR P-value	Exp-Coef GEE)-P-value	
Intercept	0.32 (0.80)				0.62	(0.715)
Age	-0.02 (0.008)	0.98	(0.96–0.99)	0.008	0.98	(0.055)
Menstrual age	0.09 (0.98)	1.11	(0.99–1.22)	0.085	1.03	(0.448)
Race	-0.04 (0.75)	0.99	(0.51–1.91)	0.989	0.83	(0.579)
Zone (urban/rural)	-1.242 (<0.001)	0.29	(0.20–0.44)	<0.001	0.34	(<0.001)
Children number	0.03 (0.37)	1.04	(0.96–1.12)	0.377	1.09	(0.740)
Breastfeeding practice	-0.39 (<0.08)	0.68	(0.44–1.05)	<0.08	1.17	(0.540)
Exclusive breastfeeding	1.20. (<0.001)	3.34	(2.12–5.26)	<0.001	1.34	(0.135)
Breast self-examination	-0.09 (0.60)	0.90	(0.60–1.36)	0.671	1.20	(0.550)
Clinical breast examination	0.71 (<0.001)	2.04	(1.31–3.16)	0.003	2.25	(<0.001)
Breast cancer screening	-0.64 (0.004)	0.53	(0.34–0.82)	0.004	0.87	(0.517)
Other screening	-0.30 (0.51)	0.74	(0.30–1.84)	0.521	1.30	(0.582)

Hosmer and Lemeshow goodness of fit (GOF) test: X^2 ¼ 20, df ¼ 8, p-value ¼ 0.007.

impact on mortality. 79.6% (76.3–82.4) of women have never had a mammography which is only available at central level. It's often docu- mented that in sub-Saharan Africa, mammography should not be the way forward regarding screening and early detection (Black and Richmond, 2019). 3.7% (2.4–5.3) of women participated in HIV and cervical cancer screening in the past.

We found that women living in urban and peri urban areas to be less likely to be aware of breast cancer compared to those living in rural areas. Niamey being the capital city, almost all women consult a doctor in an urban health centre though these are administratively conceived to be rural contrasting the recent urbanization phenomena. Ann Muthoni and Ann Neville Miller, 2010 revealed a difference between rural and urban Kenyan women's knowledge and attitudes regarding BC and BC early detection measures in a qualitative study. In fact, urban middle-income women were more informed about breast cancer risk factors and early detection measures as compared to other groups including urban low income and rural low-income women. Women with history of partici-pation to breast cancer screening were half as likely to be aware of BC compared to those who don't participate, this is surprising, maybewomen who know less on breast cancer are the ones more motivated to participate to screening.

Educational level was not found to be associated with breast cancer awareness. It should be noted that in the general women population, educational level in Niger is not that much heterogenous, in our sample only 5.5% had higher education. Trupe et al., 2017 in a study in Limpopo, South Africa, could not find an association nor between educational level neither between age on the one hand and breast cancer awareness on the other hand. Nevertheless, some studies established an association be- tween breast cancer awareness and educational level in sub SaharanAfrican context in Nigeria (Okobia et al., 2006) and in Ghana (Opoku, 2012). We found age to be associated with breast cancer awareness with younger women having more awareness than older ones, in line with findings by Allam and Abd Elaziz 2012. (Azubuike et al., 2018) statedthat younger age profile of BC women in sub-Saharan Africa is subject to controversies.

5.Conclusion

Niger women were found to have a relatively low level of breast cancer awareness. Knowledge of risk/protective factors and breast cancer good practice were main factors downscaling this knowledge. Meanwhilewomen's knowledge of breast cancer symptoms appeared to be accept- able. Clinical breast examination, age, area of residence, breastfeedingand history of participation in breast cancer screening were found to be associated with breast cancer knowledge using OLR. Using GEE, only clinical breast examination, age and area of residence were found to be associated with overall breast cancer knowledge.

This study reported an overview of Niger's women knowledge of breast cancer and can contribute in guiding awareness programs for screening/early detection. Awareness programs in Niger should promote clinical breast examination, as mammography is not common, and target older women, both in rural and urban areas, with focus on breast cancer risk/protection factors. Participation to breast cancer screening should be encouraged.

Limitations

The limitation of this study could find its root in the fact that it was conducted in the two regions of Zinder and Niamey, which historically host national reference hospitals. The study could therefore contain bias in terms of reproducibility in the whole country. Results need to be interpreted within the regions framework. Lack of wide access to equipment of mammography could introduce a bias in the proportion of women reporting having undergone a mammography, as during the period of the survey (January 2018), only one mammography machine was available in the whole country and was in the capital city.

6.Policy recommendations

- Focus breast cancer awareness programs on knowledge of breast cancer risk/protective factors and breast cancer good practice as these are areas of which women know the least.
- Support the implementation of cancer national policy in the country with support of WHO
- Awareness programs should target different age classes but focus on older women
- Design a strategy to shift from a clincial breast examination to a mammography screening program in Niger.
- Provide and decentralise mammography units and build mutilateralpartnerships to support women to have financial access to breast cancer screening.
- Design a stategy to encourage women to participate in breast cancer screening
- A national cancer policy should include awareness programs that are designed to increase earlier diagnosis of symptomatic BC disease.

Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Declarations

Author contribution statement

A. Abdou: Conceived and designed the experiments; Performed the experiments; Analyzed and interpreted the data; Contributed materials, analysis tools and data; Wrote the paper.
G. Van Hal: Conceived and designed the experiments; Analyzed and interpreted the data; Wrote the paper.
I. Dille: Conceived and designed the experiments; Wrote the paper.

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Chapter five

What can 27 years of Niger cancer registry tell us about breast cancer epidemiology? Incidence of breast cancer from 1992 to 2018 in Niger

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Breast cancer (BC) is a leading cause of cancer morbidity and mortality within the female population in sub-Saharan Africa. Growing cancer incidence and mortality are multidimensional, and often associated with the so-called ''westernization'' of lifestyle in African countries, including Niger, where there is no recent update of the cancer registry. The intent of this paper was to analyze 27 years of Niger cancer registry data and produce updated cancer trends and figures. The Niger cancer registry was established in 1992 and compiled on Canreg4. It is a member of African cancer registry network. The total number of cases included in this study was 12,340 patients and the study was conducted in 2020. Incidence trends (joint point) and survival (Kaplan Meier and Cox proportional hazards model) were used to analyze the data. Breast cancer showed high frequency among women, 18.9% (18.3-19.6) followed by gynecological cancers, with cervical and ovarian cancers accounting for 11.0% (10-12.1) and 5.4% (5.0-5.8) of total cases, respectively. Followed by liver cancer, at 13% (12.4-13.6), skin 7.1%
(5.5-7.8) and colon/rectum cancer at 4.2% (3.4-5.1). The average cancer patient age was 44.7 (44.4-45.0) years. Despite a slow startup, cancer case registration in Niger showed a significant increase, with an annual percentage change (APC) of 3.7 (1.5-6.0), from 1992 to 2018. Overall, 14.1% (13.5-14.7) of cancer patients reportedly died. Breast cancer survival was found to be associated with sex, age and diagnostic method. Cancer incidence in Niger is growing significantly; breast and gynecological cancers are the most frequent and reported mortality data suggest low survival in Niger. Multicentric cancer screening centers and systematic reporting are necessary for a wider coverage of the cancer registry.

Key words: Niger, cancer registry, breast cancer, survival.

INTRODUCTION

Breast cancer (BC) remains a leading cause of cancer morbidity and mortality within the female population (Youlden et al., 2012; Samuel et al., 2017; Joko-FW et al., 2020); its public health burden, in sub-Saharan Africa

specifically, is not well established (Mohammed and Harford, 2014; Adeloye et al., 2018). Growing cancer incidence imultidimensional, it is often associated with the so-called ''westernization'' of lifestyle in African countries (urbanization, diet change, alcohol/tobacco intake) and even changes in the maternal profile of women (Bray et al., 2018). In Niger, BC has been identified as the main cause of cancer-related incidence and mortality accounting for 18.3 and 14.6% of the overall cancer burden in the country, respectively (WHO Cancer Country Profiles, 2020). The Niger population is very young, as it is in many sub-Saharan African countries. According to the 2012 Niger Population Census (RGPH, 2012), the Niger population was estimated to be 17.138.707, with8.518.818 men (49.7%) and 8.619.889 women (50.3%).The current population is approximately 24.088.564,based on the latest United Nations data projections (*https://worldpopulationreview.com/countries/niger-population/*). Citizens aged over 15 years have a cumulative proportion of 48.3%. Age groups 0-4 years (21.6%), 5-9 years (17.5%) and 10-14 years (12.6%)have the highest proportions in the Niger population age structure. 69% of the Niger population is rural, while 31%is urban. Niger also has one of the lowest literacy rates inthe world (UNICEF, https://www.unicef.org/niger/education) and UNESCO (http://uis.unesco.org/en/country/ne).

According to WHO Cancer Country Profiles 2020, the country does not yet have operational cancer management guidelines or palliative care included in their operational integrated NCD plan. In addition, there is no national breast cancer screening program. Mammographic screening facilities are very restricted. There are 2.3 radiologists and 1.2 public cancer centers per 10,000 cancer patients in the country. Pathology services and palliative care are rated as "generally not available'' in the country. A national center for the fight against cancer (Centre National de Lutte Contre le Cancer, CNLC) was recently created (2018). It has chemotherapy services but does not yet have radiotherapy or mammography facilities. In the absence of mammography in low-income countries like Niger, screening methods such as clinical breast examination or breast self-examination, if well performed, could be alternative options (Black and Richmond, 2019; Onyije et al., 2010). Studies in relation to the epidemiology of cancer in Niger are scarce. Some studies (Zaki et al., 2013; Mamoudou et al., 2013; Nayama et al., 2006)contributed basic descriptions of cancer patients in the country without a deep epidemiological analysis of cancer registry data. Younger age and late diagnosis were reported as common features of BC patients in Niger(Zouladeny et al., 2015).

