# THE DEVELOPMENT OF A WORK-DIRECTED INTERVENTION ON RETURN TO WORK FOR PEOPLE LIVING WITH COLORECTAL CANCER

**CHOW SZE LOON** 

# FACULTY OF MEDICINE UNIVERSITY OF MALAYA KUALA LUMPUR

2016

# THE DEVELOPMENT OF A WORK-DIRECTED INTERVENTION ON RETURN TO WORK FOR PEOPLE LIVING WITH COLORECTAL CANCER

**CHOW SZE LOON** 

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> FACULTY OF MEDICINE UNIVERSITY OF MALAYA KUALA LUMPUR

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## UNIVERSITY OF MALAYA

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### ABSTRACT

Traditionally, return to work (RTW) programmes have focused on enabling physically injured workers to resume duty at the workplace as part of the vocational rehabilitation process. Nevertheless, there is a lack of such RTW initiatives for individuals with chronic disease. A focus on RTW for colorectal cancer survivors is timely since colorectal cancer is the most common cancer among Malaysian men and affects the working age population. With earlier detection and better treatment regimes, survival rates are on the rise and cancer survivors are now living indefinite periods after diagnosis. However, there are few RTW studies for cancer, now considered a form of chronic disease. Therefore, this study aimed to develop a work-directed intervention on RTW for people living with colorectal cancer, using sequential mixed-method research methodology. This is a 3-phase mixed method cross sectional design consisting of a systematic review (Phase I), in-depth interview (Phase II) and feasibility study (Phase III). A RTW framework was developed following findings from a systematic review of 27 published studies on RTW. A criteria-based, purposive, maximum variation sampling method targeting colorectal cancer survivors, employers, and healthcare professionals was conceived and used a semi-structured topic guide for in-depth interviews. All themes discovered in Phase II on barriers and motivators in relation to RTW were grouped into different categories for analysis. The feasibility study of the proposed pathway for intervention in current practice (Phase III), was developed using a parallel mixed-method, by focusing on the modifiable factors identified in Phase I and Phase II. The feasibility component of this study was carried out using a Likert scale (Quantitative study) and in-depth interviews (Qualitative study) to gauge on the aspects of timing and flow of the intervention, contents of the intervention which included the materials used in it (educational leaflet, RTW brochure and fitness to work assessment form). Both quantitative and qualitative data contributed to the richness of data for analysis. Overall, RTW among cancer survivors is feasible but it depends on multiple factors. The importance of self-perceived work ability must be considered in the RTW intervention, besides the reported barriers and motivators. The RTW framework and findings from interviews revealed the potential areas for interventions by focusing on those identified modifiable factors. Key informants who participated in the feasibility study were younger, having many years remaining before retirement (colorectal cancer survivors), and appreciated the RTW process, being aware of the importance of work after illness and interested to learn more about RTW (healthcare professionals and employers in private sectors). The majority of the key informants agreed that the flow and timing of the RTW intervention were appropriate, tasks outlined in the RTW brochure emphasising early contact and constant communication with employers as well as the educational leaflet to be helpful in assisting timely RTW among colorectal cancer survivors. This intervention on RTW is feasible when the stakeholders are aware and carry out their respective tasks. Therefore, by reducing modifiable barriers and enhancing the motivators identified, the RTW outcome can be enhanced among colorectal cancer survivors.

### ABSTRAK

Secara tradisinya, program RTW ditumpukan bagi membolehkan pekerja yang mengalami kecederaan fizikal untuk menyambung tugas di tempat kerja sebagai sebahagian daripada proses pemulihan vokasional. Walaubagaimanapun, terdapat kurang inisiatif RTW sebegini untuk individu yang menghidapi penyakit kronik. RTW untuk pesakit kanser kolorektal adalah tepat pada masanya kerana kanser kolorektal adalah kanser yang paling kerap di kalangan lelaki di Malaysia dan menjejaskan golongan yang bekerja. Dengan pengesanan awal dan rawatan yang lebih baik, kadar survivor semakin meningkat dan bekas pesakit kanser kini hidup untuk tempoh yang tidak ditentukan selepas diagnosis. Walaubagaimanapun, tidak terdapat banyak kajian RTW untuk kanser tersebut yang merupakan satu penyakit kronik yang baru. Oleh yang demikian, kajian ini bertujuan untuk membangunkan satu intervensi RTW bagi survivor kanser kolorektal dengan menggunakan urutan kaedah penyelidikan mixed-method. Kajian ini merangkumi 3 fasa mixed method cross sectional design yang terdiri daripada kajian ulasan sistematik (Fasa I), temubual secara mendalam (Fasa II) dan kajian kemungkinan (Fasa III). Kerangka RTW telah dibangunkan berikutan penemuan kajian ulasan sistematik pada 27 kajian yang diterbitkan mengenai RTW. Berasaskan criteria yang ada tujuan, maksimum variasi kaedah sampling yang mensasarkan survivor kanser kolorektal, majikan dan profesional dalam bidang perubatan dan kesihatan telah digunakan bersama-sama dengan panduan topik separuh berstruktur untuk mengadakan temu bual mendalam. Semua tema mengenai halangan dan motivator berhubung dengan RTW yang ditemui dalam Fasa II dikumpulkan ke dalam kategori yang berbeza untuk tujuan analisis. Pembentukan intervensi RTW dan kajian kemungkinan pada amalan sekarang menggunakan parallel mixed-method dan memberikan tumpuan kepada faktor-faktor yang boleh diubahsuai dan telah dikenalpasti dalam Fasa I dan Fasa II. Komponen kajian kemungkinan ini telah dijalankan dengan menggunakan Skala Likert (kajian kuantitatif) dan temubual mendalam (kajian kualitatif) untuk mengukur aspek waktu dan aliran intervensi, kandungan intervensi yang merangkumi bahan yang digunakan dalamnya (risalah pendidikan, risalah RTW dan borang penilaian fitness to *work*). Data kuantitatif dan kualitatif telah menyumbang kepada kekayaan data untuk analisis. Secara keseluruhan, RTW di kalangan survivor kanser ini boleh dilaksanakan tetapi ia bergantung kepada pelbagai faktor. Selain daripada halangan and motivator untuk RTW, kepentingan keupayaan kerja perlu dipertimbangkan dalam intervensi RTW. Kerangka kerja RTW dan penemuan daripada temubual mendalam mendedahkan kawasan yang berpotensi untuk intervensi dengan memberikan tumpuan terhadap faktor-faktor yang boleh diubahsuai. Peserta dalam kajian kemungkinan adalah didapati lebih muda, masih mempunyai bertahun-tahun lagi sebelum besara (survivor kanser kolorektal), dan meghargai proses RTW tersebut, menyedari kepentingan berkerja selepas sakit dan juga berminat untuk mengetahui lebih lanjut mengenai RTW (profesional dalam bidang perubatan dan kesihatan dan majikan di sektor swasta). Kebanyakan peserta bersetuju bahawa aliran dan masa intervensi RTW adalah bersesuaian, tugas yang digariskan dalam risalah RTW memberi penekanan pada hubungan awal dan komunikasi yang berterusan dengan majikan serta risalah pendidikan adalah berguna dalam membantu survivor kanser kolorektal kembali berkerja tepat pada masanya. Intervensi RTW ini boleh dilaksanakan apabila pihak berkepentingan menyedari dan menjalankan tugas-tugas masing-masing. Oleh yang demikian, dengan mengurangkan halangan yang boleh diubahsuai dan meningkatkan motivasi yang telah dikenalpasti, hasil RTW dapat dipertingkatkan di kalangan survivor kanser kolorektal.

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MALAYSIA

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# LIST OF SYMBOLS AND ABBREVIATIONS

ACOEM:	American College of Occupational and Environmental Medicine
ADA:	Americans with Disabilities Act
ADL:	Activities of Daily Living
AS:	Age-standardised
BMT:	Bone Marrow Transplant
CDC:	Centres for Disease Control and Prevention
CORUM:	Colorectal Cancer Survivorship Society Malaysia
DOSH:	Department of Occupational, Safety and Health
EAP:	Employee Assistance Programme
EAPA:	Employee Assistance Professional Association
EBM:	Evidence-Based Medicine
FIOH:	Finnish Institute of Occupational Health
G.O:	General Orders
HR:	Human Resource
HRQoL:	Health Related Quality of Life
ICF:	International Classification of Functioning, Disability and Health
ISCO:	International Standard Classification of Occupations
MEF:	Malaysian Employers Federation

- MNC: Multinational Companies
- MRC: Medical Research Council
- MSD: Musculoskeletal Disorders
- NBGH: National Business Group on Health
- NCCN: National Comprehensive Cancer Network
- NCCS: National Coalition for Cancer Survivorship
- NCI: National Cancer Institute
- NCPR: National Cancer Patient Registry
- NGOs: Non-Government Organisations
- NOS: Newcastle Ottawa Scale
- NRC: National Research Council
- OOP: Out-of-Pocket
- OSHA: Occupational Safety and Health Act
- PCR: Penang Cancer Registry
- PERKESO: Pertubuhan Keselamatan Social
- PRISMA: Preferred Reporting Items for Systematic Reviews
- QoL: Quality of Life
- RCT: Randomised Controlled Trial
- RM: Malaysian Ringgit

- S.E.A: South East Asia
- SEER: Surveillance, Epidemiology, and End Results
- SGH: Sarawak General Hospital
- SMI: Small Medium Industries
- SOCSO: Social Security Organisation
- TWSH: Total Workplace Safety and Health
- UM: University of Malaya
- UMMC: University Malaya Medical Centre
- USD: United States Dollar
- WAI: Work Ability Index
- WHO: World Health Organisation

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#### **CHAPTER 1: INTRODUCTION**

More than 70 percent of all cancers occur in Low and Middle Income Countries (LMICs) with the burden of cancer expected to rise rapidly following the ageing population and changes in lifestyle associated with economic development and epidemiological transition (Ferlay, Shin, Bray, Forman, Mathers, & Parkin, 2010; Jemal, Center, DeSantis & Ward, 2010). Cancer is a major morbidity and mortality concern in Malaysia. Based on the National Cancer Registry data, the Malaysian population is estimated to bear a cancer burden of about 40,000 new cases per year, and a cumulative lifetime risk of about 1:4. The incidence rates in Malaysia fall between rates typical of low-and high-income countries with an increasing incidence rate with age (Frank & Hellen, 2007).

Colon cancer and rectal cancer are collectively known as colorectal cancer, and despite being one of the leading cancers in Malaysia, research on colorectal cancer survivors is limited compared to that of breast cancer survivors.

The burden and impact on individual and family following cancer diagnosis is profound, especially in LMICs (ACS, 2010; Abegunde, Mathers, Adam, Ortegon & Strong, 2007, Frank & Hellen, 2007). This is mainly due to the loss of the source of income in the family as a result of premature death and disability associated with cancer (ACS, 2010; Frank & Hellen, 2007). Family members of cancer patients are also more susceptible to depression, most likely due to the adverse change in socioeconomic status and employment status (Lim, Kim & Lee, 2013). The impact of cancer on a country can be significant as well, in terms of the production loss especially when cancer affects the working age population, resulting in premature death, morbidity, disability and failure to resume work, in both developing and developed countries (Ferlay et al., 2010, 2015; Jemal, Bray, Center, Ferlay, Ward & Forman, 2011). Employed cancer patients with the greatest number of side effects missed significantly more workdays. Some employees

assuming a supportive or caregiver role to a working patient with cancer may also miss time from work to accompany a spouse, child, friend, or a relative who is undergoing active cancer treatments (Henry, Viswanathan, Elkin, Traina, Wade & Cella, 2008). In addition to that, indirect costs may be incurred when replacing the cancer affected individuals in the workforce, which would add on to the production cost (Hanly & Sharp, 2014). World Health Organisation (WHO) reported that in 2008 alone, cancer accounted for nearly 1 trillion USD in economic losses from premature death and disabilities. The toll of cancer and chronic diseases was greater in LMICs where individuals develop early onset chronic disease at a younger age, suffer longer periods of preventable complications and succumb to these diseases sooner than those in high income countries (Ferlay et al., 2010; Jemal et al., 2011).

### 1.1 Background

Cancer is no longer considered as a disease affecting the elderly as many adult working populations are being diagnosed with cancer annually (de Boer, Taskila, Ojajarvi, Dijik & Verbeek, 2009). Another significant phenomenon in healthcare is that cancer, once a fatal condition, is gradually taking the form of a chronic disease which patients live with and as a result, cancer survivors are becoming more common in workforce (Danielsson & Berlin, 2012; Tamminga, De Boer, Verbeek & Frings-Dresen, 2010). These changes call for more public health work and attention to be focused on survivorship issues, including facilitating the process of "returning to work" for the rising numbers of cancer survivors, specifically for colorectal cancer survivors, as they are the commonest cancer survivors among Malaysian males.

The rising cost of oncology drugs have led to reduced reimbursements for drugs, although many other important patient support services remains neglected and are not getting reimbursed (Marie, 2012). The role of the healthcare professionals does not end

at diagnosing and treating the cancer survivors, but covers beyond the treatment phase, that is the rehabilitating and reintegrating survivors into a new normal life (Desiron et al., 2010). For cancer survivors, a new normal life means incorporating the realities of cancer into their future plans and finding a new way of living (Cancer Support Community, 2013). However, the current healthcare delivery system is still predominantly focused on curative aspects of cancer, neglecting other equally important health and therapy services to help survivors manage the side effects of cancer and its treatment, for a better Quality of Life (QoL) (Loh & Yip, 2006).

A fundamental gap in cancer survivorship that needs better and greater interdisciplinary interventions is the issue of employment, especially among colorectal cancer survivors. Remaining in employment is a major concern among colorectal cancer survivors in Malaysia, given that the majority of the men are the sole breadwinner in the family. The National Colorectal Cancer Registry reported between 41 percent to 45 percent of colorectal cancer patients were diagnosed in the working age group with males having 1.33 times higher risk compared to females (Hassan, Radzi, Ismail, Suan, Azri, Ahmad, & Tan, 2016; National Cancer Patient Registry-Colorectal Cancer 2008-2013). Similar findings were reported in the University Malaya Medical Centre (UMMC) where 40.8 percent of the colorectal cases (495 out of 1212) diagnosed between 2001 and 2010 belonged to the working age population (Bello, Moy, Roslani & Law, 2014).

The existing healthcare system focuses more on delivering symptomatic relief or increasing years of survivors. After initial treatment, most cancer patients face challenges during transition to the recovery phase of survivorship as they slowly resume the role of employee, parent or spouse (Feuerstein, 2007; Parsons, Eakin, Bell, Franche & Davis, 2008). Anxiety and difficulty during this transition period were not usually explored by the healthcare providers. One of the survivorship issues that commands special attention from society is the employment status of cancer survivors. Following

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the diagnosis and treatment of cancer, many patients experienced a change of employment status, prolonged sick leave, unemployment, or work cessation due to various factors (Gordon, Lynch & Newman, 2008). Work participation in society can define an individual's self-worth, identity and societal role, and it contributes to the financial security (Ferrell, Grant, Funk, Otis-Green & Garcia, 1997; Pratt, Rockmann & Kaufmann, 2006 ). The experience of being diagnosed with cancer could potentially become a source of distress, in addition to the disruption in the work role and expensive medical bills. All these factors affect Health Related Quality of Life (HRQoL). Returning to work after cancer treatment is important for cancer survivors in maintaining a sense of normality, improves QoL and autonomy while failure to stay in employment could deprive an individual of social contacts and well-being (Peteet, 2000; Nachreiner, Dagher, McGovern, Baker, Alexander, Gerberich & Strasser, 2007).

Little work has been done to examine the role of healthcare professionals, including oncology specialists and occupational health professionals, in assisting the timely RTW process for colorectal cancer survivors. Most of such studies mainly focus on breast cancer (Désiron, 2010; Désiron, Rijk, Van & Donceel, 2011). Such a gap suggests considerable area for improvement in this potentially important scope in RTW process. The evidence available suggests that most survivors receive very little advice from medical practitioners about RTW (Amir, Neary & Luker, 2008).

At the same time, there is no systematic intervention in place to assist cancer survivors to RTW or remain in employment. Research on work directed or vocational rehabilitation among cancer survivors is limited as many aspects of vocational rehabilitation usually focus on musculoskeletal disorders, mental health problems and cardio-respiratory health conditions (Waddell, Burton & Kendall, 2008). The need to facilitate individuals living with chronic diseases, including colorectal cancer has been found wanting. At present, data on RTW and the prevalence of colorectal cancer among employed individuals in Malaysia is not known. The First Annual Report of the National Cancer Patients Registry-Colorectal Cancer, 2007-2008 and the second similar report, 2008-2013 estimated that up to 45 percent and 41 percent of the colorectal cancer patients respectively, were from the working age group. Colorectal cancer is the commonest cancer affecting the Malaysian male population and was made up about 78.4 percent to 79.4 percent of the labour workforce in this country (The World Bank, 2015). Efforts to ensure that colorectal cancer survivors remain employed are of paramount importance to the productivity of the country. Hence, assistance to RTW and leading a new normal life after cancer must be included in the existing cancer care for the survivors.

In countries like the USA and Australia, cancer survivors who RTW may benefit from the legal protection under the Americans with Disabilities Act (ADA) 1992 and Disability Discrimination Act 1992 respectively. Such legal protection aims at preventing the employers from discriminating against workers with disabilities in the workplace and it covers all employment practices, including termination, advancement, compensation, training, leave as well as all other privileges related to employment. Cancer is considered as a disability condition, under the Act whereby the cancer, treatment of it or its side effects have significantly limited one or more of the individual's current major life activities. It is clearly stated in the ADA that it is illegal for employer to discriminate the workers who has disability but is otherwise qualified for a job (Americans with Disabilities Act, 1990).

Unfortunately, not all cancer survivors around the world enjoy such legal protection. In Malaysia, there is no provision of law that offers protection against discrimination of cancer survivors at workplace. Thus, the prevalence of unemployment or loss of job as a result of workplace discrimination due to cancer is not known in Malaysia. As such, the issue of workplace discrimination need to be explored and studied as part of barriers in order to assist cancer survivors to RTW. However, civil servants in Malaysia enjoy full paid leave up to not more than 24 months upon being diagnosed with cancer. As for those individuals working in private sectors, paid sick leave is dependent on the period of their service. If hospitalisation is deemed necessary, then irrespective of the period of service, an employee is entitled to 60 days paid leave.

Apart from workplace discrimination, there are multiple factors affecting the decision to resume work upon cancer treatment (Spelten, Verbeek, Uitterhoeve, Ansink, Van der Lelie, de Reijke & Sprangers, 2003a; Feuerstein, 2007).

### 1.2 Research questions and problem statements

Research questions refer to answerable inquiries into a specific concern or issue, which guide the decisions about research design and research methods (Bryman, 2007). Hence, developing the research questions is the initial step in research. The research will answer the question posed. The answer to a research question will help address "Problem Statements" which are the problems researchers and readers think are worth solving (Booth, Colomb & Williams, 2003).

Intervention on RTW among colorectal cancer survivors is a relatively new field in Malaysia. Unlike rehabilitation for assisting injured workers resuming work, survivors having completed cancer treatment are living with cancer as a form of new chronic disease. In order to develop a new work-directed intervention on RTW for individuals living with colorectal cancer, this study set out to answer the following fundamental research questions:

i) What are the various factors and their interactions associated with RTW among cancer survivors?

- What are the motivators, barriers and challenges faced by local colorectal cancer survivors in resuming work after cancer.
- iii) What kind of work-directed intervention can be developed to assist local colorectal cancer survivors in returning to work in current practice?
- iv) How feasible is the newly developed work-directed intervention on RTW in current practice?

Currently, there is lack of integrated assistance or referral for colorectal cancer survivors after the usual cancer therapy on RTW issues. The model and rehabilitation for injured workers are not readily helpful for colorectal cancer survivors as injury is an acute episode while cancer recovery could potentially be a chronic condition. RTW for colorectal cancer survivors is timely as the numbers of survivors among the working population are expected to increase following cancer screening as well as advanced cancer treatment. Therefore, there is an urgency to start looking at interventions on RTW for these employed colorectal cancer survivors upon completion of treatment.

### **1.3 Aim and objectives**

The aim of this study is to develop a work-directed intervention on RTW for colorectal cancer survivors. In order to achieve this general objective, specific objectives were outlined:

- i) To systematically review the motivators, barriers and challengers faced by cancer survivors in resuming work after cancer.
- ii) To develop a RTW framework that examines various factors and their interactions associated with RTW among cancer survivors.
- iii) To develop a work-directed intervention to assist RTW among local colorectal cancer survivors based on findings from (i) and (ii).

iv) To gain the perceptions of key informants about the potential feasibility of implementing various components involved in the newly developed proposed pathway for work-directed intervention in current practice.

### **1.4 Conceptual framework**

Health, disability and functioning should be viewed as dynamic and interactive concepts that recognise individual and environment factors as equally important. The International Classification of Functioning, Disability and Health (ICF) (WHO, 2001), a universal classification system, developed by the World Health Organisation is adopted to guide the study (Figure 1.1). Under this classification system, all aspects of health are covered and described in terms of health domains and health-related domains (Stewart, Cheung, Duff, Wong, McQuestion, Cheng & Bunston, 2001a).

This study intends to examine these factors (disease factors, environmental factors and personal factors) and explore any interactions between other relevant factors that were not mentioned in the ICF model. A revised RTW framework, with reference to the ICF model would allow researchers and policy makers to review the current healthcare delivery system and future interventions that address the issues pertaining to RTW among the working population.

The ICF model informs the study with the range of effects following a health condition (disorder/disease), from impairment, limitation to restriction. It offers researchers insight into the effect of colorectal cancer on work participation, allowing researchers to further explore the various factors within (environmental and personal factors) and beyond the ICF which are important in relation to employment after cancer.

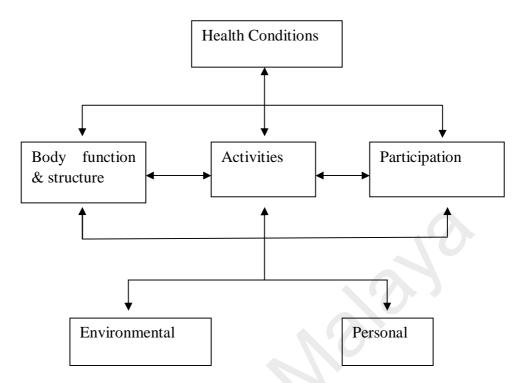


Figure 1.1: The International Classification of Functioning, Disability and Health (ICF) (WHO, 2001)

This study focuses on the development of a work-directed intervention to assist colorectal cancer survivors' RTW. This study may not qualify as a full complex intervention but the process involved in its development goes in the same direction as the Medical Research Council (MRC) Framework for Development and Evaluation of RCTs for Complex Interventions to Improve Health.

However, this study does not involve the "traditional mode of intervention", but rather, it is a proposal pathway for directing the intervention.

Traditionally, complex interventions are "built up from a number of components, which may act both independently and interdependently." Many healthcare service programmes are complex and consist of several interacting components which are essential to the proper functioning of the intervention (Campbell, Fitzpatrick, Haines, Kinmonth, Sandercock, Spiegelhalter & Tyrer, 2000). Therefore, evaluating such complex interventions can pose a considerable challenge and requires a substantial investment of time (Craig, Dieppe, Macintyre, Michie, Nazareth & Petticrew, 2008; Medical Research Council, MRC, 2008).

There are several dimensions of complexity (Medical Research Council, MRC, 2008) met in this study: a range of possible outcomes (e.g. successful RTW, unsuccessful trial of RTW, "Not fit" for work, "May be fit" for work and medical retirement), variability in the interactions between target stakeholders (e.g. colorectal cancer survivors, employers, healthcare professionals and the current service delivery system) and the degree of flexibility of the intervention (e.g. trial of RTW, flexibility in RTW recommendations).

#### 1.5 Significance of the study

Care for cancer patients does not end once active treatment has ended. The impact of cancer on patients' quality of life (QoL) can be significant even after completing the treatment and entering the stage of survivorship. Survivors living with colorectal cancer are worth studying given the increasing number of survivors following the heightened awareness of cancer screening and advancement of cancer treatment (Taskila & Lindbohm, 2007; Mehnert, 2011).

For some patients, returning to work presents as a usual milestone, going back to their normal life after cancer, and such a transition varies from being a difficult to a complicated process. The transition involved may not be that smooth or easy, but research into this area is critically lacking. However, there is a gradual increasing recognition of the employment and work consequences following cancer treatment (de Boer, 2009). Unfavourable consequences have been reported as unemployment or adverse work changes, career changes and a variety of physical and functional disabilities as well as increasing psychological distress or mental disorders may adversely affect a patient's work ability, working conditions, and work satisfaction (Catalano & Satariano, 1998; de Boer, 2009; Peteet, 2000).

Cancer survivorship care is a relatively new field for many developing countries, including Malaysia. Therefore, a systematic intervention to assist cancer survivors to resume work at the post active-treatment phase is critically lacking. Work-directed interventions on RTW should be an extension of the present, usual care for cancer survivors, which very often end at the treatment phase.

Following the advocacy of colorectal cancer screening and the advancements in treatment, colorectal cancer survivors in the working population are increasing in number. Thus, there is a compelling reason and urgency for policy makers to look into various strategies in keeping these productive working employees in the workforce after cancer treatment. For the colorectal cancer survivors, the work-directed intervention offers them a systematic approach and assistance to reintegrate back to work, without having to look for guidance elsewhere.

This study can potentially be an impetus for further research work on work issues after cancer. More importantly, this study is in tandem with the timely calls for the empowerment of colorectal cancer survivors in handling issues at workplace by working together with their respective employers and healthcare teams.

### 1.6 Structure of the thesis

There are a total of six chapters in this thesis. Chapter one (Introduction) offers the reader a general view on the background of the study, the rationale and problem statements which lead to the formation of the research questions, study objectives as well as the significance of this study.

The main purpose of Chapter two (Literature review) is to emphasise the presence of the gap in the current knowledge outlined in Chapter one. The subjects of interest in the review of literature, including cancer survivors and the scope of the study, returning to work after cancer, have been introduced in the "Background" and "Problem Statement" in Chapter one. The literature review was undertaken with the aim of gathering some essential information from published work to incorporate into the work-directed intervention on RTW. The recommendations highlighted in previous studies on RTW were taken into account, along with the current RTW programmes available in Malaysia.

The research methodology (Chapter three) outlines the sequential and parallel mixedmethod methodology employed in this study, starting from Phase I (Systematic review), followed by Phase II (Qualitative study) and Phase III (Feasibility study of the proposed pathway for work-directed intervention). Different types of data and data collection methodology were observed and outlined separately, according to the phases in Chapter three.

The findings and results from the study were reported according to the phases of study in Chapter four. The answers to the research questions outlined in Chapter one, were reported in this section as well. Essentially, the findings and results from each phase formed the foundation for the subsequent phase of the study.

In Chapter five (Discussion), the findings and results of each phase of the study were compared to the findings from other studies on RTW. The challenges encountered in carrying out the entire study were reported in Chapter five as well. In addition to that, the strengths and limitations of the study were also discussed, based on the research methodology employed in different stage of the study. Conclusions and recommendations are presented in the final chapter of the thesis. Each phase of the study answers the specific objective. Hence, the conclusions are drawn concerning the findings obtained from each phase of the study, which were subsequently used to carry out the next phase of the study in this mixed method, sequential approach.

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#### **CHAPTER 2: LITERATURE REVIEW**

Following the introduction of this thesis, this chapter presents the relevant background knowledge to understand the importance of assisting cancer survivors, especially colorectal cancer survivors to resume work after cancer and highlights the significance of employment during survivorship. Therefore, a literature review will address the current research gap (Hart, 1998) in intervention on RTW by examining the findings of previous relevant studies.

This literature review adopted a focus characteristic on practices or applications under Cooper's (1998) Taxonomy of Literature Reviews, which concentrated on how interventions on RTW have been applied or how a group of healthcare professionals tend to carry out the intervention. Such approach also allowed researcher to identify the potential relationship between the key concepts, and provide direction as well as insights into developing a work-directed intervention on RTW for individuals living with colorectal cancer in Malaysia. Hence, this review provides an overview of interventions on RTW to improve RTW outcome among cancer survivors, especially colorectal cancer survivors from the previous literature.