The latest published analyses of Niger cancer registry data were in 2013 and they analyzed data up to 2009 (Salamatou et al., 2013), after more than a decade, thereis a real need to produce an updated analysis of the cancer registry data in the country.

METHODOLOGY

The Niger cancer registry data

The Niger cancer registry data is hosted by the Laboratory of Pathological Anatomy and Cytology, (which provides histopathology and cytology services for the whole country) Faculty of Health Sciences, Abdou Moumouni University, Niamey, Niger. It was established in 1992 and is a member of the African cancer registry network. The data is compiled on CanReg4, a tool produced by the International Agency for Research on Cancer (IARC) in collaboration with the International Association of Cancer Registries(IACR).

The data is collected via a network of hospitals, primarily the university teaching hospital where it is physically located and to which most of the cancer patients are primarily referred. Then follow the maternity reference hospital (Maternity Issaka Gazobi, MIG), the national reference hospital, the national center on reproduction, the regional hospitals and even recently some private clinics. There is ateam (two pathologists, one data manager, one cancer registrar, a nurse, often assisted by medical students, and the epidemiologists of the national center for the fight against cancer) who conduct the data collection and entry. They travel around the different hospitals in Niamey and the inpatient services (surgery, urology, medicine, gynecology, pediatrics and biology laboratory services) to collect data (see data collection form in the annexes section) that arerequired by the registrar. The team also consults records they findin these services to track cancer cases. As of 2019, the WHO officein Niger and the West African Health Organization (WAHO) also provides support to the cancer registry. Data collection is not systematically done in view of the limited available humanresources. Quality control tools are in place to ensure accuracy and refinement of the collected data. For instance, some variables such as age are compulsory for registering the patient and there is duplication recognition. The coverage of the Niger cancer registry isnot very high but is continuously growing. While it was limited to Niamey and the surroundings in the first phase of its implementation, the support of the national center for the fight against cancer has helped the network of data collection extend to other parts of the country, with periodic supervision and data collection trips by the cancer registry team. The data is compiled using the International Classification of Disease - Oncology (ICD-O) and Classification Internationale des Maladies pour l'oncologie (CIM-O, third version-V3).

Data analysis and tools

The data was analyzed retrospectively in two steps: firstly, theoverall cancer database was analyzed to give statistical summaries and global incidence trends, and then a subset of data of all BC patients from 1992 to 2018 was analyzed to focus on BC disease.

Summary statistics

The proportion of cancer types, age, sex, ethnic group, maritalstatus, diagnosis method, stage and reported mortality were givenspecific attention. Frequencies, percentages and 95% confidenceinterval (CI) were computed in Epi data analysis v2.2.2.183 and IBM SPSS Statistics v27.

Trends analysis

A chronological evolution of reported cases from 1992 to 2018 was performed, and an annual percentage change (APC) was computed for the overall cancer registry data. A regression model was fitted using joint point analysis (https://surveillance.cancer.gov/joinpoint/), the reference population was obtained from the 2012 national census.

Survival analysis

Kaplan Meier curves were used to perform the first step of the survival analysis. Out of the 2347 BC patients introduced earlier, we took a data sample for the 10 years from 2009 to 2018 (1347 patients). This was to have the most recent overview of the reported BC mortality. Then a Cox proportional hazards model was used to assess factors associated with breast cancer survival using hazard ratio. R studio Version 1.3.1093 was used to perform these analyses.
The study was approved by the Head of the Laboratory of Pathological Anatomy and Cytology and the Dean of the Faculty of Health Sciences, Abdou Moumouni University, Niamey, Niger. Patients' nominal information was coded in the data set using a dossier ID.

RESULTS

Description of the sample

Overall cancer sample

According to results summarized in Table 1, the main types of cancer cases recorded in Niger, breast is the most common cancer 18.9% (18.3-19.6) followed by gynecological cancers with cervical and ovarian accounting for 11.0% (10-12.1) and 5.4% (5.0-5.8) of total cases, respectively. Liver 13.0% (12.4-13.6), skin 7.1% (5.5-7.8) and colon/rectum cancers 4.2% (3.4-5.1) are next in frequency.
About 60% of reported cancer cases in Niger are female, linked with the predominance of breast and gynecological cancers.
It was observed that two out of three cancer cases are diagnosed clinically in Niger, and most of the time, these clinically diagnosed cases are the ones presenting to the clinicians at late stage. Only 30% had a histological confirmation. Reported mortality (the proportion of cancer patients that died from the startup of cancer registry) for all cancer cases is 14.1% (13.5-14.7).
From this sample, the main reported ethnic groups are Djerma-Sonrai 49.9 (49.1-50.8) and Haussa 34.7 (33.8-35.5). It should be noted that from the country's general statistics, the main ethnic groups in Niger are Hausa(54.0%) and Djerma/Sonrai (22.2%). We also have Tuareg (10.0%), Fulani (Peuhl) 6.5%, Kanuri 5.9%, other small groups include Gourmantchés, Arab and Tubu. Niamey is populated by many different ethnic groups, although Djerma and Haussa are the majority.
(44.4-45) years. The average age of male patients is 45.0 years (44.4-45.5) while the average age of female patients is 44.4 years (44.1-44.8).

Breast cancer patients

The average age of BC patients is 46.0 years (45.4 - 46.5). For male patients it is 54.7 years (51.1 - 58.2) while the average age for female patients is 45.7 (45.1- 46.2) years. Reported mortality for BC is 9.7%, that is, the proportion of cancer patients that have died since the startup of the cancer registry. It should be noted that not all death cases are systematically reported, and follow up of death cases remains a challenge, depending on patients' trajectory and information availability. 97.1% of breast cancer burden are female cases.
The two main ethnics groups of Djerma-Sonrai and Hausa are the majority. This reflects the main ethnic groups in Niger.

Stage of cancer cases

As for all cancers, diagnosis method for breast cancers is mainly clinical, then histological and cytological as explained earlier.

Trend analysis

Breast cancer incidence grew in Niger from 1992 to 2018 with a significant annual percentage change (APC) of 3.7 (1.5-6) from 1992 to 2018. Despite a slow startup, cancer data registration saw an increase from 2000 to 2010 with a boost in 2003. Recently, with the help of the National Center for the Fight Against Cancer, Ministry of Health teams started supporting data collection within the country for a wider coverage, which is why there is an increase from 2016 (figure 1).

Survival analysis, modeling of factors associated with BC survival

Overall BC survival was found to be low; it turned out to be 13% at 12 months. Both univariate and multivariate Cox proportional hazards models were fitted with age, sex, diagnosis method and marital status as covariates. Results are shown in Table 1 to 12.
On univariate analysis, sex and diagnosis method (histological) were associated with BC survival. Patients diagnosed with histological conformation had a lower hazard of dying. With multivariate analysis, a lower death risk

Table 1. Main types of cancer recorded from 1992 to 2018.

Cancer types	No.	Percent	(95% CI)
Breast	2347	18.9	(18.3-19.6)
Liver	1608	13.0	(12.4-13.6)
Cervical	1349	11.0	(10.0-12.1)
Skin	874	7.1	(5.5-7.8)
Ovarian	659	5.4	(5.0-5.8)
Colon and rectum	510	4.2	(3.4-5.1)
Blood	449	3.7	(3.1-4.3)
Bladder	403	3.2	(2.9-3.8)
Bone	396	3 .0	(2.4-4.7)
Stomach	362	2.8	(2.4-3.4)
Prostate	270	2.2	(1.9-2.5)
Eye	228	1.8	(1.5-2.4)
Lymphatic gland	218	1.7	(1.5-1.9)
Kidney	205	1.6	(1.5-1.8)

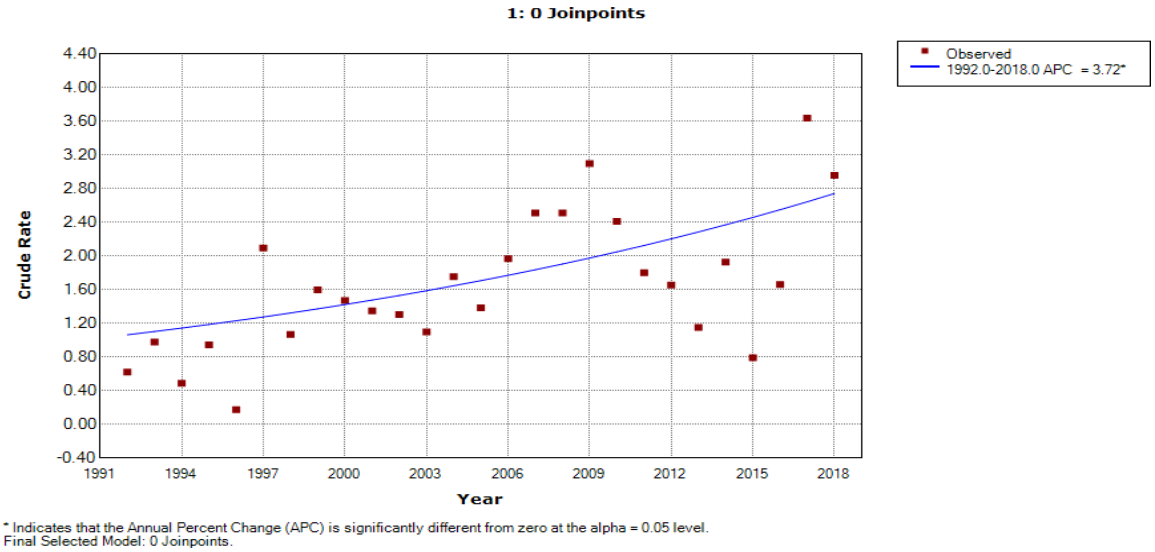

Figure1. Incidence of breast cancer trend.

was found also for patients with histological confirmation. Most of the time, patients with histological confirmation were undergoing treatment, mainly surgical. Many patients were diagnosed clinically and these include most liver cancer cases (Figure 2).

DISCUSSION

The current study demonstrated that breast cancer is the most common cancer followed by gynecological cancers

(cervical and ovarian) in Niger; this is in line with findings from Salamatou et al. (2013) who explored 17 years of cancer registry data in Niger (from 1992 to 2009). They reported that BC is the most frequent female cancer (27.4%) followed by cervical cancer (13.4%) and ovarian cancer (8.83%). Cancer affects more women than men in Niger. For BC, the majority of cases occur in women. The unbalanced sample size between the two sexes will not allow us to focus on comparison (Figure 3).

In this study, an overall average cancer patient's age of 44.7 (44.4-45) years and an average age for BC patients

Table 2. Sex distribution of patients.

Sex	No.	Percent	(95% CI)
Male	4963	40.2	(37.8-45.4)
Female	7378	59.8	(54.6-62.2)

Table 3. Ethnic group distribution .

Ethnic group	No.	Percent	(95% CI)
Djerma-Sonrai	6166	49.9	(49.1-50.8)
Hausa	4279	34.7	(33.8-35.5)
Touareg	802	6.5	(6.1-6.9)
Fulani/Peuhl	466	3.8	(3.5-4.1)
Kanuri-Manga	172	1.4	(1.2-1.6)
Gourmantche	78	0.6	(0.5-0.8)
Foreigners_Africa	253	2.0	(1.6-2.8)
Unknown	20	0.2	(0.1-0.3)

Table 4. Diagnosis method,

Diagnosis	No.	Percent	(95% CI)
Clinical	8045	65.2	(64.3-66.0)
Primary histology	3708	30.0	(29.2-30.8)
Macroscopy	293	2.4	(2.1-2.7)
Cytological	197	1.6	(1.4-1.8)
Histology metastasis	31	0.3	(0.2-0.4)
Biological	66	0.5	(0.4-0.7)

Table 5. Marital status of patients.

Status	No.	Percent	(95% CI)
Single	1400	11.3	(10.8-11.9)
Married	10227	82.8	(82.2-83.5)
Divorced	87	0.7	(0.6-0.9)
Widowed	406	3.3	(3.0-3.6)
Unknown	213	1.7	(1.5-2.0)

of 46.0 years (45.4 - 46.5) was found. Nayama et al.(2006) reported an average age of 36.5 years for cancer patients. Zaki et al. (2013) reported an average age of 44.1 years in BC women patients. Cancer patients' age is documented to be low generally in Africa as compared to other parts of the world (Joko-Fru WY, 2020;Dickens et al., 2014; Ibrahim and Oludara, 2012), as is also the casefor Niger (Figure 5).

This study found an increasing BC incidence trend in Niger over the 27 years of cancer registry. Many recent

Table 6. Sex distribution for BC patients.

Sex	No.	Percent	(95% CI)
Male	69	2.9	(2.3-3.7)
Female	2278	97.1	(96.3-97.7)

Table 7. Marital status for BC patients.

Marital status	No.	Percent	(95% CI)
Single	33	1.4	(1.0-2.0)
Married	2064	90.6	(89.3-91.7)
Divorced	38	1.7	(1.2-2.3)
Widowed	118	5.2	(4.3-6.2)
Unknown	25	1.1	(0.7-1.6)

Table 8. Ethnic group for BC.

Ethnic group	No.	Percent	(95% CI)
Djerma-Sonrai	1104	48.5	(46.4-50.5)
Haussa	828	36.3	(34.4-38.3)
Kanuri-Manga	36	1.6	(1.1-2.2)
Fulani/Pheul	102	4.5	(3.7-5.4)
Touareg	124	5.4	(4.6-6.5)
Foreigners_Africa*	51	2.2	(1.1-4.1)
Unknown	1	0.0	(0.0-0.2)

*Foreigners mean other African citizens, not from Niger republic but living there. It includes most of the neighboring countries (Togo, Benin, Burkina, Cote d'ivoire, Nigeria, Senegal…..).

Table 9. Stages of overall cancer cases.

Stage	No.	Percent	(95% CI)
0	2108	17.1	(16.4-17.7)
In situ	23	0.2	(0.1-0.3)
Localized	10189	82.5	(81.8-83.2)
Regional	26	0.2	(0.1-0.3)

studies reported a continuously increasing BC incidence in sub-Saharan Africa (Azubuike et al., 2018; Brinton et al., 2014). Reporting on the GLOBOCAN 2018, Bray etal. (2018) estimated the age standardized BC incidenceto be 37.3/100,000). In Western Africa, Sighoko et al. (2013) have analyzed trends of BC over two different periods in two population-based cancer registries, in Mali (1987-1997; 1998-2009) and in The Gambia (1988-1997;
1998-2006). They found that BC incidence rates have increased by 20% (incidence rate ratio (IRR)) 1.20 (1.07-1.35) in Bamako (Mali), with an annual percentage change of 2.0% (0.4-3.6). Moreover, they found a similar pattern in The Gambia for women under 50 years, IRR
1.47 (1.07-2.01). In the Niger context, the opening ofsome small-scale centers where cancer diagnosis is done, a cancer screening campaign from a non- governmental organization (SOS Cancer Niger), and the creation of the new national center for the Fight Against

Table 10. Stages of BC cases.

Stage	No.	Percent	(95% CI)
0	219	9.6	(8.5-10.9)
In situ	11	0.5	(0.3-0.9)
Localized	2033	89.4	(88.0-90.6)
Regional	12	0.5	(0.3-0.9)

Table 11. Diagnosis method for BC.

Diagnosis method	No.	Percent	(95% CI)
Clinical	1460	64.1	(62.1-66.0)
Histological	781	34.3	(32.4-36.3)
Cytological	31	1.4	(1.0-1.9)
Macroscopic	6	0.3	(0.1-0.6)

Table 12. Factors associated with mortality, univariate/multivariate Cox proportional hazards model/OLR.

Factor	Univariate CoxHR- (95% CI)	Multivariate CoxHR- (95% CI)	OLR AdjustedOR (95% CI)	Pr(>|Z|)
Age	1.13 (0.80- 1.59)	1.11 (0.78-1.57)	0.68 (0.47- 0.98)	0.04
Sex*	0.34 (0.12- 0.94)	0.41 (0.14-1.15)	0.79 (0.27-2.34)	0.68
Diagnosis**	0.64 (0.52- 0.78)	0.63 (0.52-0.78)	0.33 (0.19- 0.56)	0.0058
Marital status	1.0 (0.61-1.62)	0.91 (0.56-1.48)	0.72(0.48-1.07)	0.11

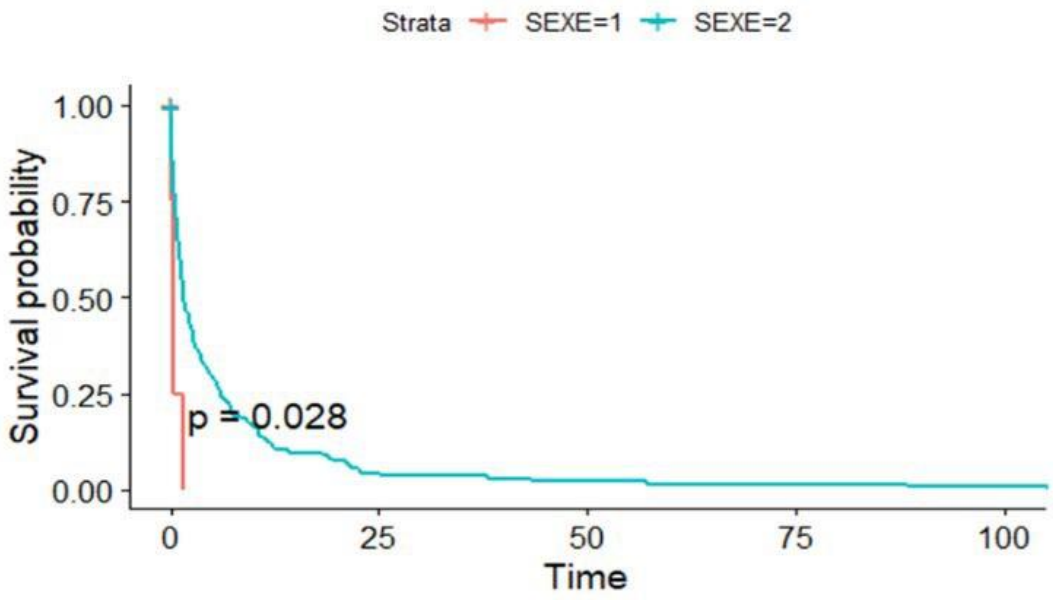

Figure 2. Breast Survival curves by sex (in months). Sex 1=Male, Sex 2=Female.