The chapter of literature review commences with the concept of survivorship with cancer being a chronic illness and justifications on keeping cancer survivors employed following the impact of cancer to survivors and working life. The importance of employment is being examined as well.

Then, a few RTW models are being described and compared to identify the strength and weakness for the development of a new RTW intervention.

Subsequently, the international practice and best evidence based intervention for RTW among cancer survivors is outlined. Next, the RTW programme in Malaysia is presented and being compared to the international practice. Subsequently, researcher

highlights some potential room for improvement and areas to be explored in RTW intervention for Malaysia.

### 2.1 Prevalence of colorectal cancer among working population and its impacts

Cancer, a major public health problem is a leading cause of disease worldwide, causing 1 in 8 deaths globally and rapidly becoming a global pandemic (Jemal et al., 2010; Siegel, Miller & Jemal, 2015). Over the years, the burden has shifted to less developed countries, which currently account for about 57 percent of cases and 65 percent of cancer deaths worldwide.

Colorectal cancer is a major public health concern globally; there are nearly one million new cases of colorectal cancer diagnosed worldwide annually and half a million deaths (Boyle & Leon, 2002). It ranks as the third most frequent cancer worldwide, and the third and second most frequent cancer in men and women respectively (Jemal et al., 2011). The incidence of colorectal cancer in Asia, and particularly South East Asia, has assumed the global trend. Currently, colorectal cancer is the third most frequent cancer in Asian men and women (Pourhoseingholi, 2012). The upward trend in incidence of colorectal cancer in Asia environmental factors, such as smoking, physical inactivity, obesity and, to some extent, the ethnic background of the patients (Chong, Abdullah, Telisinghe & Jalihal, 2009; Tsukuma, Ioka & Tanaka, 2011).

Colorectal cancer is no longer predominantly a disease of the western world. Colon and rectal cancers are now a major public health problem in Malaysia as well (Bello, Moy, Roslani & Law, 2014). Overall incidence rate for colorectal cancer was 21.3 cases per 100,000 populations in Malaysia as compared to United States of America which was 43.7 per 100,000 populations and Japan which had incidence rate of 41.7 per 100,000 populations. Age-adjusted incidence rate of colorectal cancer was 1.33 times higher

among males compared to females in Malaysia. As for the ethnicity, Chinese people were reported to have the highest risk overall of developing colorectal cancer (27.4 cases per 100,000 populations).

The incidence of colorectal cancer for both genders increases with age (Figure 2.1). From 2008 to 2013, the mean age for colorectal cancer patients in Malaysia was 61.6 years (standard deviation of 12.7) affecting the working age population (NCPR-Colorectal Cancer 2008-2013).

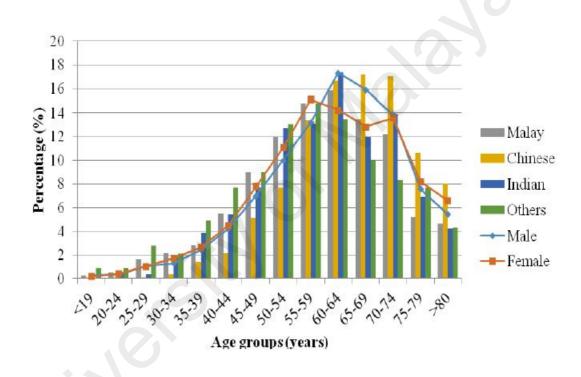


Figure 2.1: Distribution of colorectal cancer patients (gender & ethnicity) by age group (NCPR, 2008-2013)

The survival rate for cancer reflects the proportion of people alive at a specified period after a diagnosis, usually five years. Observed survival rate and the relative survival rate are the two basic measures used. The observed survival rate quantifies the proportion of cancer patients alive after five years follow up since diagnosis, regardless of deaths due to conditions other than cancer. In contrast, relative survival rate measures the proportion of cancer patients who are still alive five years after diagnosis compared to that in a general population who are of the same age and gender without cancer. Since a cohort of cancer-free individuals is difficult to obtain, expected life tables representing survival of the general population are used instead (Cho, Howlader, Mariotto & Cronin, 2011). Cancer survival rates in a given population are affected by various factors. Among the determining factors are the types of cancer, the stage at which diagnosis was made and the availability of treatment. The survival of cancers of breast, colorectal and certain childhood cancers were reported to be affected by screening and or the treatment (Hankey et al., 1999; Edwards et al., 2010). As a result, there have been large differences in cancer survival rates in developed and developing countries.

Colorectal cancer survival largely depends upon the stage of the disease at diagnosis. The overall five-year survival rates for colorectal cancer typically range from 90 percent for localised cancers, 70 percent for regional cancers, to 10 percent for distant metastatic cancers (Jemal et al., 2010). Over the last five decades, survival for colorectal cancer at all stages has increased considerably (Jemal et al., 2011). The relative improvement in the five-year survival rates after diagnosis of colorectal cancer during this period is reportedly better in countries with high life-expectancy and improved access to specialised health care services. In Malaysia, Kong, Roslani, Law, Law & Arumugam. (2010) compared patients presenting with colorectal cancer in the University Malaya Medical Centre (UMMC), Kuala Lumpur and the Sarawak General Hospital (SGH), Kuching over seven years from 2000-2006. The five-year survival rates by stage were: Stage I (79%), Stage II (65%), Stage III (44%) and Stage IV (9.3%) at UMMC and Stage I (75%), Stage II (53%), Stage III (36%) and Stage IV (5.2%) in SGH (Kong et al., 2010).

Cancer survivor refers to any person who has been diagnosed with cancer, starting from the time of diagnosis through the remaining years of life. A cancer survivor is someone who is living with or beyond their cancer. This could be someone who has completed their treatment or having ongoing treatment (Macmillan Cancer Support, 2014). Cancer survivorship can be categorised into three different phases: beginning from diagnosis till end of initial treatment, the transition from treatment to extended survival and long term survival. However, in reality, the concept of survivorship is often referred to as the period after active treatment is completed. Interestingly, it encompasses a wide range of cancer status from cancer-free, living with intermittent periods of active disease requiring treatment to living with cancer continuously without disease-free period (Feuerstein, 2007; Mullan, 1985). The 5-year survival rate is dependent on the stage of cancer. Localised-stage of cancer enjoys 5-year survival rate up to 90 percent while cancer involving regional and distant metastasis are 70 percent and 12 percent respectively in USA. The introduction of 5-fluoroucil-based adjuvant chemotherapy for resectable stage III colon cancer in the late 1980s has successfully reduced the mortality rate by 30 percent. The improved overall survival in colorectal cancer cases attributable to better chemotherapy has been reported in various studies (Moertel et al., 1990; Kopetz et al., 2009; André et al., 2009).

## 2.1.1 Colorectal cancer as a chronic illness in survivorship

Improved survival of colorectal cancer has been observed over the past three decades. Such improvement could be attributed to early detection through organised screening, and better treatment options (Chua, Liauw, Chu & Morris, 2012). As a result, colorectal cancer is progressively taking the form of a chronic illness (Chua et al., 2012; Benson, 2014).

Survivorship refers to the state or condition of being a survivor; survival (Oxford, 2015). Overall, the term cancer survivor covers a wide range of individuals ranging from an individual who is in remission, or is not undergoing active treatment, or is living with progressive disease and may be receiving cancer treatment but is not in the

terminal phase of illness, or who has had cancer in the past. These cancer survivors encounter numerous physical, psychological, social, spiritual and financial issues for the remaining years of their lives (Centre for Disease Control, 2004). Thus, cancer survivorship focuses on the health and life of an individual with cancer post treatment, until end of life. Survivorship covers not only issues related to the ability to get healthcare and follow-up treatment, but also the late effects of treatment, recurrences, second cancers, and aspects of QoL issues. Family members, friends and care givers are also considered part of the survivorship experience (National Coalition for Cancer Survivorship, 2015).

The three-phase of cancer survivorship (Mullan, 1985) underscored the various unique concerns and issues encountered by cancer survivors as they journeyed through the phase (Table 2.1). This essential information is crucial for researcher to address in developing a work-directed intervention on RTW, targeting different possible phases of the cancer survivorship.

The concept of cancer survivorship was further developed into several potential cancer survival trajectories (Hewitt, Greenfield & Stovall, 2006). Cancer survivors may live cancer free for many years while some may die of late recurrence or develop second primary cancer. Other survivors live with the chronic illness or intermittent periods of active disease (Figure 2.2). Early diagnosis following colorectal cancer screening, along with cancer treatment advancements, more survivors are expected to reach permanent survival phase and live with colorectal cancer as a form of chronic illness. Therefore, the prevalence of colorectal cancer survivors among the working population will increase and managing employment issues during cancer survivorship warrants immediate attention from all stakeholders involved.

Phases of cancer survivorship	Concerns and Issues				
Acute survival:	Survivors going through diagnostic and				
Begins with the diagnosis of the	therapeutic process. The fear and anxiety an				
cancer till the end of active	important and constant elements of this phase.				
treatment.					
Extended survival:	Survivors going into a phase of watchful waiting,				
Extends from the end of active	with periodic examinations and "consolidation" or				
treatment to the new normal life.	intermittent therapy. This phase is dominated by				
	fear of recurrence. Survivors need to deal with				
	symptoms following treatment in the home,				
	workplace and community.				
Permanent survival:	Survivors have come through cancer experience				
Living with cancer.	which has permanently affected them. Some ma				
	develop late effects, appear months to years after				
	treatment.				
	Concerns with employment and insurance				
	coverage are common for individuals who have				
	been treated for cancer and ready to resume a fu				
	life. The secondary effects of cancer treatment of				
	health are another issue that they might face.				
in the second se					

# Table 2.1: The three-phase of cancer survivorship (Mullan, 1985)

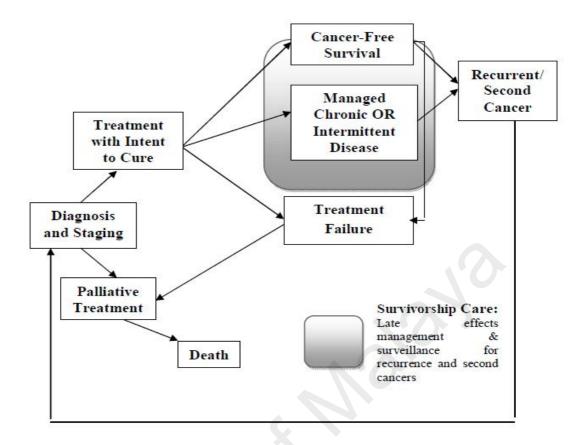


Figure 2.2: Potential cancer survival trajectories during cancer survivorship (Hewitt, Greenfield & Stovall, 2006)

#### 2.1.2 Impact of cancer on employees

The impact of cancer on paid work is of increasing importance as the higher rates of cancer survivorship translate into more survivors in the workplace, as a result of improvements in screening, diagnosis and treatment. There are about 2.5 million people in the U.K living with cancer today, with an increase of almost half a million in the previous five years, 2010-2015 (Maddams, Utley & Møller, 2012) and approximately 36.4 percent of these individuals belong to the working population (Cancer Research UK, 2012). It is estimated that by year 2020, at least 37 percent of cancer survivors will be below the age 65 years in US (Parry, Kent, Mariotto, Alfano & Rowland, 2011). Despite many individual views of the importance of work after cancer diagnosis and treatment, not all survivors managed to resume work. Cancer has been shown to have a

negative impact on employment patterns; an estimated 10 to 38 % of employees do not resume work after all types of cancer treatment. For many of these survivors, their RTW journey is disrupted by cancer treatments; follow up appointments, intermittent absences and periods of short term disability and impairment (Kenneth, Philip & Market, 2008).

The impact of cancer on employees can be examined in three aspects: negative impact on work performance, financial impact and positive impacts.

#### Negative impacts

Cancer is associated with by far the highest reported prevalence of any impairment (66.2%) and the highest number of impairment days in the past 30 days (16.4 days) (Kessler, Greenberg, Mickelson, Meneades & Wang, 2001). Most cancer survivors report negative impacts of cancer on work performance, as diminished physical or mental capacity affects their performance at work. Many attributed that to the side-effects of the cancer treatment which cause fatigue and tiredness (Spelten et al., 2003a; Carter, 2006; Molina et al., 2008). Fatigue is common among survivors treated with chemotherapy. It is supported by studies that shown up to 88 % of the survivors required changes in their daily routine due to fatigue, and 75 % of them changed employment status as a result of fatigue (Mock, 1998; Curt et al., 2000).

Mental functions including memory loss or cognitive impairment have also been reported to trouble survivors' work performance. Emotional effects such as depression, diminished confidence, inappropriate guilt about poor work ability act as additional barrier to workplace have been mentioned as part of the negative impacts on work performance among employees after cancer (Short, Vasey & Tunceli, 2005; Carter, 2006).

#### Financial impacts

Cancer is also known to have a profound economic effect on individuals and their households, especially among poor and under-insured survivors (Azzani, Roslani & Su, 2015). The financial implications of a cancer diagnosis may not be equitable because out-of-pocket (OOP) payments are the principal means of financing health care (O' Donnell et al., 2008). This relates beyond the primary cancer treatment, and may include long-term costs of adjuvant therapy and follow-up care (Arrossi S et al., 2003; Adedapo, Fadiji, Orunmuyi, Ejeh & Osifo, 2012; Lan, Laohasiriwong, Stewart, Tung & Coyte, 2013). The potential change or loss of health insurance may be an additional negative impact to the employees. The choice to leave or stay in employment would take that into consideration given that the treatment for cancer is expensive and the potential for further medical expenses is great. Many employees stay in employment for fear of losing their health insurance benefit. Bradley & Bednarek (2002) argued that survivors would remain in the workforce as long as they are able to continue working. Breast cancer survivors, who are single, divorced or widowed, are more likely to return to their workplace (Islam et al., 2014) to cover their medical expenses due to insufficient health insurance and future health expenditure and escalating medical costs (Polinsky, 1994). Hence, the high cost of cancer treatment coupled with significant out of pocket expenses, indirectly send cancer survivors back to workforce out of financial pressure (Amir et al., 2008; Roelen et al., 2011b).