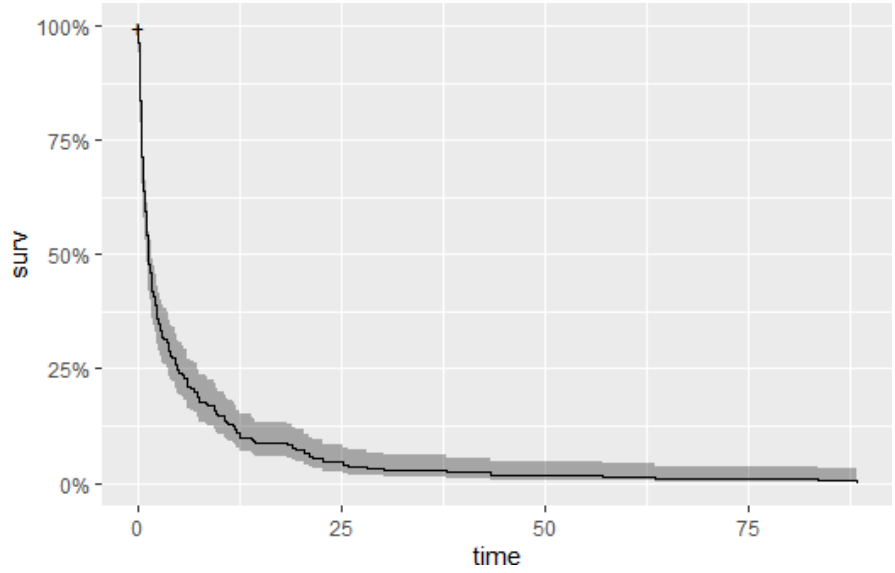

Figure 3. overall breast cancer survival by months

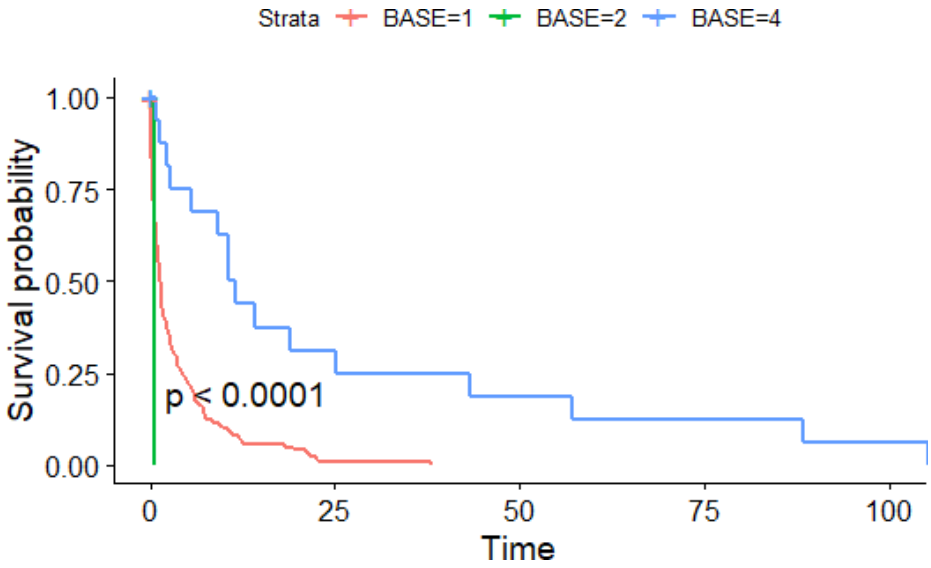

Figure 4. Survival curves by diagnosis.
Base 1: orange = clinical , base 4 : blue= Histological.

Cancer, have all contributed to the wider cancer screening scope and growing incidence.

Overall BC survival was found to be low. First of all, the reader should be cautioned that the Niger Cancer Registry is located in Niamey and patients coming from the 7 other regions of the country are not easily traceable for mortality information. Patient results are very often censored, incomplete information is available about the survival time and it is not absolutely clear whether death is due to cancer or other causes. In short, follow upremains a recognized challenge in the country, given the available resources of the cancer registry network. On univariate analysis, sex and diagnosis method (histological) were associated with BC survival. With multivariate analysis, we found only a higher hazard for patients with histological confirmation. Patients clinically diagnosed are mainly those that attend health centers at advanced stages, hence their higher mortality (Figure 4).

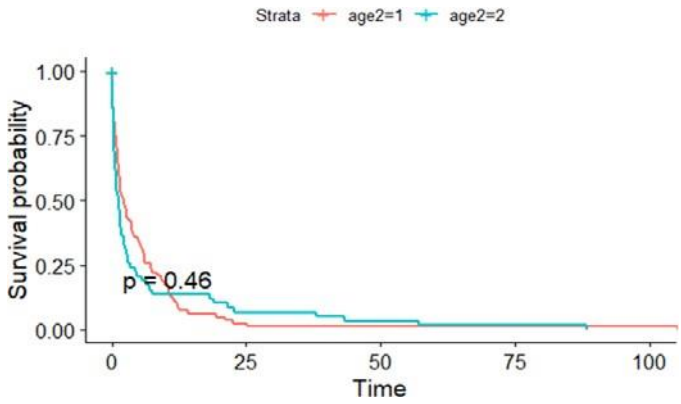

Figure 5. Survival curves by age group age group 1= >45; agegroup 2= ≤45.

Surgery or other treatments could only be palliative. The Breast Cancer Survival and Survival Gap Apportionmentin sub-Saharan Africa (ABC-DO) prospective cohortstudy by McCormack et al. (2013) was conducted at eight hospitals across five sub-Saharan African countries (Namibia, Nigeria, South Africa, Uganda, and Zambia). It reported about 50% (48-53), 3-year overall survival globally. Nevertheless, they observed significant variations between different countries (44% in Uganda, 47% in Zambia vs 36% in Nigeria which is closer toNiger). From this data, less than 10% of Niger patientshave 3-year survival. In a recent study by (Joko-Fru WY,2020) entitled "Breast cancer survival in sub-SaharanAfrica by age, stage at diagnosis and human development index: A population-based registry study'', age at diagnosis was found to be associated with increased mortality risk after adjusting for the effect of stage and country-level Human Development Index(HDI). They analyzed 2,588 BC cases, diagnosed in2008-2015 from 14 population-based cancer registries in12 countries: Benin, Cote d'Ivoire, Ethiopia, Kenya, Mali, Mauritius, Mozambique, Namibia, Seychelles, SouthAfrica, Uganda and Zimbabwe. (Allemani et al., 2015)found that five-year relative survival estimates range from12% in parts of Africa to almost 90% in the United States,Australia and Canada. In Saudi Arabia, the relativesurvival probabilities at one, three and five years from theincidence data were 96, 83 and 65%, respectively, withthe differential linked to a combination of early detection,access to treatment services and cultural barriers.

Conclusion

Cancer incidence and mortality are growing in Niger, and overall BC survival remains low. The prominence of breast and gynecological cancers explained the majority of female cancers. This study should contribute to setting out milestones for further research. Given the scarcity of epidemiological research on BC in Niger, there is need to conduct more studies, especially on cancer trends and survival.

Recommendations

Based on the findings of this, study, it could be recommended to strengthen screening and report to the cancer registry for a wider coverage. More human resources are needed to analyze laboratory samples. Main hospitals (at least the university teaching hospital and national reference hospital) should be equipped with mammography equipment.

Limitations

The limitations of this study include the coverage of the Niger cancer registry, especially in the first year of its creation, when the registry reported cancer cases in Niamey and the surroundings before expanding to inner regions of the country. Moreover, lack of proper information on some patient's follow-up can influence the survival of patients.
The study was approved by the Faculty of Health Sciences, Abdou Moumouni University, Niamey, Nigerand the Head of the Laboratory of Pathological Anatomy and Cytology (reference number: 0331/10-03-2020).

CONFLICT OF INTERESTS

The authors have not declared any conflict of interests.

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Chapter six

Main findings and general discussion

In Niger Republic, overall, literature on the epidemiology and public health scrutiny of breast cancer is very limited. The review based on the PRISMA model confirmed this by retaining only 6 articles out of 24 initially scanned and 14 articles reviewed. None of the screened papers had clinical trial methodology or survival analysis. Ly et al., (2011) reviewed studies on Breast cancer in Sub-Saharan African women in Pubmed from 1989 and 2009, and concluded that ''data on the epidemiology and biology of breast cancer in Sub-Saharan African women are still scarce and need more extensive studies''. In our study, no peer-reviewed paper was found on breast cancer screening. Zaki et al., (2013) and Nayama et al., (2006) reported a retrospective analysis of cancer registry data in Niger from 1992 to 2009. Both were descriptive approaches to breast cancer data. In addition, Nayama et al., (2006) explored 9 years (from 1992 to 2000) of Niger cancer registry data, found that gynecological and breast cancer represented 54.3% of women's cancers and 33.1% of diagnosed cancers for both sexes, with a patient mean age of 36.5 years. Zaki et al., (2013) found an average age of 43±17.53 years for breast cancer patients. Our review, scanning data from 1992 to 2018, revealed an average of 46.0 years (45.4 – 46.5) for breast cancer patients. Furthermore, in Niger, breast cancer is usually diagnosed in younger women than in developed countries. Ly et al., (2011), and Zouladeny et al. (2015) reported younger age of breast cancer, with 1/3 of cancers under age 44 In Niger. Cancer patients' age is documented to be low generally in Africa as compared to other parts of the world (Walburga Y J al.; 2020 , Dickens, C et al.; 2020; Ibrahim, N and M A Oludara; 2012).

So far, there has been no validation of BCAM in Niger and our paper established the first milestone on this topic in the country. Guthega et al. (2019), using the PRISMA model, found two papers on validation of the Breast Cancer Awareness Measure tool in Kenya (Wachira, 2017; Violet et al., 2015). We found that the BCAM was an acceptable, reliable and valid tool when applied to women and midwives in Niger. Nevertheless, it requires some refining to better suit some social and contextual factors. Wachira et al. [16] also suggested an adaptation for Kenyan women when translated into Swahili.

We documented that in Niger, overall, women's knowledge of breast cancer is low. A cross-sectional study, conducted in Niamey and Zinder regions, showed that only 41.6% (37.8–45.4) have an adequate level of breast cancer awareness. Women's knowledge of breast cancer risk and protective factors remains poor, and only reached 27.4 % (24.0–31.0). Only 27.0% (23.8–30.4) of Niger women have reported practicing clinical breast examination with a general practitioner, and it should be noted that this was found to be associated with breast cancer knowledge. Mamane et al. (2012) found that non-medical health professionals were mostly insufficiently informed about BC and diagnostic methods. 32.7% (29.3–36.4) of women reported performing breast self-examination. While breast self-examination is important, the meta-analysis conducted by Hackshaw and Paul, (2003) in Russia and China showed its low impact on mortality. But in Niger, Trupe et al., (2017) found that educational level was not associated with breast cancer awareness. It should be noted that in the general female population, educational level in Niger is not very heterogenous; in our sample only 5.5% had received higher education. Nevertheless, some studies established an association between breast cancer awareness and educational level in the sub-Saharan African context, in Nigeria (Okobia et al., 2006) and in Ghana (Opoku, 2012). We found age to be associated with breast cancer awareness, with younger women having more awareness than older ones, in line with findings by Allam and Abd Elaziz (2012). Azubuike et al., (2018) stated that the younger age profile of BC women in sub-Saharan Africa is subject to controversy.

We analyzed 27 years of cancer registry in Niger from 1992 to 2018. It revealed that breast cancer is the most common cancer recorded in Niger at 18.9% (18.3-19.6), followed by gynecological cancers, with cervical and ovarian cancers accounting for 11.0% (10-12.1) and 5.4% (5.0-5.8) of total cases, respectively. This is followed by liver 13.0% (12.4-13.6), skin 7.1% (5.5-7.8) and colon/rectum cancer 4.2% (3.4-5.1). About 60% of reported cancer cases in Niger are in female patients, with the predominance of breast and gynecological cancers, in line with findings from Salamatou et al., (2013).

It was observed that despite a slow startup, cancer cases registration in Niger showed a significant increase, with an annual percentage change (APC) of 3.7 (1.5-6.0) from 1992 to 2018. This is in line with other researches that established an increasing trend for BC in sub-Saharan Africa (Azubuike, Samuel O et al.; 2018, Brinton L A et al.; 2014, Sighoko D et al.; 2013, F. Bray et al.; 2018).

Overall, 14.1% (13.5-14.7) of cancer patients are reported as having died and BC survival was found to be low. First, the reader should be cautioned that the Niger cancer registry is in Niamey and patients coming from the 7 other regions of the country are not easily traceable for mortality information. Many patients are censored, in fact very often, and incomplete information is available about the survival time, which is not exactly known, and it is not absolutely clear whether death is due to cancer or other causes. In short, follow up remains a recognized challenge in the country, given the available resources of the cancer registry network. Patients clinically diagnosed are mainly those that attend health centers at advanced stages, and hence their higher mortality, as surgery or other treatments could only be palliative. Breast cancer survival and survival gap apportionment in sub-Saharan Africa (ABC-DO), a prospective cohort study by McCormack V al.; (2013) was conducted at eight hospitals across five sub-Saharan African countries (Namibia, Nigeria, South Africa, Uganda, and Zambia). It reported about 50% (48–53), 3-year overall survival globally. Nevertheless, they observed significant variations between different countries (44% in Uganda, 47% in Zambia vs 36% in Nigeria which is closer to Niger). From this data, less than 10% of Niger patients have 3 years survival. Breast cancer survival was found to be associated with sex, age and diagnostic method. In a recent study by Joko-F, W Y et al.; (2020) entitled “Breast cancer survival in sub-Saharan Africa by age, stage at diagnosis and human development index: A population-based registry study’’, age at diagnosis was found to be associated with increased mortality risk after adjusting for the effect of stage and country-level Human Development Index (HDI). They analyzed 2,588 BC cases, diagnosed in 2008–2015 from 14 population-based cancer registries in 12 countries (Benin, Cote d'Ivoire, Ethiopia, Kenya, Mali, Mauritius, Mozambique, Namibia, Seychelles, South Africa, Uganda and Zimbabwe). Zaidi and Hamdi (2015) found that five-year relative survival estimates range from 12% in parts of Africa to almost 90% in the United States, Australia and Canada. In Saudi Arabia, the relative survival probabilities at one, three and five years from the incidence date were 96%, 83% and 65%, respectively, with the differential linked to a combination of early detection, access to treatment services and cultural barriers.

Chapter seven

Conclusion and recommendations

Conclusion

Breast and gynecological cancers are the predominant cancers in women in Niger. Given the scarcity of epidemiological research on BC in Niger, there is need to conduct more studies, especially on cancer trends and survival.

While screening of breast and cervical cancer is conducted in Niger, its structured documentation is still lacking, given its importance in cancer prevention in this low-income country, which does not yet have a national breast cancer screening program and suffers from lack of equipment and human resources.

Breast cancer patients in Niger are younger compared to those in other parts of the world. A validation of the 'Breast Cancer Awareness Measure, (BCAM) for women and midwives' tool was conducted in Niger and can be used to assess women's and midwives' knowledge of BC.

Niger women were found to have a relatively low level of breast cancer awareness. Knowledge of risk/protective factors and breast cancer good practice were the main factors influencing this lack of knowledge.

Cancer incidence and mortality are growing in Niger, and overall BC survival remains low.

Recommendations:

- In Niger, efforts should be made to extend studies on the feasibility and acceptability of alternative screening methods adapted to low-resource countries.
  As governmental budget allocated to non-communicable diseases is limited, for instance, a mapping of breast cancer cases could be done to understand areas of provenance and put few available equipment like mammography there. Future studies can investigate alternative screening method adapted to the context.

- Given the specific profile of the country (highest fertility rate in the world, one of the youngest populations, one of the largest countries in Africa, poor workforce in public health), national and international research into public health in Niger should be enhanced and supported, and the country could be included in some multicentric BC clinical trials. Investment in research on cancer in general, and BC in particular, could bring clarity and inform clinicians about both the prevention and management of cancer in a country still struggling through its epidemiological transition.
  Niger should be considered for international multicentric breast cancer research. This will allow the country to gain international knowledge and experience in a transnational health approach and capacity building

- We recommend the support of multicentric cancer screening centers and systematic reporting to a national cancer registry for a wider coverage.
  The national center for fight against Cancer has started some advance mobile screening to increase coverage of national cancer registry. The ministry of health and other partners should increase human and financial resource to support that activity

- Given the large amount of clinically diagnosed cancer cases, more human resources are needed to promptly analyze samples brought to the laboratory; often patients wait a long time before getting their cytology and histology results because of the shortage of pathologists and cytologists.
  The training of qualified pathologists and cytologists should be supported at different levels including though international bilateral of inter university collaboration. On job training could also be organized with technicians from the faculty of heath science, university of Niamey.

- Main hospitals (at least the university teaching hospital and national reference hospital) should be equipped with mammography material.
  The government should increase financial resources allocated to national reference hospital to allow them to acquire at least mammography material.

- The country should have a national screening program with an updated analysis of cancer registry data.
  Regular analysis of breast cancer data should be done, and quality of mortality registration closely monitored

- When conducting breast cancer screening in Niger, female doctors would be more suitable than male doctors as 8.5 % (5.1–11.9 %) of women see a male doctor as a 'barrier'.
  From a cultural perspective, breast cancer programs especially the clinical dimension should be led by women clinicians as its an important factor of acceptance and patient adherence.

- In Niger, midwives could be used as ambassadors for breast cancer awareness as they are champions of exclusive breastfeeding and are more in contact with women during prenatal and postnatal consultations.

- Breast cancer awareness programs with a tailored tool should be strengthened in the country as this can prevent late diagnosis and contribute to mortality reduction through earlier presentation.

- Breast cancer modules could be inserted into the training curriculum for midwives and medical doctors.

  The universities of Niamey and Zinder should include breast cancer modules in the training of medical doctors and institutes training midwives as this would prepare them contribute handling the disease once on job

- Breast cancer awareness programs should focus on knowledge of breast cancer risk/protective factors and breast cancer good practice as these are areas in which women know the least.

- Awareness programs should target different age groups but focus on older women

  As older women are in general less educated than younger one, a tailored awareness program can target older women as they are more likely to have breast cancer in general.

- Mammography units should be provided and decentralized, and multilateral partnerships built to support women, so they have financial access to breast cancer screening.

- Strategies to encourage women to participate in breast cancer screening should be designed.

Milestones are set to preview women attitudes and practice towards breast cancer, breast cancer screening programs should take it into account. Further socio-anthropological studies are needed to have a holistic understanding of breast cancer disease in the country

- The startup of radiotherapy combined with chemotherapy at the National Center for the Fight Against Cancer should be strengthened as it could contribute to better cancer survival.