### Positive impacts

Cancer also created some positive impact for employees. The desire to maintain organisational health insurance motivated survivors to remain in the workforce (Bradley & Bednarek, 2002). Of those employees who claimed to have experienced an impact on their working life, nearly as many mentioned positive impact as those who reported

negative ones. Many discovered the importance of work and personal life balance for themselves (Carter, 2006). Some took the opportunity to re-evaluate their priorities in life, putting life challenges into perspective and refocusing on personal and family matters more than work matters. Taking life easy or slowing down has also been a positive impact from cancer among the survivors who were previously workaholics (Cordova, Cunningham, Carlson & Andrykowski, 2001; Stewart et al., 2001b; Bellizzi & Blank, 2006).

Survivors were primarily concerned with disclosing their diagnosis to their employer. However, those who disclosed their cancer diagnosis shared positive supports from employers and work colleagues (Tiedtke et al., 2012a). This has been a reason to motivate cancer patients to report the diagnosis to the workplace in order for the employer to render necessary assistance and support (Amir et al., 2008; Yarker, Munir, Bains, Kalawsky & Haslam, 2010). The value of workplace emotional and instrumental support, for example, in getting duties covered outweighed the potential discomfort associated with a loss of privacy (Wells et al., 2013).

Limited research has been carried out to examine the RTW or employment outcomes following colorectal cancer diagnosis. Delay in RTW, working part time, changing work duties and work cessation were among the changes in employment after colorectal cancer (Sanchez, Richardson & Mason, 2004; Gordon et al., 2008; Earle et al., 2010). Therefore, it is reasonable to expect a significant proportion of employed colorectal cancer survivors were temporarily displaced from the workforce, directly or indirectly, following a cancer diagnosis (Sanchez et al., 2004). The negative effect on work performance and hence employment status can be ameliorated by creating a supportive working environment for these survivors (Short et al., 2005; de Boer & Frings-Dresen, 2009).

#### 2.1.3 Impact of colorectal cancer on work organisations

The increased number of cancer survivors in the workforce poses an immediate challenge for organisations. Being one of the most costly medical conditions, cancer creates a huge impact to organisations including: increased rates of disability, impairment and absenteeism among employees, loss of overall productivity and potential loss of valued, skilled employees. The impact of cancer on organisations is dependent, to great extent on the organisation's response (Kenneth et al., 2008). These impacts would adversely take a toll on the overall direct and indirect costs operating in an organisation.

Direct costs refer to the costs that can be completely attributed to the use of resources for the production of specific goods or services (Barcelo, Aedo, Rajpathak & Robles, 2003). Generally, direct costs include the salaries for the employees, employee fringe benefits, consultant services contracted for certain projects, travel of employees, material, supplies and equipment purchased and also communication costs such as long distance telephone calls (Miracel, 2014). However, if a cost is not directly traceable to a product, activity, department or customer, then it is known as an indirect cost (Investopedia, 2006). Premature mortality, absenteeism and disability contribute to the indirect cost (Barcelo et al., 2003). Therefore, the impact of cancer in organisations includes overall direct and indirect costs.

Spending on cancer treatment has increased by USD 63 billion from 1990 to 2008, partly due to the rising costs of new drugs and treatments, adding to the burden on organisations as a whole (Elkin & Bach, 2010). Up to 10 percent of all medical cost claims were made for cancer treatment among the commercial population (Host, 2008). Up to 11.8 percent of all claims were reported for cancer related long-term disability in the U.S with colorectal cancer survivors experiencing higher short-term disability cost

in the first year following diagnosis. Overall direct costs have increased for the past two decades following more of the working population being diagnosed with cancer, and the increased cost was consistent with the overall increased cost in medical expenditures. The introduction of new and advanced cancer treatment may have raised the cost substantially (Meropol & Schulman, 2007). Decrease in the average length of stay in hospital, and the percentage of cancer patients admitted to hospital has been observed over the last two decades. Thus, organisations spent more on outpatient expenditure, especially for prescription drugs (Tangka et al., 2010).

Absenteeism is habitual failure to appear, especially for work or other regular duties (Allen, Robinson, Aucoin & Leeming, 2014). Contrary to that, presenteeism is the practice of being present at workplace for more hours than is required or working while ill, an economic indicator of disease burden and as a manifestation of insecurity about one's job (Johns, 2010; Sanderson & Cocker, 2013). Being at work when unwell is a silent and growing phenomenon which reduces the degree of productivity at workplace as it cuts down individual productivity by one-third or more and can appear to be more costlier than its productivity-reducing counterpart, absenteeism (Hemp, 2004; Dewe, O'Driscoll & Cooper, 2010). Thus, absenteeism, presenteeism and reduced workplace productivity are contributing factors to indirect costs for organisations.

According to a nationwide survey done by the Malaysian Employers Federation (MEF), Malaysian employers lose RM 2.9 billion a year in overtime payments to workers replacing those on sick leave. At the end of the month, another RM 1.92 billion is paid to workers who did not work on specific days due to health reasons while an estimated RM 3.3 billion is spent on medical bills of workers needing treatment. In addition to that, employers in Malaysia jointly suffered 26.3 million days lost a year as a result of sick leave (The Sun Daily, 2014). Due to the side-effects following cancer treatment and clinic follow up, patients often have high rates of absenteeism at their workplace. Patients' ability to work may be compromised by the disturbing side-effects and it is not uncommon for older employees and those with multiple co- morbidities to have in patient treatment.

For those employees who are at work, they may not be as productive as before. Employees with breast cancer reported a mean reduction of productivity of 3.1 percent below those healthy workers. This amount translates to a loss of 2.48 hours of work over two weeks of full-time employment (Lavigne, Griggs, Tu & Lerner, 2008). Hence, there are many other issues that may affect productivity at work: side-effects, the fear of death, interruption of life plans, financial pressures and fear concerning impact on families.

Absenteeism comes with a huge price. According to the Malaysia Employers' Federation, it costs about RM 100 per day, with the additional costs of replacing absent workers, making the total loss due to sick leaves stands about RM 9 billion yearly, or 1 % of Malaysia's Gross Domestic Product, GDP of RM 850 billion. Cancer impacts the workplace in many ways and if not addressed, the growth and productivity of organisations could be hindered.

# 2.1.4 The importance of RTW among colorectal cancer survivors

The evidence over the last 20 years shows that individuals who are out of work in the medium- to long-term are at greater risk of developing negative health outcomes (Artazcoz, Benach, Borrell, Cortes, 2004; Bartley, 1994; Jin, Shah, Svoboda, 1995; Waddell & Burton, 2006).

Generally, being employed has a positive impact for the well-being of an individual compared to those without a job (Waddell & Burton, 2006; Hobson, 2007) after

colorectal cancer. Unemployment can have psychological and social consequences, as well as creating stress and financial problems (Waddell & Burton, 2006). Being unemployed does not only have an impact on a person's physical and mental health, but also affects their family (Artazcoz L et al., 2004). Unemployed individuals and their families suffer a higher rate of premature death, increased rates of depression and anxiety, higher rates of self-reported ill health, heart disease and risk factors for heart disease (Waddell et al, 2007). Marital problems and emotional distress have been linked to the financial stress of unemployment. Studies have also shown that children's health and well-being is affected by a parent's long-term unemployment (Sleskova et al, 2006).

Repetitive exposure to required work tasks facilitates recovery in physical, cognitive, emotional, and interpersonal domains of functioning that may have declined following cancer treatment (Hoving et al., 2009). Hence, returning to work serves as a measure of recovery from and control over the cancer, as well as a positive step toward the future (Ferrell et al., 1997; Feuerstein, 2009; MacEachen et al., 2006). The likelihood of an employee making a full recovery, both physically and emotionally, is improved the earlier that they are able to RTW in some capacity while RTW is reduced to 50 % after 45 days off work (The Royal Australasian College of Physicians, 2010). Therefore, in all RTW programmes, it is helpful and beneficial to initiate early RTW in order to achieve full recovery, both physically and emotionally (Hagen, Grasdal & Eriksen, 2003; WorkSafe Victoria, 2007). Conversely, delay and failure to RTW may hamper rather than promote health, (Waddell et al, 2007).

Returning to work also offers individuals social support and networks. Thus, as a result of not resuming work, social support and networks become limited and decreasingly available. These supports and networks are crucial for individuals in the phase of cancer survivorship, by reducing or avoiding social isolation, boredom, and loss of self-esteem (Amir et al., 2008; Rasmussen & Elverdam, 2008; Spelten et al., 2003b). In the absence of social supports and networks, individuals may be marginalised from society with an impact on their emotional vulnerability besides delaying the recovery process (The Royal Australasian College of Physicians, 2010) after cancer treatment.

Work is perceived as not only providing an income, but giving individuals a source of personal identity, mediating the sense of being valued as a person, necessary for self-esteem (Sturm & Dellert, 2015).

An individual's concept and perception of self is partly derived from the work, and considerable personal satisfaction is obtained through the achievement, social recognition and social interactions provided through work participation (Feldman, 1989; Ferrell et al., 1997). The ability to fulfil social and occupational roles while undergoing active cancer treatment is a sign of re-establishing normality and health besides contributing to society (Kagawa-Singer, 1993; Feuerstein, 2009).

The understanding that it is inappropriate to be at work unless a person is certified 100 % fit by healthcare professionals requires change as RTW does not necessarily harm the recovery process (Black, 2008). Therefore, an early intervention programme of RTW could be introduced as part of healthcare services to prevent short-term sickness absence from work from developing into long-term sickness absence and, ultimately, loss of work (Linton & Andersson, 2000; Black, 2008).

The overall focus of RTW is to minimise the cost of medical absenteeism to both the employer (Allen, 2003; Krause, 2002) and the employee (Abrams et al., 1993; Halpern, 2005; Olivier, 2012). This is achieved by assisting employees remain in work or RTW in a timely manner (Arnetz et al., 2003).

#### 2.2 Models on cancer and return to work

Over the past decades, there have been few models regarding cancer and RTW (Bradley, Bednarek & Neumark, 2002; Short et al., 2005; Steiner et al., 2004). Some of these models were developed from the perspective of health economics (Bradley et al., 2002; Short et al., 2005). While others (Steiner et al., 2004) were derived from a generic model of health-related quality of life. The primary intent of these models was to better understand various factors involved in RTW among cancer survivors in general, and not to directly provide guidance for evaluation, prevention, and management of issues surrounding RTW process (Feuerstein et al., 2010). However, in order to address the needs of colorectal cancer survivors in RTW after cancer treatment, a model based on the survivors' perspective is useful apart from these models.

## 2.2.1 The S.P.I.C.E model

This S.P.I.C.E model underscores the importance of early contact with the workplace, introducing timely intervention for RTW and working together with all stakeholders in achieving the common goal of RTW (Colledge & Johnson, 2000a). Using these key essential components, the work-directed intervention on RTW focuses on encouraging colorectal cancer survivors to engage with their employer soon after diagnosis, without delay. At the same time, relevant stakeholders (employers and healthcare professionals) are identified and engaged to carry out the specific tasks towards the common goal of assisting colorectal cancer survivors' RTW.

The S.P.I.C.E model consists of five essential components, involving the colorectal cancer survivors, treating physicians as well as the employer in the workplace: Simplicity (avoid over complicated treatment), Proximity (keep worker associated with workplace), Immediacy (prompt handling of industrial claims), Centrality (all parties

work towards the common goal of RTW) and Expectant (expectations of RTW are set appropriately; and work towards those goals).

# Simplicity

Treating uncomplicated conditions in a complicated manner may strengthen the belief of serious illness among the individuals treated with a chronic illness. When failure to address the significant psychosocial problem (Colledge & Johnson, 2000a), coupled with sophisticated tests and treatments for minor problems, colorectal cancer survivors like other individuals with chronic illness could succumb to the vicious cycle of continuously seeking for medical intervention. Therefore, it delays the anticipated treatment outcome and QoL, including resuming work after treatment (Colledge & Johnson, 2000b).

### Proximity

According to the S.P.I.C.E model, the concept of proximity suggests the treatment outcome would be enhanced if patients are treated in their normal environment in an uncomplicated manner, along with a supportive approach. Hence, the work-directed intervention for RTW must emphasise that survivors initiate immediate contact with their employer, and encourage communication between healthcare professionals and employers in assisting the smooth and timely RTW upon completion of treatment.

# Immediacy

The proximity of the supportive environment facilitates the timely management of colorectal cancer survivors during and after cancer treatment. Immediacy refers to prompt management of the survivors' health-related issues by identifying individuals who need treatment and helping them to access medical care without delay. In order to

achieve a favourable RTW outcome, adjusted working hours, meaningful modified duties and subsequent full duties can be introduced gradually (Baanders et al., 2001).

# Centrality

Centrality outlines the importance of having a common goal for successful RTW among all individuals involved in the process. As such, all stakeholders have roles to play in various stages of the RTW process, with treating physician co-ordinating treatment and setting up the expectations and goals within suitable timeframes. Communication and periodic feedback among all stakeholders ensure the colorectal cancer survivor is on the right track in their RTW, as scheduled.

#### Expectant

A proactive, work-directed intervention for RTW which establishes the short-term goals and periodic follow-up on barriers encountered by the colorectal cancer survivors would prevent these survivors from subscribing to the negative labelling expectations placed on them. They need to be informed that RTW improves recovery (Strong, 1998) and the myths about RTW after illness also need to be addressed. Among the usual misconceptions about RTW are: the first effort to RTW after a health-related absence marks the end of the problem of work disability, and RTW is only possible after complete recovery from illness (Baldwin & Johnson, 1998).

#### 2.3 Interventions to enhance RTW for cancer survivors in developed countries

Most of the literature on RTW focus on vocational intervention for musculoskeletal disorders (Jousset et., 2004; Joy et al., 2001; Lambeek et al., 2010), injuries (Sullivan et al., 2006; Vanderploeg et al., 2008) and mental health (Schene et al., 2006). The Cochrane Systematic Review on interventions to enhance return to work for cancer survivors (2015) reviewed fifteen RCTs including 1835 cancer survivors, conducted in

high income; developed countries concluded that multidisciplinary interventions have moderate quality evidence in enhancing the RTW among individuals with cancer. Though this Cochrane systematic review is the largest review looking at work resumption among cancer survivors, the majority of the survivors were made up of individuals living with breast cancer (46.7 %) or prostate cancer (13.3 %) (de Boer et al., 2015).