  The activities of this center should be strengthened, its training opportunities and financing increased also though bilateral and international partnership to contribute building a national workforce and experience of breast cancer management in the country

CV:

Aissami Abdou is born on 26 February 1980 in Diffa, south-east of Niger on the edge of Lac Tchad Basin.

He holds Bachelor of science degree in Statistics from Usmanu Dan Fodio University (2006) and a Master of Science in Biostatistics from Hasselt University, Belgium (2012)

He started working in 2006 as a data manager and epidemiologist for Médecins Sans Frontieres (Artsen zonder Grenzen), Epicentre and Center for medical research (CERMES) affiliated to Pasteur institute in Niger.

Later, he went working for MSF, ALIMA (Alliance for international Medical Action) and ICRC (International Committee of Red Cross) in different parts of the word mainly as field coordinator, emergency coordinator, head of sub delegation and country director.

He has a robust work experience and acquaintance with coordination positions in medical humanitarian action, field operations and management in different contexts/countries (DRC, Sudan, Mali, Ethiopia/Somali region, Niger, Cameroun, Tchad, Nigeria, Afghanistan).

He is now working as coordinator of operations for Sahel counties at MSF HQ in Brussels

Publications:

- Aissami Abdou, Guido Van Hal, Hassan Nouhou, Malam Abari M . " What can 27 years of Niger cancer registry tell us about breast cancer epidemiology" JPHE/06.08.21/1348, https://academicjournals.org/journal/JPHE/article-abstract/077ED2F68229

- Aissami Abdou and Guido Van Hal. "Epidemiology of female breast cancer in Niger: A literature review." Journal of Public Health and Epidemiology 13, no. 3 (2021): 192-199. https://doi.org/10.5897/JPHE2021.1336

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- Training of data officer and registrar of the cancer registry at faculty of heath science, university of Niamey, training and brainstorming sessions with epidemiologist at national center for fight against cancer

Annexes:

Annex 1.1: Women KAP Survey questionnaire on Breast Cancer, Zinder-Niamey, Niger

The interviewed confirmed to hereby give her consent to participate to the survey. (consent to be confirmed)

Identification of area and data collector

Name of the data collector_____ __/__/__/

Heath district _____ __/__/__/

Village _____ /__/__/__/__/

Unique identifier for each questionnaire (to be coded in epi data software) /__/__/__/__/__/__/__/__/__/

Socio demographic information

How old are you? /_/_/ years. What is your residence area? Urban: 1. /_/ 2. Rural: /_/

What is your marital status?

1 ☐ Married
2 ☐ Single
3 ☐ Divorced
4 ☐ Widow
5 ☐ Others

What is your religion?

1 ☐ Islam
2 ☐ Christianity
3 ☐ Traditional
4 ☐ No faith
5 ☐ Others……

What is your ethnic group?

1. ☐ Haussa
2. ☐ Djerma
3. ☐ Pheul
4. ☐ Kanuri
4. ☐ Sonrai
5: ☐ Arabe
6: ☐ Touareg
7: ☐ Other……...

What is your education level?

1 ☐ Not educated
2 ☐ Primary
3 ☐ Secondary
4 ☐ High
5 ☐ Traditional
6 ☐ Others:……

What is your profession?

1 ☐ Farmer
2 ☐ Herdswoman
3 ☐ Vendor
4 ☐ Bureaucrat
5 ☐ Craftswoman
6 ☐ Jobless/house woman
7 ☐ Others……..

Do you take alcohol?

1. ☐ Yes 2. ☐ No
3. If yes how many glasses per week? ……..

Do you smoke?

1. ☐ Yes 2. ☐ No
3. If yes how many cigarettes per week? ……..

What contraception method do you use? Do you practice breastfeeding?

1 ☐ Oral/Pills
1 ☐ Injectable
2 ☐ Condoms
3 ☐ Traditional
4 ☐ Sterilization
5 ☐ No contraception
7 ☐ Other:……

1 ☐ Yes
2 No ☐

-Did you have an abortion history? 1. Yes 2. No
-What was your age at first menstrual function? /_//_/ years
-How many children do you have? /_//_/
-What is your race /_/ Black /_/ White /_/ Other
- What is your source of income: ……..

BCAM, Knowledge (symptoms, risk/protective factors, diagnosis), attitudes, practice and perception

1. Are these breast cancer symptoms?

-Change in the position of your nipple:	1. ☐ Yes	2. ☐ No	☐ 3. I don't know
-Pulling in off your nipple:	1. ☐ Yes	2. ☐ No	☐ 3. I don't know
-blurred vision	1. ☐ Yes	2. ☐ No	☐ 3. I don't know
-Pain in one of your breasts or armpit:	1. ☐ Yes	2. ☐ No	☐ 3. I don't know
-Puckering or dimpling of your breast skin	1. ☐ Yes	2. ☐ No	☐ 3. I don't know
-Discharge of bleeding from your nipple:	1. ☐ Yes	2. ☐ No	☐ 3. I don't know
-hunger and strong appetite	1. ☐ Yes	2. ☐ No	☐ 3. I don't know
-A lump or thickening in your breast:	1. ☐ Yes	2. ☐ No	☐ 3. I don't know
-Nipple rash:	1. ☐ Yes	2. ☐ No	☐ 3. I don't know
-Redness of your breast skin:	1. ☐ Yes	2. ☐ No	☐ 3. I don't know
-tooth pain	1. ☐ Yes	2. ☐ No	☐ 3. I don't know
-A lump or thickening under your armpit:	1. ☐ Yes	2. ☐ No	☐ 3. I don't know
-neurological disorders and memory loss	1. ☐ Yes	2. ☐ No	☐ 3. I don't know

-Change in the size of your breast or nipple: 1. ☐ Yes 2. No 3. I don't know
-Change in the shape of your breast or nipple: 1. ☐ Yes 2. No 3. I don't know
-chest pain or discomfort 1. ☐ Yes 2. No 3. I don't know

-What do you do when you have one or more of the breast cancer symptoms? (You can give more than one answers)

1. ☐ Go to the doctor 2 ☐ Discuss with my family 3 ☐ Consult a traditional healer 4. ☐ Buy drugs on the market

2. Who is most likely to get breast cancer? Please select only one answer

-A 30-year-old woman
-A 50-year-old woman
-A 70-year-old woman
-A woman of any age

Do you practice?

1. ☐ Self-breast examination
2. ☐ Clinical breast examination (by expert)
3. ☐ Mammography

2. How do you practice self-breast examination?

1. ☐ Rarely or never
2. ☐ A least once every 6 months
3. ☐ At least once a month
4. ☐ At least once a week

-Long term survival (greater than 5 years) is common when early diagnosis breast cancer is treated

1=strongly disagree,
2=Disagree
3=neither agree nor disagree
4=Agree
5=strongly agree

-Have you participated in breast cancer screening? ☐ Yes ☐ No To any other screening program? ☐ Yes ☐ No

If yes, which one? ……. And when? /_/__/ (years)

-Do you intend to participate in breast cancer Screening? ☐ Yes ☐ No if not why? (You can give more than one answers)

1. I don't have money 2. I m afraid of the doctor 3 there is no hospital around 4. The doctor is a man

5 Others (Specify)……..

-Are the following breast cancer risk factors?

-Alcohol intake

1=strongly disagree,
2=Disagree
3=neither agree nor disagree
4=Agree
5=strongly agree

-Physical inactivity and obesity

1=strongly disagree
2=Disagree
3=NAND
4=Agree
5=strongly agree

-Smoking

1=strongly disagree
2=Disagree
3=NAND
4=Agree
5=strongly agree

-Having children late or not

1=strongly disagree
2=Disagree
3=NAND
4=Agree
5=strongly agree

-Are the following breast cancer protecting factors?

-Breastfeeding

1=strongly disagree,
2=Disagree
3=neither agree nor disagree
4=Agree
5=strongly agree

-Early maternity

1=strongly disagree
2=Disagree
3=neither agree nor disagree
4=Agree
5=strongly agree

-Balance diet and lifestyle

1=strongly disagree
2=Disagree
3=neither agree nor disagree
4=Agree
5=strongly agree

-Breast cancer can be treated and early diagnosis increase the chance of good treatment outcome

1=strongly disagree,
2=Disagree
3=neither agree nor disagree
4=Agree
5=strongly agree

Annex 1.2: Midwives KAP Survey questionnaire on Breast Cancer Zinder-Niamey, Niger

The interviewed confirmed to hereby give her consent to participate to the survey, (consent to be confirmed)

Identification of survey area and data collector

Name of the data collector_____

Heath district _____ __/__/__/

Village _____ /__/__/__/__/

Unique identifier for each questionnaire (to be coded in epi data software) /__/__/__/__/__/__/__/__/__/__/

Socio demographic information

How old are you? /_/_/ years. What is your residence area? Urban: 1. /_/ 2. Rural: /_/

How many years of professional experience do you have? /_//_/

Where do you work? /_/ Primary health structure /_/ District hospital /_/ National reference hospital

Did you have any training on breast cancer? Yes /_/ No /_/ , if yes when/_/ /_/

What kind of training? …….. by whom? ……..

How many children do you have? /_//_/ What is your race? /_/ Black /_/ White /_/ Others……...

What is your marital status?

5 ☐ Married
6 ☐ Single
7 ☐ Divorced
8 ☐ Widow
9 ☐ Others……

What is your religion?

1 ☐ Islam
2 ☐ Christianity
3 ☐ Traditional
4 ☐ No faith
5 ☐ Others……..