Interventions on RTW among cancer survivors have been categorised into four main types: psycho-educational intervention (e.g. focus on physical side effects, stress and coping mechanism) (Bains et al., 2011), physical intervention (e.g. participating in exercises), medical intervention (e.g. cancer drugs to surgery) and multidisciplinary intervention (e.g. vocational counselling or physical training or both, in combination with patient education or counselling or both). However, vocational intervention aimed at employment issues after cancer diagnosis were not reported (de Boer et al., 2015) despite cancer survivors are 1.4 times more likely to be unemployed than healthy individuals (de Boer et al., 2009). Work-directed rehabilitation or vocational interventions are commonly developed to assist RTW among individuals recovering from injuries and musculoskeletal disorders, and these vocational rehabilitations involved elements of or combinations of Functional Restoration Programme (FRP), Active Individual Therapy (AIT) (Jousset et al., 2004), work hardening (Joy et al., 2001), integrated care by team that consists of occupational health physician, occupational therapist, medical specialist and physiotherapist (Lambeek et al., 2010).

One of the earliest psycho-educational interventions on RTW among cancer survivors was carried out in the U.K which assigned a specialist nurse to counsel breast cancer patients undergoing mastectomy and monitor their recovery and RTW progress after discharge. Results showed that patients counselled by nurse shower greater social recovery and RTW than those who received care as usual (75 % versus 54 %) (Maguire,

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Brooke, Tait, Thomas & Sellwood, 1983). This study suggested that advice or discussion on RTW could be offered very early during the treatment process and that reintegration to work could start within the hospital setting prior to discharge. A rehabilitation programme for cancer survivors, "Starting Again" emphasising physical strength, information and coping skills was found to have no effect on employment or sick leave duration (Berglund, Bolund, Gustafsson & Sjoden, 1994) though participants improved significantly more than the controls with respect to appraisal of having received sufficient information, physical training, physical strength and coping skills. This finding suggested that having sufficient information and improved physical strength may not necessarily improve the employment outcome after cancer. "Starting Again" programme considered the non-participants as its control group while the participants in the physical exercise activities were physically fitter. Hence, there was evidence of selection bias in recruiting these participants for the programme.

Given the evidence that early advice on RTW in the hospital setting is feasible and may be effective, a pilot intervention study was conducted in the Netherlands to explore whether enhanced communication between treating physician and occupational health physician could improve employment outcome. Communication was enhanced by letters from treating physician to the occupational health physician informing the diagnosis, treatment plan and treatment outcome. In addition to that, cancer survivors and occupational health physicians received a leaflet with practical guideline on 10-step plan for RTW based on the principles of graded activity and RTW goal setting (Nieuwenhuijsen et al., 2006). It was found that the approach for RTW is feasible in hospital setting (Bains et al., 2011) though level of adherence to educational leaflet was not associated with an improvement in RTW in cancer survivors. Such finding could be attributed to the relatively small sample size in the study (26 cancer survivors and 24 occupational health physicians were interviewed).

Two studies looked into the performance of occupational health physicians in the RTW process of cancer survivors (Taskila et al., 2006; Verbeek et al., 2003). In Finland, Taskila et al. (2006) studied the amount of emotional and practical support cancer survivors needed and actually received from their co-workers, supervisors, and the occupational health physicians. Long-term cancer survivors of breast cancer, lymphoma, testicular and prostate cancer in the study reported most support was received from colleagues and least from the occupational health services. Cancer survivors who had received chemotherapy, female survivors and those with low education level needed more support (Taskila et al., 2006). Hence, there was a clear need for better and organised occupational health services for cancer survivors given that the needs are different for survivors of different cancer. Occupational health services must be tailored according to the survivors' needs in order to offer meaningful support towards favourable employment outcome. In the Netherlands, Verbeek et al. (2003) evaluated the quality of care delivered by their occupational health physicians in a cohort of 100 cancer survivors, 1-2 years after diagnosis. There was minimal communication between treating physician and the occupational health physician as only 6 % of the cases was there any formal exchange of information on work and diagnosis. As for the continuity of care, most survivors were reviewed by the occupational health physician with only 60 % had follow-up appointments. While the quality of occupational health support was reasonable but communication between treating physician and occupational health physician was open for further improvement. Therefore intervention for timely RTW starts with early and constant communication between treating physician and occupational health physician as survivors journey through the cancer care continuum (Table 2.2), from diagnosis, treatment towards survivorship phase (Franche et al., 2005; Tjulin, MacEachen & Ekberg, 2010).

The Dutch Society of Occupational Medicine studied the experience of cancer survivors and line managers concerning RTW after diagnosis and cancer treatment by means of three focus groups (de Boer, Zanten-Przybysz, Maes & Frings-Dresen, 2008). The most significant themes for the cancer survivors were early contact with and support from colleagues and line managers, getting relevant advice from occupational health physician and treating physician besides equipping oneself with the knowledge of late effects of cancer. As for the line managers, the main tasks identified were communication with the occupational health physicians, understanding their role in the RTW process and work adjustments. The evidence-based guideline by the Dutch Society of Occupational Medicine was developed by multidisciplinary group of healthcare professionals (e.g. occupational health physicians, oncologists, oncological nurses, general practitioners and psychiatrists) together with employers and consists of two parts. In the first part, advice is given on how to include the employment issue in current monodisciplinary approach. The second part is targeted at professionals counselling by allied healthcare professionals for working cancer survivors at three phases: diagnosis, treatment and recovery and re-integration and follow-up. For each phase, guidance on appropriate activities is provided. For example, in the diagnostic phase, information on the work-related impacts of the upcoming treatment is given and advice that an occupational physician should preferably communicate between treating physician, employer or line-manager and the survivor about work-related issues (Bains et al., 2011). In the re-integration phase, special attention should be paid to physical limitations and fatigue. Furthermore, re-integration programmes aimed at re-entry to the workforce of cancer survivors should be offered to the patient when appropriate.

The future work-directed intervention for RTW among cancer survivors must be developed as part of rehabilitation process (Tamminga et al., 2010) and an extension from the usual cancer care which ends with treatment. The concept of continuum of

cancer begins with risk assessment, primary prevention, screening, detection, diagnosis, treatment, survivorship, and end-of-life cancer (Table 2.2) (Mufazzal & Sandeep, 2012). Movement across the span of the continuum with a set of interactions involves multidisciplinary group of healthcare professionals (Jane & Matthew, 2009; Nekhlyudov, Levit, Hurria & Ganz, 2014) and various types of care targeting specific goal, such as detection, diagnosis, or treatment (Levit, Smith, Benz & Ferrell, 2010; National Cancer Institute, 2014). Hence, rehabilitation can focus on health, functional or work ability and employment during survivorship (Kuoppala & Lamminpää, 2008; Khan, Ng & Turner, Stokes, 2009) in order to resume work. The outcomes of rehabilitation include prevention of the loss of function, slowing the rate of loss of function, restoration of function, compensation for lost function, and maintenance of current function (Social Security Organisation, 2012).

However, it is important to note that not all cancer survivors require assistance to resume work after cancer (Amir & Brocky, 2009; Kennedy et al., 2007). Therefore, there must be a mechanism in the work-directed intervention to screen for the cancer survivor who needs additional support and assistance in returning to work. Treating physician could play the role in assessing these cancer survivors based on their preferences and evidence-based predictors of RTW (de Boer et al., 2009b; Mols et al., 2009) since physician contact with the survivors earliest in the cancer care continuum. Those cancer survivors who are in need of RTW support could be assisted through various RTW recommendations (e.g. work adaptation, communication with the employer or line manager and attending to cancer and treatment-related symptoms). Psychological concern is also a key element in the survivorship phase (Ferrell et al., 2004; Ganz, 2000; Muzzin et al., 1994; Vachon, 2001) and warrant relevant attention as part of multidisciplinary approach in the RTW process.

Prevention	Early Detection	Diagnosis	Treatment	Survivorship	End-of- Life Care
Tobacco	Colorectal	Biopsy	Chemotherapy	Surveillance	Hospice
control	cancer	Histological			care
	screening	assessment	Hormone	Psychosocial	
Diet			therapy	care	Palliation
	Breast	Pathology			
Physical	cancer	reporting	Pain	Management	
activity	screening		management	of long-term	
2	C	Tumour	C	effects	
Sun	Cervical	stage	Psychosocial		
exposure	cancer	documented	care		
	screening				
Alcohol			Radiation		
use					
			Surgery	5	

 Table 2.2: The cancer care continuum (National Cancer Institute, 2014)

## 2.4 RTW programmes in Malaysia

# 2.4.1 Introduction of RTW programme

RTW programmes are part of an organisational and business strategy to retain valued employees and to enhance the productivity of the workforce (Orslene & MPIA M, 2013). Generally, the RTW programmes are designed to return an injured, disable, or temporarily impaired worker to resume full duty at the workplace as soon as medically feasible. The anticipated result of an RTW program is the progressive return of the employee to full duty after an injury or a brief illness (Orslene, 2013). At present, specific RTW programmes for employees with chronic disease like cancer have not been outlined, though the prevalence of cancer affecting the working age population is expected to rise annually.

Among the common interventions and work adjustments included in a RTW programme are temporary or permanent accommodations such as modified schedules,

modified job duties, modified methods for completing job duties (Krause, Dasinger & Neuhauser, 1998; Cronin et al., 2013; Shaw et al., 2014) or reassignment to an alternate position (Franche et al., 2005b).

Immaterial work adjustments, such as flexible working hours or modified job duties (Wainwright, Wainwright, Keogh & Eccleston, 2014), are more commonly introduced and preferred than material adjustments, such as assistive devices or adjustments to the workplace, or furniture as part of the RTW programme (Baanders et al., 2001) because flexible hours and modified duties are more practical, fitted in easily along with other recommendations in RTW programme in navigating in the working life during survivorship (Baanders et al., 2001; Pryce et al., 2007).

### 2.4.2 The current RTW model in Malaysia

Currently, the only systematic, evidence-based RTW programme, involving multiple stakeholders in Malaysia, is undertaken by the Social Security Organisation (SOCSO), also known as PERKESO (Pertubuhan Keselamatan Social) in the Malay language, a statutory body under the Ministry of Human Resources. The SOCSO RTW programme for insured injured workers was introduced free of charge in Malaysia, as part of physical and vocational rehabilitation in accordance with the Employees' Social Security Act 1969, Section 57(1) (PERKESO, 2009). Registered Malaysian citizens and permanent residents (earning less than RM 3,000 a month) contribute monthly to SOCSO, and are entitled to benefit from the protection scheme if they are injured or disabled in the course of their employment, including workplace or commuting accidents and occupational diseases (PERKESO, 2008).

The Labour Force Survey Report, Malaysia (2014) reported there were 13.5 million employed workers in 2014 and only 6.4 million (48%) employees are covered by SOCSO, and close to one-third of these employees were 40 years and above (Social Security Organisation, 2012). In other words, there are more than half of the working population in Malaysia who are not insured by the SOCSO.

In early 2008, SOCSO adopted the holistic, multidisciplinary approach based on the bio-psychosocial RTW programme model developed in several countries such as Australia, Canada, Sweden and the United States. The main objectives of the SOCSO RTW programme are to improve QoL, retain skilled workers at the workplace, and reduce compensation claim costs by returning injured or ill workers to work safely, without delay, following rehabilitation (Social Security Organisation, 2012).

The RTW programme by SOCSO involves a proactive approach taken in helping insured people suffering from employment injury or claiming to be an invalid, the opportunity to return to safe and productive work activities. The entire RTW process is facilitated by a case manager who is responsible for implementing and coordinating the rehabilitation plan with the healthcare providers, and the insured person to ensure provision of appropriate medical care for timely and safe RTW (Social Security Organisation, 2012).

Statistics on SOCSO RTW from 2007 till 2011 (Figure 2.4) shows a steady growth in the number of insured employees who have successfully RTW via the programme since its introduction. In 2010, 65 % of insured employees successfully RTW and 84 % of these employees continued working for the same employers, while 70 % of those working for the same employers also continued doing the same tasks (Zero Project, 2014). This positive trend suggests that through effective treatment, rehabilitation and specific case management, individuals are able to RTW effectively, despite previous injury or illness. Hence, this effort in RTW inadvertently helps the employers to benefit in terms of human capital (Tan, Johari & Sukery, 2015).

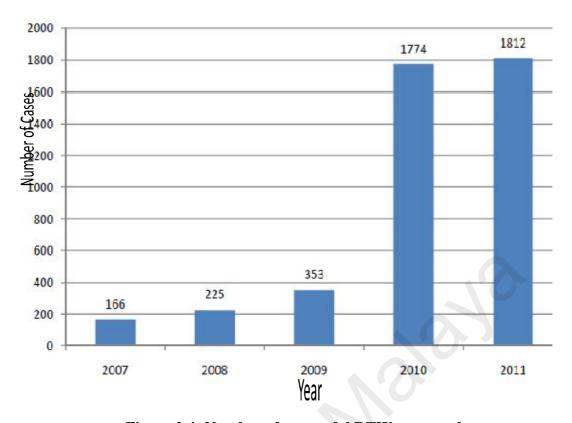


Figure 2.4: Number of successful RTW cases under "SOCSO RTW Programme" (Social Security Organisation, 2012)

Despite the increasing number of successful RTW cases under the SOCSO RTW programme, it is noted that the vast majority of the returnees are those affected by workplace injuries and accidents. Existing data from SOCSO also suggests that the RTW programme provides rehabilitation for musculoskeletal disorders (MSD) and pain management (Social Security Organisation, 2012). While the SOCSO RTW programme has not published any data or reports on facilitating insured individuals living with chronic condition, like colorectal cancer to RTW, the burden of the disease at the workplace and society at large continues to rise.