What is your ethnic group?

1. ☐ Haussa
2. ☐ Djerma
3. ☐ Pheul
4. ☐ Kanuri
4. ☐ Sonrai
5: ☐ Arabe
6: ☐ Touareg
7: ☐ Others……

What is your diploma?

2 ☐ Midwifery
3 ☐ Technician Gynecology
4 ☐ Nurse
4 ☐ Others……

What is your profession?

1 ☐ Midwife
2 ☐ Head of service
3 ☐ Maternity nurse
4 ☐ Others……...

Do you take alcohol?

1. ☐ Yes
2. ☐ No
3 ☐ If yes how often, how many glasses per week?
……..

Do you smoke?

1. ☐ Yes
2. ☐ No 3 If yes how often how many cigarettes per week? ……

What contraception method do you use?

6 ☐ Oral/Pills
7 ☐ Injectable
8 ☐ Condoms
9 ☐ Traditional
10 ☐ Sterilization
11 ☐ No contraception
7 ☐ Others:……

Do you practice breastfeeding?

1 ☐ Yes
2 ☐ No

-What was your age at first menstrual function? /_//_/ years

-Did you have an abortion history? 1. Yes 2. No

Do you have any other source of income? ……..

BC Knowledge (symptoms, risk/protective factors, diagnosis), attitudes, practice and perception

1. Are these breast cancer symptoms?

-Change in the position of your nipple:	1. ☐ Yes	2. ☐ No	☐ 3. I don't know
-Pulling in off your nipple:	1. ☐ Yes	2. ☐ No	☐ 3. I don't know
-blurred vision	1. ☐ Yes	2. ☐ No	☐ 3. I don't know
-Pain in one of your breasts or armpit:	1. ☐ Yes	2. ☐ No	☐ 3. I don't know
-Puckering or dimpling of your breast skin	1. ☐ Yes	2. ☐ No	☐ 3. I don't know
-Discharge of bleeding from your nipple:	1. ☐ Yes	2. ☐ No	☐ 3. I don't know
-hunger and strong appetite	1. ☐ Yes	2. ☐ No	☐ 3. I don't know
-A lump or thickening in your breast:	1. ☐ Yes	2. ☐ No	☐ 3. I don't know
-Nipple rash:	1. ☐ Yes	2. ☐ No	☐ 3. I don't know
-Redness of your breast skin:	1. ☐ Yes	2. ☐ No	☐ 3. I don't know
-tooth pain	1. ☐ Yes	2. ☐ No	☐ 3. I don't know
-A lump or thickening under your armpit:	1. ☐ Yes	2. ☐ No	☐ 3. I don't know
neurological disorders and memory loss	1. ☐ Yes	2. ☐ No	☐ 3. I don't know

-Change in the size of your breast or nipple: 1. ☐ Yes 2. ☐ No ☐ 3. I don't know
-Change in the shape of your breast or nipple: 1. ☐ Yes 2. ☐ No ☐ 3. I don't know
-chest pain or discomfort 1. ☐ Yes 2. ☐ No ☐ 3. I don't know
-What do you do when a woman with one of some of the breast cancer symptoms comes to you? (You can give more than one answers)
1.☐ refer to the doctor 2 ☐ Prescribe her drugs 3 Let her decide what to do 4 ☐ Discuss with her husband
5. Others: ……..
2. Who is most likely to get breast cancer? Please select only one answer
-A 30-year-old woman
-A 50-year-old woman
-A 70-year-old woman
-A woman of any age

Do you practice?
1.☐ Self-breast examination
2.☐ Clinical breast examination (by expert)
3.☐ Mammography

2. How often do you practice self-breast examination?
1.☐ Rarely or never
2.☐ A least once every 6 months
3.☐ At least once a month
4.☐ At least once a week

-Long term survival (greater than 5 years) is common when early diagnosis breast cancer is treated
1=strongly disagree,
2=Disagree
3=neither agree nor disagree
4=Agree
5=strongly agree

Dis you participate in Breast cancer screening? ☐ Yes ☐ No, To any other screening program? ☐ yes ☐ no
-If yes, which one? ……. When /_/__/ (years)
-Do you intend to participate in breast cancer Screening? ☐ Yes ☐ No if not why? (You can give more than one answers)
1 I'm not interested 2. I don't see many cases 3. Its organized far from here at central level
4. Others (Specify)……..
-Does Niger have: An operational cancer policy? ☐ Yes ☐ No A cancer registry? ☐ Yes ☐ No

-Are the following breast cancer risk factors?

-Alcohol intake	**-Physical inactivity and obesity**	**-Smoking/drinking**	**-Having children late or not**
1=strongly disagree,	1=strongly disagree	1=strongly disagree	1=strongly agree
2=Disagree	2=Disagree	2=Disagree	2=Disagree
3=neither agree nor disagree, NAND		3=NAND	3=NAND
4=Agree	4=Agree	4=Agree	4=Agree
5=strongly agree	5=strongly agree	5=strongly agree	5=strongly agree

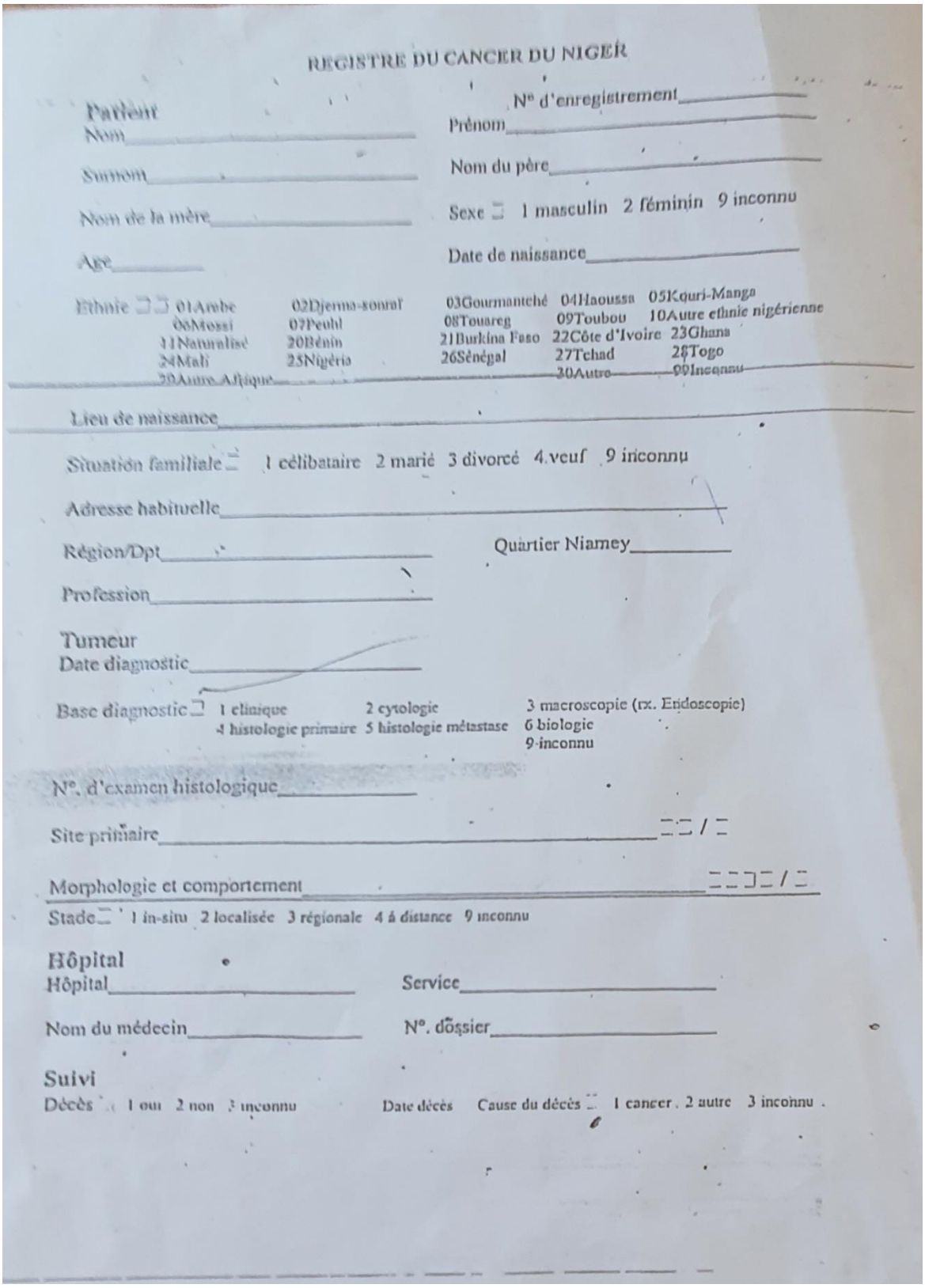
-Family history of cancer/Genetic	**-Hormone replacement therapy**
1=strongly disagree,	1=strongly disagree
2=Disagree	2=Disagree
3=neither agree nor disagree, NAND	3=NAND
4=Agree	4=Agree
5=strongly agree	5=strongly agree

Are the followings breast cancer protecting factors?