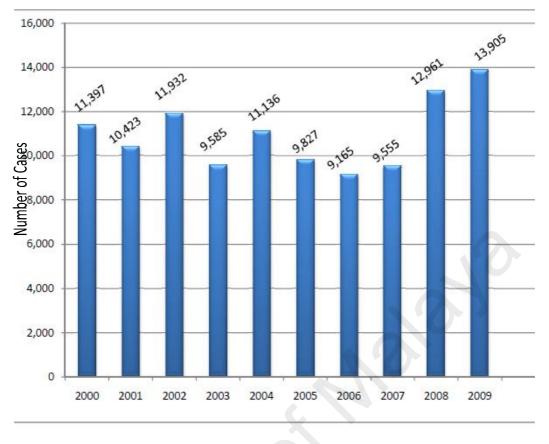
The current RTW model and coverage by SOCSO highlight some essential gaps of paramount importance. Firstly, not every single employee in the country is eligible to be insured by SOCSO. As a result, up to more than half of the working population has no access to SOCSO RTW programmes; however comprehensive and holistic approach it can be. Secondly, for those employees who are insured, the SOCSO RTW programme, at present does not cover all medical and health conditions. Hence, insured workers suffering from conditions apart from injury and MSD may not be readily fit in the existing RTW programme which was originally designed for the disability management following injury and MSD.

Therefore, a different approach is being used in this study to assess fitness to work as part of an intervention for RTW among individuals living with colorectal cancer, as a form of chronic disease. The work-directed intervention on RTW focuses on the individual, workplace support as well as the communication between healthcare provider and employer to achieve timely and safe RTW.

# 2.4.3 Justification of RTW policy in Malaysia

The SOCSO RTW policy in Malaysia attempts to benefit a number of people by having a positive influence on injured employees, employers and any existing compensation fund or relevant government institution, such as SOCSO.

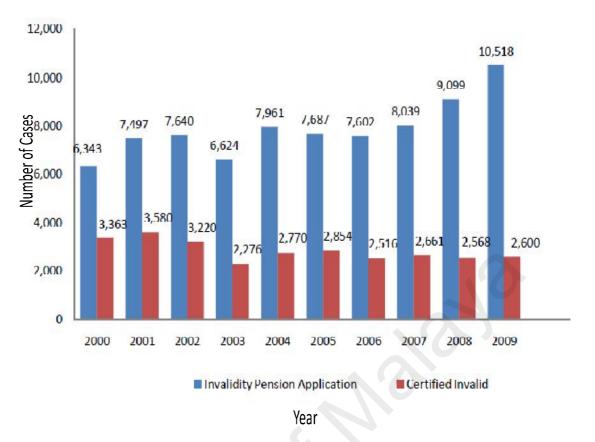
The following chart (Figure 2.5) demonstrates the high number of new cases of employment-related permanent disability experienced in Malaysia per year between 2000 and 2009. A large, increasing number of people who are becoming permanently disabled as a result of an employment-related injury, forcing them to leave their employment (Social Security Organisation, 2012).

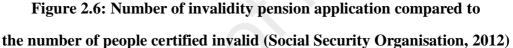


Year

Figure 2.5: Number of new cases of employment-related permanent disability in Malaysia, 2000-2009 (Social Security Organisation, 2012)

The cumulative number of invalidity pension recipients was 49,959 recipients, indicating an increase of 7.70 % from the previous year. In line with the increase in the number of recipients, the total sum of payments for the invalidity pension increased by 9.52 % or RM 43.17 million from RM 453.65 million in 2013 to RM 496.82 million (PERKESO M, 2014). However, research undertaken between 2000 and 2009 shows that between one half and three quarters of people who applied for an invalidity pension in Malaysia did not receive a certificate of invalidity, as shown in the graph (Figure 2.6) (Social Security Organisation, 2012).





The increasing trend of new cases of employment-related permanent disability and invalidity pension application annually underscore the need to keep these productive insured workers employed via a multidisciplinary RTW approach. Intention to RTW, regardless of the injury or type of illness, has been shown to be influenced by the individual's attitude and subjective norms (Tan et al., 2015). An individual's evaluation of their health status may affect the duration of work inability (Brouwer et al., 2009) and the individual's perception of other people's view and thoughts on their particular behaviour can play an influential role and put pressure on an individual to perform a behaviour, such as RTW or applying for invalidity pension (Brouwer et al., 2009; Vermeulen et al., 2011). The trend of applying for an invalidity pension could be part of the subjective norms among all insured workers recovering from injury or illness, hoping to be certified invalid and avoid RTW. Hence, judging from the trend of

invalidity pension application, the intention to RTW, conceptualised as the level of motivation to RTW (De Rijk, Janssen, Van Lierop, Alexanderson & Nijhuis, 2009) among these workers was not encouraging.

Many workers believe that their health condition warrants them to stay away from work without knowing that the longer a person stays away from work, the less likely the person could RTW successfully (The Royal Australasian College of Physicians, 2010). Such negative attitudes about RTW and the subjective norms of applying for compensation instead of undergoing rehabilitation are some of the common challenges faced by healthcare providers in returning injured and ill workers to their workplace.

As a response to the negative attitude towards RTW and overzealous applications for compensation, SOCSO has taken initiatives in actively promoting awareness on workplace injury, accident prevention and various rehabilitation efforts as part of the SOCSO RTW programme.

The urgency to expand the coverage beyond the scope of musculoskeletal disorders for SOCSO RTW programmes is clear. More insured workers living with chronic illness, including cancer during survivorship phase could then look forward to resuming productive working life. SOCSO may also consider some forms of incentives for organisations which take part in the RTW programmes to encourage more employers in participating in the programme.

# 2.4.4 RTW as part of the Employee Assistance Programme (EAP)

The EAP is defined as "a worksite-based programme that utilises specific core technologies to assist (a) work organisations in addressing productivity issues, and (b) 'employee clients' in identifying and resolving personal concerns, including, but not

limited to, health, marital, family, financial, alcohol, drug, legal, emotional, stress or other personal or work-related issues that may affect job performance" (EAPA, 2010).

One of the services provided by the EAP is assistance in RTW after a long absence due to sickness. These services offer support to the organisation and employee alike, addressing issues related to prevention as well as supportive intervention. Implementing a RTW programme can meet the employer's duty to accommodate and facilitate the employees RTW after injury or illness (Jacobson & Mark, 2010; Richard, 2014). Counselling, case management and assistance in the RTW process and follow-up are among the services rendered under the EAP, involving various healthcare providers (Crandall & Perrewe, 1995; Arthur, 2000). Counselling, is provided within strict standards of confidentiality, is helpful for a wide range of personal, family and work concerns, including concerns arising from an employee's physical disability, impairment and gradual RTW (Sonnenstuhl & Trice, 1990; Berridge, Cooper & Highley-Marchington, 1997). Counsellors specialised in short term, solution-focused approaches, coordinate with or make referrals, with employee's written and informed consent, to other healthcare professionals when the need arises (Berridge, Cooper & Highley-Marchington, 1997; Rothermel et al., 2008). Hence, EAP adopts a multidisciplinary approach in managing employees' personal and work-related issues.

Mental health disorders are rapidly growing in Malaysia and it was estimated in 2000 that prevalence of mental illness in the population was between 9.6 % to 10.7 % (Crabtree & Chong, 2000; Jamaiyah, 2000). Up to 30 percent of the chronic diabetes patients in Malaysia are reported to have anxiety symptoms (Kaur, Tee, Ariaratnam, Krishnapillai & China, 2013). Diabetes mellitus is the second most common chronic disease, after hypertension among the Malaysian population. With the prevalence of chronic illness in Malaysia being 15.5 % and growing (Amal et al., 2011) and, about 40 % of colorectal cancer patients from the working population in Malaysia (First Annual

Report of the National Cancer Patient Registry-Colorectal Cancer 2007-2008, 2010), opportunities for the EAP to collaborate more with treating physicians, disease management programme, and disability case managers, as part of multidisciplinary approach become more evident. Therefore, the EAP can potentially play a significant role in assisting colorectal cancer survivors and other employees with chronic conditions to navigate through the RTW process in Malaysia.

An Employer's Guide to Cancer Treatment & Prevention was developed by the National Comprehensive Cancer Network (NCCN) and National Business Group on Health (NBGH) and aims to help professionals deal effectively with the many issues about cancer that arise in the workplace (National Business Group on Health, 2013). One of the key recommendations outlined in the guide was to increase the awareness of the RTW programme under the EAP which could be utilised by employee with chronic illness, including cancer. Once the awareness of RTW programme is created, supervisors and managers can consult with the EAP and refer employees with serious illness, including cancer for further assistance by the EAP. Access to health psychology/behavioural medicine specialists and health coaches could be arranged by managers to consult on managing employee RTW, including EAP case accommodations and other short-term workplace intervention (National Business Group on Health, 2013). Therefore, survivors of colorectal cancer and other types of cancer would benefit from such integrated, systematic, evidence-based, multidisciplinary RTW programmes under the EAP for timely and safe work resumption.

## 2.4.5 Employee Assistance Programme in Malaysia

In Malaysia, the EAP was first introduced by Motorola in 1999 and subsequently in 2003, Dupont and Kimberly Clarke started a small-scale EAP for their local employees. The telecommunications company, Telekom Malaysia started with an internal EAP that

focused on peer counselling to 25,000 employees scattered throughout thirteen states in Malaysia (Khrishnan, 2000) as a form of confidential assistance and guidance to the work organisation and its employees in managing various issues pertaining to work productivity (Dickman & Challenger, 2009; Walsh, 1982). Personal concerns including health, marital, family, financial, alcohol, drug, legal, emotional, stress, or other personal issues that may affect job productivity and performance at workplace will be identified and resolved through EAP (Dickman, 2009).

However, unlike in developed countries, the EAP is still in the development stage in Malaysia where many companies are still not willing to invest in the programme (Low, 2010). These multinational companies either employ a team of private local and regional companies or work along with professional counsellors to establish their EAP. Some companies also engage occupational health physicians or occupational health doctors to run the EAP. The acceptance of EAPs among employers in Malaysia is low and this is attributed to the lack of research on EAP in Malaysia. In addition, the stigma towards mental health problems (Ng, 1997; Reddy, Tan, Azmi, Shaharom, Rosdinom, Maniam & Minas, 2005), which is part of the focus of the EAP is another major challenge faced by EAP providers in a developing country like Malaysia (Low, 2010).

Job strain and stress at work have been reported in both, the public (Hadi, Naing, Daud, Nordin & Sulong, 2009; Masilamani R et al., 2013; Mukosolu, Ibrahim, Rampal & Ibrahim, 2015) and private sectors (Swee, Anza & Hassim, 2007; Maizura, Retneswari, Moe, Hoe & Bulgiba, 2010) in Malaysia. Stress-related illnesses and family issues are among the common issues affecting the Malaysian workforce and productivity (Razak, Yusof, Azidin, Latif & Ismail, 2014). About one-third of policemen reported stress (Masilamani et al., 2013) while up to 70 % of managers and executives were found to be stressed in an international tobacco company in Malaysia (Swee et al., 2007).

Mental health conditions, especially depression, produce the greatest decline in health compared with chronic diseases like asthma, arthritis, diabetes and cancer. Hence, the co-morbid state of depression further worsen health and QoL (Moussavi et al., 2007) which would take a toll on the productivity of the workforce in a developing country like Malaysia. Sick absenteeism at the workplace contributed to the costs to employers of RM 2.9 billion in replacing the employees, another RM 1.92 billion for the employees and RM 3.3 billion in a year for medical treatment (Annie, 2014). Therefore, it is evident that there is a real need for workplace EAPs to be implemented to reduce the implications of sick absenteeism in Malaysia.

EAPs understand the impact of emotional and behavioural issues following a brief period of sick leave on work performance and organisations. The strength of EAPs is in providing strategic consultation, problem identification and solution management to corporations for complex employee relation issues, organisation development, transitions, health and wellness. EAP providers offer Transition Support (Transition Management) which includes consultative and educational components to the workers returning from sick leave, also to the managers and key business partners when an organisation undergoes major changes (Dickman, 2009).

At present, EAPs make good business sense as employees are the most essential asset in an organisation (Low, 2010). Therefore, EAPs would be relevant and helpful to include RTW component in order to address poor employment outcome following cancer as it offers these employees a platform to communicate and engage with the workplace after completion of active treatment.

### 2.5 Assessment of fitness to work as part of RTW programme

#### 2.5.1 The importance of assessing fitness to work as part of RTW programme

Cancer survivors encountered various issues in reintegrating into workforce after cancer diagnosis (Amir et al., 2008; Hoffman B, 2005; Mellette, 1985) but received most support from colleagues rather than occupational health physicians (Taskila et al., 2006). However, the employers have difficulties in identifying the functional capacity of survivor and ways to introduce safe RTW (Taskila & Lindbohm, 2007). Very often, employers are unaware of the improved prognosis and adjuvant treatment which required some forms of work adjustment on work schedule. While cancer survivors' needs may alter as they navigate from treatment to survivorship phase, the objective of RTW programme remains the same, which is timely and safe RTW.

Fitness to work examinations require an objective assessment of functional capacity in terms of the physical and mental health of employees in relation to the requirements and working conditions of specific jobs (Rayson, 2000). The outcome of the assessment is influenced by the interaction between functional capacity, state of health, the nature of work tasks, and possibilities for work accommodation at the workplace (Chan, Tan & Koh, 2000). It is aimed at determining if an individual is fit to perform the tasks without risk to self or others which include their employing company or a third party (Cox, Brown, Palmer, 2000).

The scope of fitness to work specifically excludes medical surveillance and general health and well-being promotion of the workforce. Fitness to work approach once adopted by an organisation, it is considered mandatory for the employees to comply with its requirements while participation in health promotion programme is voluntary. However, the elements of all three types of examination (i.e. fitness to work, medical surveillance and health promotion) are included at one clinic visit despite the distinction of each component is crucial and has meaning in terms of the outcome of the assessment (IPIECA-OGP, 2011).

#### 2.5.2 Indications for assessment of fitness to work

Essentially, fitness to work assessments are indicated in various circumstances, and they must be job-related, with judgements of fitness being based on the principle that an employees' state of health in relation to their jobs will not be hazardous to themselves or others (Palmer, Cox & Brown, 2007). It is commonly required in pre placement assessment when an employee has been offered a full or part time job subject to passing such medical evaluation (Serra et al., 2007).

Fitness to work assessment is also being carried out for employees returning to work after an illness or injury whose work performance after a period of absence is not known (Glozier, 2002). For those who have returned to work at a modified job and are still undergoing rehabilitation, therapy or both, such assessment can help to gauge the extended period needed for the modified job.

For the purpose of paying workers' compensation, fitness to work evaluation is used to assess employees' short term or long term disability as a result of illness or injury (Glozier, 2002; Gross, Battié & Asante, 2007).

Occasionally, fitness to work evaluation can help the organisation to identify the potential health issues of the employees attributed to poor work performance (Gebhardt & Crump, 1990). This could be part of an Employee Assistance Programme to help employee to achieve better work performance at workplace.

#### 2.5.3 Principles of a fitness to work assessment

A well-designed fitness to work assessment as part of a RTW programme will reduce risk and liability, and will determine whether employees are capable of conducting their assigned tasks in the workplace. When a fitness to work assessment is carried out according to its principles and objectives, the RTW programme will avoid waste, discrimination (Mellette, 1985), and unnecessary and inappropriate exclusion of individuals from work that they could perform safely and productively (Glozier, 2002).

Unlike health promotion, fitness to work is mandatory, not optional as part of an assessment before employees return to work after illness or injury (IPIECA-OGP, 2011).

The fitness to work assessment should be based on the evaluation of the risk and potential hazard at the workplace considering the requirements of a position with the reasonable (and foreseeable) health and capacity requirements for an employee in that position. Therefore, during the fitness to work assessment on colorectal cancer survivors after surgery, the work capacity, safety issues and the level of motivation must be considered along with factors like the wound healing process, age and smoking (Williams, 1995).

Jobs that requires manual lifting of more than 5-10 kg should not be done until remodelling of collagen starts in the healing process following surgery for colorectal cancer and wounds get strengthened enough by four to six weeks after surgery. Smoking, obesity and diabetes affect the inflammatory process and can impair wound healing, while age has only a minimal effect on recovery time. Recovery takes an additional one or two days overall, between 18 and 65 years adults (Amid, Shulman & Lichtenstein, 1993; Williams T, 1995; Royal College of Obstetricians and Gynaecologists, 2011; The Royal College of Surgeons, 2012).

Any tests of functional capacity or medical examinations should therefore focus on an assessment of the fitness for the work assignment or tasks (Glozier, 2002; Oesch et al.,

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2006). These tests and examinations must be legal in the country in which they are applied and should produce repeatable and consistent results (IPIECA-OGP, 2011).

#### 2.5.4 Methods used in fitness to work assessment

Serra et al. (2007) in a systematic review on criteria and methods used for the assessment of fitness for work, found out that the majority of the assessment tools applied to individuals were basic diagnostic tests, while more sophisticated tests are selected in specific situations. Apart from the diagnostic tests, clinical interview and examination were among the commonly used assessment tools for fitness to work. In the review, an occupational history, along with specific health questionnaires such as the Work Ability Index or other standardised questionnaires, are used on some occasions as the only means or the first step to assess fitness to work (Hainer, 1994).

The objective of medical examinations, which include clinical interview and physical examination, is to identify physical and psychological barriers or limitations which may hinder the employee from performing a specific task. In a well planned process of a fitness to work assessment, the likelihood of mismatch between an employee's work capability, their health and assigned position will be identified. However, employers must recognise that these evaluations offer an assessment at a moment in time and have limited predictive value for future development of medical or capability issues. The employer therefore may need to investigate the necessity for subsequent reviews of any individual returning to work after an illness. Workplace supervisors should refer employees for review if they have reasonable grounds to consider an employee is unfit or unable to perform the assigned work.

It is known that medical examinations targeting an employee alone is not enough as the doctor's awareness and knowledge of a particular job is another key aspect when determining fitness to work (Cowell, 1986; Verbeek et al., 2003). Most of the tools

agree that detailed information is needed on work conditions, such as job tasks, exposure to hazards and organisation of workplace. This may warrant a work site visit to obtain first hand information (Hainer, 1994). However, such information is often lacking and unspecific, and too often provided solely by the employee. Assessment on fitness to work should be focused on the functional requirements and risks of the job, and the functional capacity of the employee's work ability to carry out the essential tasks of the job. This could be achieved through a job analysis during a worksite visit to further analyse the work demands of the particular job. The essential job functions in any given work role could be sought from the employers prior to the job analysis (Rayson, 2000).

In summary, the methods used for fitness to work assessment as part of a RTW programme must be cost-effective (McGregor, 2003), and determined by the specific risks involved in the workplace (Hessel, Zeiss, 1988), information on job requirements, targeted occupational and medical histories, selective physical examination and laboratory and specialised testing if necessary (Hainer, 1994).

# 2.5.5 Outcome of fitness to work assessment

The fitness to work assessment should be reported in a clear statement to the employing company on the status of the employee as a preparation to RTW.

Fit for assigned work or tasks and location means the employee is able to perform the job without danger to self or others without reservations, after taking into consideration of the employee's health status, work ability and any safety hazards at the workplace (Department of Work and Pensions, 2011; Irvine, 2011).

When the employee is unable to perform the job without being a hazard to self or others, the employee is deemed unfit for the assigned work, or tasks and work location.

The term "temporarily" indicates the medical condition or limitation may improve with time, hence allowing RTW or transfer to some other job before the subsequent review ensues (Fraser, 2003). When the employee is found to be permanently unfit, it means the employee is unable to do any available job with or without job modifications (Department of Work and Pensions, 2011).

Clear recommendations on potential work accommodations and specific tasks to be avoided facilitate the RTW process. When an employee is found to be unfit, either temporarily or permanently, the employee must be fully informed of the assessment findings (Cowell, 1986) and the subsequent plan for RTW.

Overall, this literature review has revealed the emergence of colorectal cancer as a chronic disease, its disease burden on the workplace and some important aspects to be considered while designing a work-directed intervention on RTW. This review also opens up the current gap in addressing the issues of survivorship, after active cancer treatment, as colorectal cancer has gradually being acknowledged as a chronic disease. While the bio-psychosocial model has been proposed for RTW among injured workers; survivors of colorectal cancer, require a different approach to manage the disease and treatment-related impairments as they resume their duty at the workplace. It has been shown in various literature that RTW is a multidisciplinary and team effort, comprising employer, treating physicians, occupational health doctors and rehabilitation providers. Therefore, the commitment and engagement of these key stakeholders is the cornerstone of RTW efforts in returning the colorectal cancer survivors timely and safely to the workplace.

#### 2.6 The role of work ability in RTW programme

#### 2.6.1 Background of work ability

The concept of work ability arose from the concerns that Finland's ageing population, combined with early departures from the workforce, could seriously damage the economic success of the country (Ilmarinen et al., 1991).

In many organisations, the core of the workforce is made up of those aged between 40 to 50 years of age. Employers also aware that this cohort of working population will constitute the core working group in ten years. This concern leads to the question about how to maintain a continued productive workforce in the future. Thus, the concept of 'work ability' has gained increasing attention from various organisations (Ilmarinen & Rantanen, 1999).

Work ability has also been studied in the ageing population (Ilmarinen & Rantanen 1999; Costa & Sartori, 2007), those with chronic diseases (Slebus et al., 2007) and musculoskeletal disorders (Berggvist et al., 1995; Helena et al., 2010). In the field of oncology, work ability was examined along with employment status in general cancer groups (Taskila & Lindbohm, 2007) and breast cancer (Munir et al., 2009; Beate et al., 2012). However, work ability has not been studied among colorectal cancer survivors. This study aims at introducing work ability assessment as part of the RTW process among the survivors of the most common cancer among Malaysian men.

#### 2.6.2 The work ability concept

Work ability is the measure of the degree to which employees are capable of working, given their individual physical, mental and social resources on one hand and the demands of the job on the other. It should be understood as the interplay between personal resources (competences, capabilities and characteristics) and the demands of

the work task. Work ability is not independent of life outside work as family and close community to which an individual belongs can all have an impact (Roelen & van der Klink, 2014; Nevanperä et al., 2015). Poor work ability might be due to poor health, poor work competence, skill or knowledge, inappropriate attitudes and values, poor management or working conditions. Effective work ability is characterised by the maximum possible fit between the work performed by an employee and the requirement of a company (Nevanperä et al., 2015). Hence, good work ability can facilitate the RTW process and enhances the employment outcome in survivors living with colorectal cancer.

Employee work ability is of fundamental importance for companies and organisations. It has a decisive influence on productivity, performance, innovativeness and ultimately the value created by a company. It has been shown that targeted measures can help maintain work ability for longer, improve it, or at least reduce its decline. In a way, work ability is a resource that can be improved, even in old age in any workplace and setting. Therefore, a target work-directed RTW intervention is helpful to maintain the work ability among the employees with a chronic condition in the workplace in order to create an impact on the productivity of the workplace (Mehnert et al., 2013).

# 2.6.3 The house of work ability

The translation of the 'concept of work ability' into an organisation may be illustrated by the 'house of work ability', its floor, and the surrounding environment (Ilmarinen & Lehtinen, 2004). According to this 'house of work ability', there are four essential individual factors for work ability: the most crucial factors are health, competence and values, in the sense of attitudes and motivation. Work demands concern work content, work organisation, working time, working environment and management. Organisation, individual and social aspects are closely related. The foundation for the four-storey 'house of work ability' is the workers' health which encompasses physical, psychological and social health. Such a foundation must be identified and prioritised prior to assisting RTW among colorectal cancer survivors, as a form of chronic disease. Barriers, motivators and enablers in terms of physical, psychological and social health of the colorectal cancer survivors need to be explored together with the work demands (environmental factor) in order to achieve timely RTW via an integrated RTW intervention looking at these multiple factors.

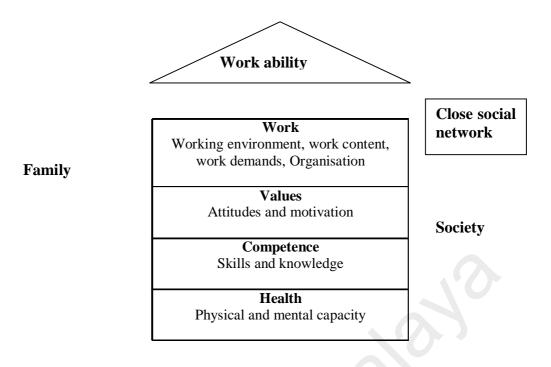


Figure 2.3: The house of work ability (Ilmarinen & Lehtinen, 2004)

Essentially, the work ability of an individual is dependent on numerous factors, both internal and external factors. All four floors (factors) must be considered if work ability is low in an individual or in workplace groups (Figure 2.3), following ill health in the workplace. This model is very useful when a work-directed RTW intervention for colorectal cancer survivor is being developed as it offers a holistic view on workplace health promotion, looking at the optimal communication between the four floors and mobilising internal and external expertise for each floor (when the needs arise). Having such a view enables an organisation to respond to adverse developments at an early stage and to timely implement adequate measures for assuring continued 'organisational health' and for preventing an early occupational exit (Ilmarinen, 2006).

#### 2.6.4 Promoting or maintaining work ability

The challenge of the need to increase work participation, especially among older workers is not new. Hence, many policies are being implemented to increase the age of full retirement, as a response to the imbalanced ratio of employed over dependent individuals (Ilmarinen, 2006). However, in most countries the average age of permanent departure from paid labour is well below the statutory pension age. Such early exit trend, attributable to prevalence of chronic disease, among many other health issues, is hardly sustainable due to growing financial pressure on the governments (Stattin, 2005). The ageing population, as a result of increased life expectancy and a falling birth rate, coupled with the premature departure from the workforce, leads to a relative shortage of active workers, which is incompatible with the anticipated labour shortage in the near future (Stattin, 2005; Van Nimwegen & Beets, 2005). Consequently, researchers and policy makers are searching for ways to "shift the vicious circle of early exit to the virtuous circle of active aging population" which may be accompanied with changes in physical and mental capacities as well as some co-morbidities (Gall, Evans & Howard, 1997).

Evidence from studies have suggested that a poor work ability increases the risk of early retirement (Salonen et al., 2003), long-term sickness absence, and work disability (Burdorf A et al., 2005). A systematic evaluation by van den Berg T et al. (2008) revealed the importance of work-related and individual determinants of work ability, measured by the WAI. Under the individual characteristics, a decreased score on the WAI was reported with older age (Tuomi et al., 1991; Goedhard et al., 1998; Pohjonen, 2001a; Monteiro et al., 2006), being overweight (Tuomi et al., 1991; Pohjonen & Ranta, 2001; Tuomi et al., 2001; Fischer et al., 2006) and smoking (Tuomi et al., 1991) while a positive association was found between better cardio-respiratory fitness and the WAI score (Goedhard et al., 1998). High mental work demands (Tuomi et al., 2001; Sjogren-Ronka et al., 2002; Tuomi et al., 2004; Pranjić et al., 2006), lack of autonomy (Pohjonen & Ranta, 2001; Tuomi et al., 2001; Tuomi

Promoting and maintaining work ability helps in keeping workers with chronic disease, like colorectal cancer from premature retirement or departure from workplace as a result of ill-health. The decline in work ability can be slowed down, halted or reversed by the choice of timely interventions along with cooperation between supervisors and employees and the entire work community. Modifiable barriers for RTW within workrelated and individual determinants of WAI must be identified early in order to ameliorate the effects following colorectal cancer and its treatment.

Promoting excellent work ability appeared to be more dependent on physical factors, positive feedback and clear work tasks while preventing poor work ability was dependent on recuperation, organisational, and psychosocial factors (Lindberg et al., 2006). Reducing the current risk of sick leave among employees is essential for future work ability in the workforce (Lindberg, 2006). Hence, the work-directed RTW intervention must take all these factors into account in order to promote excellent, and prevent poor work ability. This could be achieved via work adjustments which aim at overcoming specific work problems by affording a better fit between work demands and the work capacities of the chronically ill worker (Baanders et al., 2001). Excellent work ability among colorectal cancer survivors enhances the RTW rate and favourable employment outcome after the treatment phase.

Somewhat different approaches, interventions may be needed to address excellent and poor work ability based on those identified determinants. However, supporting health promotion does not reduce the importance of ongoing risk elimination (Lindberg et al., 2006).