-Breastfeeding	**-Early maternity**	**-Balance diet and lifestyle**
1=strongly disagree,	1=strongly disagree	1=strongly disagree
2=Disagree	2=Disagree	2=Disagree
3=NAND	3= NAND	3= NAND
4=Agree	4=Agree	4=Agree
5=strongly agree	5=strongly agree	5=strongly agree

-Breast cancer can be treated and early diagnosis increase the chance of good treatment outcome
1=strongly disagree,
2=Disagree
3=neither agree nor disagree
4=Agree
5=strongly agree

Annex 1.3: Cancer registry Data collection sheet, breast cancer registry, Niger



REGISTRE DU CANCER DU NIGER

N° d'enregistrement_____

Patient

Nom_____ Prénom_____

Surnom_____ Nom du père_____

Nom de la mère_____ Sexe ☐ 1 masculin 2 féminin 9 inconnu

Age_____ Date de naissance_____

Ethnie ☐☐ 01Arabe 02Djerma-sonraï 03Gourmantché 04Haoussa 05Kouri-Manga
06Mossi 07Peuhl 08Touareg 09Toubou 10Autre ethnie nigérienne
11Naturalisé 20Bénin 21Burkina Faso 22Côte d'Ivoire 23Ghana
24Mali 25Nigéria 26Sénégal 27Tchad 28Togo
29Autre Afrique 30Autre 99Inconnu

Lieu de naissance_____

Situation familiale ☐ 1 célibataire 2 marié 3 divorcé 4 veuf 9 inconnu

Adresse habituelle_____

Région/Dpt_____ Quartier Niamey_____

Profession_____

Tumeur

Date diagnostic_____

Base diagnostic ☐ 1 clinique 2 cytologie 3 macroscopie (rx. Endoscopie)
4 histologie primaire 5 histologie métastase 6 biologie
9 inconnu

N°. d'examen histologique_____

Site primaire_____ ☐☐ / ☐

Morphologie et comportement_____ ☐☐☐☐ / ☐

Stade ☐ 1 in-situ 2 localisée 3 régionale 4 à distance 9 inconnu

Hôpital

Hôpital_____ Service_____

Nom du médecin_____ N°. dossier_____

Suivi

Décès 1 oui 2 non 3 inconnu Date décès Cause du décès ☐ 1 cancer 2 autre 3 inconnu

Annex 1.4: BCAM tool for Women

BCAM, Knowledge of breast cancer symptoms

1. Are these breast cancer symptoms?

-Change in the position of your nipple:	1. ☐ Yes	2. ☐ No	☐ 3. I don't know
-Pulling in off your nipple:	1. ☐ Yes	2. ☐ No	☐ 3. I don't know
-blurred vision	1. ☐ Yes	2. ☐ No	☐ 3. I don't know
-Pain in one of your breasts or armpit:	1. ☐ Yes	2. ☐ No	☐ 3. I don't know
-Puckering or dimpling of your breast skin	1. ☐ Yes	2. ☐ No	☐ 3. I don't know
-Discharge of bleeding from your nipple:	1. ☐ Yes	2. ☐ No	☐ 3. I don't know
-hunger and strong appetite	1. ☐ Yes	2. ☐ No	☐ 3. I don't know
-A lump or thickening in your breast:	1. ☐ Yes	2. ☐ No	☐ 3. I don't know
-Nipple rash:	1. ☐ Yes	2. ☐ No	☐ 3. I don't know
-Redness of your breast skin:	1. ☐ Yes	2. ☐ No	☐ 3. I don't know
-tooth pain	1. ☐ Yes	2. ☐ No	☐ 3. I don't know
-A lump or thickening under your armpit:	1. ☐ Yes	2. ☐ No	☐ 3. I don't know
-neurological disorders and memory loss	1. ☐ Yes	2. ☐ No	☐ 3. I don't know
-Change in the size of your breast or nipple:	1. ☐ Yes	2. ☐ No	☐ 3. I don't know
-Change in the shape of your breast or nipple:	1. ☐ Yes	2. ☐ No	☐ 3. I don't know
-chest pain or discomfort	1. ☐ Yes	2. ☐ No	☐ 3. I don't know

BCAM, Knowledge of breast cancer risk/protective factors, diagnosis

-Are the following breast cancer risk factors?

-Alcohol intake	**-Physical inactivity and obesity**	**-Smoking**	**-Having children late or not**
1=strongly disagree,	1=strongly disagree	1=strongly disagree	1=strongly disagree
2=Disagree	2=Disagree	2=Disagree	2=Disagree
3=neither agree nor disagree	3=NAND	3=NAND	3=NAND
4=Agree	4=Agree	4=Agree	4=Agree
5=strongly agree	5=strongly agree	5=strongly agree	5=strongly agree

-Are the following breast cancer protecting factors?

-Breastfeeding	**-Early maternity**	**-Balance diet and lifestyle**
1=strongly disagree,	1=strongly disagree	1=strongly disagree
2=Disagree	2=Disagree	2=Disagree
3=neither agree nor disagree	3=neither agree nor disagree	3=neither agree nor disagree
4=Agree	4=Agree	4=Agree
5=strongly agree	5=strongly agree	5=strongly agree

-Who is most likely to get breast cancer? Please select only one answer

-A 30-year-old woman
-A 50-year-old woman
-A 70-year-old woman
-A woman of any age

Do you practice?

1. ☐ Self-breast examination
2. ☐ Clinical breast examination (by expert)
3. ☐ Mammography

2. How do you practice self-breast examination? (if answer is yes)

1. ☐ Rarely or never
2. ☐ A least once every 6 months
3. ☐ At least once a month
4. ☐ At least once a week

-Long term survival (greater than 5 years) is common when early diagnosis breast cancer is treated

1=strongly disagree,
2=Disagree
3=neither agree nor disagree

4=Agree
5=strongly agree

-Breast cancer can be treated and early diagnosis increase the chance of good treatment outcome

1=strongly disagree,
2=Disagree
3=neither agree nor disagree
4=Agree
5=strongly agree

Annex 1.5: BCAM tool for midwives

BCAM, Knowledge of breast cancer symptoms

1. Are these breast cancer symptoms?

-Change in the position of your nipple:	1. ☐ Yes	2. ☐ No	☐ 3. I don't know
-Pulling in off your nipple:	1. ☐ Yes	2. ☐ No	☐ 3. I don't know
-blurred vision	1. ☐ Yes	2. ☐ No	☐ 3. I don't know
-Pain in one of your breasts or armpit:	1. ☐ Yes	2. ☐ No	☐ 3. I don't know
-Puckering or dimpling of your breast skin	1. ☐ Yes	2. ☐ No	☐ 3. I don't know
-Discharge of bleeding from your nipple:	1. ☐ Yes	2. ☐ No	☐ 3. I don't know
-hunger and strong appetite	1. ☐ Yes	2. ☐ No	☐ 3. I don't know
-A lump or thickening in your breast:	1. ☐ Yes	2. ☐ No	☐ 3. I don't know
-Nipple rash:	1. ☐ Yes	2. ☐ No	☐ 3. I don't know
-Redness of your breast skin:	1. ☐ Yes	2. ☐ No	☐ 3. I don't know
-tooth pain	1. ☐ Yes	2. ☐ No	☐ 3. I don't know
-A lump or thickening under your armpit:	1. ☐ Yes	2. ☐ No	☐ 3. I don't know
-neurological disorders and memory loss	1. ☐ Yes	2. ☐ No	☐ 3. I don't know
-Change in the size of your breast or nipple:	1. ☐ Yes	2. ☐ No	☐ 3. I don't know
-Change in the shape of your breast or nipple:	1. ☐ Yes	2. ☐ No	☐ 3. I don't know
-chest pain or discomfort	1. ☐ Yes	2. ☐ No	☐ 3. I don't know

BCAM, Knowledge of breast cancer risk/protective factors, diagnosis

-Are the following breast cancer risk factors?

-Alcohol intake late or not	**-Physical inactivity and obesity**	**-Smoking**	**-Having children**
1=strongly disagree, disagree	1=strongly disagree	1=strongly disagree	1=strongly
2=Disagree	2=Disagree	2=Disagree	2=Disagree
3=neither agree nor disagree	3=NAND	3=NAND	3=NAND
4=Agree	4=Agree	4=Agree	4=Agree
5=strongly agree agree	5=strongly agree	5=strongly agree	5=strongly

-Family history of cancer/Genetic	**-Hormone replacement therapy**
1=strongly disagree,	1=strongly disagree
2=Disagree	2=Disagree
3=neither agree nor disagree, NAND	3=NAND
4=Agree	4=Agree
5=strongly agree	5=strongly agree

-Are the following breast cancer protecting factors?

-Breastfeeding	**-Early maternity**	**-Balance diet and lifestyle**
1=strongly disagree,	1=strongly disagree	1=strongly disagree
2=Disagree	2=Disagree	2=Disagree
3=neither agree nor disagree	3=neither agree nor disagree	3=neither agree nor disagree
4=Agree	4=Agree	4=Agree
5=strongly agree	5=strongly agree	5=strongly agree

-Who is most likely to get breast cancer? Please select only one answer

-A 30-year-old woman
-A 50-year-old woman
-A 70-year-old woman
-A woman of any age

Do you practice?
1. ☐ Self-breast examination

2. How do you practice self-breast examination? (if answer is yes)
1. ☐ Rarely or never

2. ☐ Clinical breast examination (by expert)
3. ☐ Mammography

2. ☐ A least once every 6 months
3. ☐ At least once a month
4. ☐ At least once a week

-Long term survival (greater than 5 years) is common when early diagnosis breast cancer is treated

1=strongly disagree,
2=Disagree
3=neither agree nor disagree
4=Agree
5=strongly agree

-Breast cancer can be treated and early diagnosis increase the chance of good treatment outcome

1=strongly disagree,
2=Disagree
3=neither agree nor disagree
4=Agree
5=strongly agree