#### 2.6.5 Work ability index (WAI)

The work ability index (WAI) is an instrument designed for occupational health services and is used today in clinical practice as well as for research purposes worldwide to assess work ability (Ilmarinen 2006). There are seven elements in the calculation of the index: individual's current work ability compared to his/her lifetime best, work ability in relation to the demands of the job, number of diagnosed illness or limiting conditions from which they suffer, estimated impairment due to disease/illness or limiting conditions, duration of sick leaves taken last year, own prognosis of the work ability in two years time, estimated mental resources (Tuomi et al., 1991).

The WAI score ranges from 7 to 49. A maximum score of 49 points indicates maximum work ability whereas 7 points denote very poor work ability (Tuomi et al., 1998; Tuomi et al., 2001; El Fassi et al., 2013). Poor work ability means the demands of the work and the resources of the employee do not fit. This may be due to adverse working conditions, limitations of the workers, or both. Those employees with top WAI scores ranging from 44 to 49 are considered to have 'excellent work ability'. Those with 'good work ability' scoring between 37 to 43 points should still consider some improvements to maintain their work ability high in future and until retirement. For employees with 'moderate' WAI scores from 28 to 36 points, the various potential factors for their comparably low scores should be considered to assure continued work ability. Personal and organisational factors need to be taken into account while addressing this. Employees with 'poor work ability' (less than 28 points), definitely need to have measures introduced to improve work ability before it is too late and to assure continued work participation (Tuomi et al., 1998; Tuomi et al., 2001).

Survivors of breast cancer (Bradley & Bednarek, 2002; Maunsell et al., 2004), malignant brain tumour (Feuerstein et al., 2007), stomach, prostate and colorectal cancer (Gudbergsson et al., 2006; Short, Vasey & Moran, 2008) are reported to have lower physical and mental work ability, compared to a comparison group of those without history of cancer. Thus, work-directed intervention on RTW must target these groups of survivors to improve their work ability as individuals with high WAI scores have a lower risk for early retirement and enjoy a higher quality of life, even after retirement (Ilmarinen & Lehtinen, 2004). Various studies have suggested that if timely interventions are introduced, it is possible to sustain and improve work ability among employees, even among those at older age. The WAI questionnaire has become a methodological benchmark of a comprehensive approach to 'work ability'. It is being used for groups as well as for individuals for workplace health promotion, in occupational health and re-integration (Hasselhorn, 2008).

However, one of the main criticisms raised against the WAI is that it contains many disparate questions more or less indirectly measuring work ability (eg. relating to diagnosis of chronic conditions and sick leave). This may have implications when the WAI is used among employees already on long-term sick-leaves during cancer treatment or a recuperative phase after therapy. Few elements in the WAI appear to give too much weight to diagnosis not necessarily related to work ability. A single-item question on the WAI item is "current work ability compared with life-time best", or the Work Ability Score (WAS) was advocated by Ahlstrom et al., 2014 as an alternative indicator for assessing the status and progress of work ability among workers on longterm sick leave. Using the single-item question can be beneficial in terms of simplicity, cost, and ease of interpretation. However, agreement between the single-item question on work ability and the WAI has not been fully investigated. The single-item question, WAS was found to be useful in systematic screening for work ability during health examinations by occupational health physicians (El Fassi et al., 2013) but was not sensitive enough to identify and predict workers at risk of needing a future disability pension (Roelen et al., 2014).

In this study, self perceived work ability is a component of fitness to work in the workdirected intervention on RTW programme and not used as a screening tool during health examinations to predict future disability pensions. Therefore, in addition to the singleitem advocated by Ahlstrom et al. (2014), "work ability in relation to the job's demands" and "number of co-morbidities diagnosed by physicians" were used in this study to gauge the colorectal cancer survivors' self perceived work ability at different stages of RTW after cancer treatment. The mismatch of work ability and the job demands as well as the presence of co-morbidities could be identified by using these three elements from the WAI. With these findings, occupational health providers are well informed on issues to be addressed before recommending any workplace support, work adjustments to the colorectal cancer survivors as a corrective measure to the mismatched work ability and work demands (Baanders et al., 2001). At the same time, these key elements may help occupational health providers and colorectal cancer survivors to draw up a written, specific and realistic RTW plan which could be reviewed at different stages of RTW.

#### **CHAPTER 3: RESEARCH METHODOLOGY**

This study was designed based on a pragmatist paradigm by using a mixed-method approach (Morgan, 2007), which is best suited to address the research questions (Feilzer, 2010; Johnson, Onwuegbuzie & Turner, 2007). Therefore, this study was designed as a three phase study, with each phase addressing specific objectives of the research, as part of the Medical Research Council, MRC's (Craig et al., 2008; MRC, 2008) complex intervention to gather incremental evidence (Cameron, 2011, Gitlin, 2013) in the phase of development and feasibility of the proposed pathway for work-directed intervention on RTW among individuals living with colorectal cancer.

The development of a research structure is helpful in communicating the relationship between methodology, methods and established frameworks for healthcare research (Marcy, 2015). A mixed methods research design has been useful to identify the evidence base requirement as outlined by the MRC's framework and EBM guidelines for developing high-quality healthcare research (Hardeman, Sutton, Griffin, Johnston, White, Wareham & Kinmonth, 2005).

The development phase involved retrieving primary and secondary data, which included a literature review and a systematic review (Hardeman et al., 2005) on RTW and colorectal cancer survivors. In view of the limited literature specifically focusing on colorectal cancer, the scope of the systematic review (Phase I) has been extended to all types of cancer, except childhood and occupational cancer, to evaluate their potential relevance for local colorectal cancer survivors. Hence, the development of the interventions was tailored to local circumstances, rather than being completely standardised (Craig et al., 2008). In-depth interviews with the local key stakeholders (Phase II) involved in the RTW process also contributed the primary data in building up the relevant evidence in the development phase (MRC, 2008). Subsequently, the feasibility study of the proposed pathway for work-directed intervention (Phase III)

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explored the perception and acceptance of the intervention by key stakeholders (Trompette, Kivits, Minary, Cambon & Alla, 2014) using both survey (quantitative) and in-depth interview (qualitative) as a parallel mix-methods approach.

The research structure outlines the relationship between methodology, methods and established frameworks employed in this study, as shown in Table 3.1.

	Development Phase				Feasibility		
MRC Framework	Identify theory	Identify evidence	Modelling outcomes	process and	Testing procedure	Estimating recruitment and adherence	
Mixed-	Secondary	Research	Primary Research           QUAL         QUANT         QUANT/QUAL				
Methods Approach	QUAL & QUANT		(qualitative)	(quantitative)	(quantitative/qualitative)		
	(qualitative quantitative		$\mathbf{O}$	>			
	Design, Im	plementation a	and Analysis				
Research Method	Literature Review	Systematic Review		Key Stakeholders n-Depth Interview		Key Stakeholders Survey and In-Depth Interview	

 Table 3.1: The research structure connecting methodology,

methods approach and the established framework

A mixed-methods design was chosen since the strengths of both quantitative and qualitative methods can be brought together to provide richer answers to research questions (Morgan, 1998). Mixed-methods approaches are useful not only in exploring social and behavioural processes that are difficult to capture using either quantitative or qualitative methods in isolation (Lewin, Glenton, & Oxman, 2009) but also in asking important questions about connecting parts of a social whole, using an integrative approach that considers multiple viewpoints (Feilzer, 2010; Johnson, Onwuegbuzie, & Turner, 2007; Mason, 2010). While mixed-method research may employ multiple research designs, it may also include different data collection techniques such as structured observations, key informant interviews, and reviews of secondary data.

Therefore, a mixed-method research involves the systematic integration of various types of data, usually drawn from various designs. As a result, mixed-method research requires advanced planning and careful management of the findings at each phase of the research (USAID, 2013).

In this study, the value of using mixed-methods for identifying, answering various research questions and arriving at the specific objectives is evident. By choosing mixed-methods, the development and feasibility of the proposed pathway for the work-directed intervention on RTW among colorectal cancer survivors could be enhanced by adding scope, depth, and description to the research findings (Morse & Cheek, 2014; Shneerson & Gale, 2015).

The flow of this study is structured as follows: first (Phase I) and second phase (Phase II) of the study aimed at identifying the relevant evidence pertaining to intervention, barriers and facilitators associated with RTW among colorectal cancer survivors. Identification of theory and relevant evidence are the cornerstone of the development phase of an intervention (Craig et al., 2008; MRC, 2008). Systematic review of the published studies over the past two decades on RTW among cancer survivors, as well as the in-depth interviews conducted with local key stakeholders (colorectal cancer survivors, employers and healthcare professionals) contributed to the richness of evidence gathered through the development phase.

Evidence discovered from Phase I related to the conceptual framework for RTW, also served as the basis for informing the design and implementation of the topic guide (Bamberger, 2000; Morgan, 1998; Shneerson & Gale, 2015) and sampling strategy for qualitative, in-depth interview with the stakeholders in Phase II. Hence, the sequential mixed-method was applied in this phase of the study (Fetters, Curry & Creswell, 2013). In this study, the findings from a systematic review (Phase I) and qualitative interviews (Phase II) were also compared and combined in parallel combinations, to form the foundation and support for the Phase III, feasibility study of the proposed pathway for work-directed intervention (Creswell, Plano, Gutmann & Hanson, 2003; Lewin et al., 2009; USAID, 2013; Zhang & Creswell, 2013). The final phase of the study, Phase III aimed at testing the potential feasibility of the proposed pathway for work-directed intervention, in terms of the acceptance by the key stakeholders by survey (quantitative method) and in-depth interview (qualitative method) (Creswell, 2003). Data collected from both methods were integrated by parallel combination to gather the perception of key stakeholders about the flow, timing and materials used in the intervention.

The methodolgy is explained separately according to the phase of the study in this chapter. In Phase I, the methodology mainly covers the systematic approach in selecting articles which met the criteria for review, the process of data extraction and quality appraisal of the selected articles. In both qualitative and quantitative methods, study design, study population, study area, sampling method, study instrument, the process of data collection, and data management and analysis are covered in this methodology chapter.

# 3.1 Phase I: Systematic review

A review protocol that takes into account the search strategy, study selection and data extraction was drafted. The Preferred Reporting Items for Systematic Reviews (PRISMA statement) was referred to as formal guidelines for the systematic review.

## 3.1.1 Search strategy

The following electronic databases were searched: Medline, EMBASE, ProQuest, PubMed and ScienceDirect restricted to articles in English, publication year from 19902013 and human studies. The following main medical subject headings [MeSH] were used for the search: "cancer survivors" AND "return to work". These medical subject headings were then combined with other medical subject headings, text words which are synonyms for "cancer" and "return to work".

Occupational cancers and childhood cancers were both excluded as these cancers have different concerns pertaining to RTW. Occupational cancer may warrant employees to work at a different workplace in order to avoid the occupational hazards, if returning to workplace ever takes place. Besides that, occupational cancer takes years and decades to develop upon exposure to workplace carcinogens. As a result, employees may be diagnosed with occupational cancer at or after retirement age. Hence, the issue of returning to work may be of no significance to them. As for individuals with a history of childhood cancers, getting employed during adulthood may not be a major issue.

In order to exclude irrelevant articles on occupational cancer, occupational diseases, childhood cancer, screening for cancer, intervention, treatment and prevention, the search strategy was being refined by introducing additional medical subject headings as "NOT-terms".

## 3.1.2 Selection of articles

Article selection was conducted in three steps. All searches were carried out by the researcher and reviewed by one supervisor. The details of all selected studies were saved in the EndNote X6 software which was then used for screening of duplicated studies. In the first step, articles were independently selected by the researcher and one supervisor based on the title and abstract after excluding the duplicate articles in the list. The second step involved the retrieval of full text articles if the inclusion criteria were met. Finally, the reference lists of the selected articles and selected review papers were searched for additional references and experts were asked to recommend relevant

articles. Once the selected studies were identified, a meeting was held between the researcher and the supervisor to compare and further discuss the selected studies.

The following inclusion criteria were applied for selecting the full text articles.

i) Types of Participants

Adults (18 years and above) of both genders who were diagnosed with cancer of any types, except occupational and childhood cancer.

ii) Types of Studies

Both qualitative and quantitative studies which consisted of cancer patients' selfreported data or patients' point of view on factors associated with RTW or employment.

iii) Year of publication

Full articles that were published in journals for the past 24 years (1990-2013) since cancer treatment and workplace law have developed tremendously during that period.

# 3.1.3 Data extraction

Using a pre-designed data extraction form, the data were extracted by the researcher and checked by a supervisor. Disagreement in data extraction between reviewers was solved by consensus and consultation of the second supervisor. The extracted data included the following: first author, year and journal of publication, place of study, type of study design, number of participants, participants' characteristics (age, type of cancer), and factors associated with RTW or employment as well as the authors' conclusion.

## 3.1.4 Criteria for quality appraisal of selected studies

Quality appraisal tools are usually based on individual aspects or components of study design, methods and analysis for which there is theoretical evidence of bias. Such items

can be grouped into a checklist which could be used to evaluate each study systematically (Ciliska, Thomas & Buffett, 2008). Quantitative and qualitative indices of the study quality may be reflected by scales with assigned numerical values and checklists. Quality scores can be generated using the scales and various generic checklists (Parsons, Harlan, Lynch, Hamilton, Wu, Kato & Keegan, 2012).

However, there is no "gold standard' critical appraisal tool, nor is there any widely accepted generic tool that can be applied equally well across study types. Therefore, interpretation of any critical appraisal of research reports needs to be considered in light of the properties and intent of the critical appraisal tool chosen for the task (Katrak, Bialocerkowski, Massy-Westropp, Kumar & Grimmer, 2004).

Different quality assessment tools with quality ratings were used based on the type of study design. Randomisation technique, double blind and description of withdrawals and drop outs are the important aspects in randomised trial study. A high quality rating is considered if the study addressed all the aspects and scored  $\geq$ 3 out of 5 (Mehnert & Koch, 2012). The Newcastle Ottawa Scale, NOS was selected to assess the quality of observational studies which examines the study on three sections: selection, comparability and the outcome (Prins & Van Der Wurff, 2009; Stang , 2010; Torp, Nielsen, Gudbergsson, & Dahl, 2012; Wells, Shea, O'connell, Peterson, Welch, Losos & Tugwell, 2000). A study can be awarded a maximum of one star for each numbered item within the selection and outcome categories. A maximum of two stars can be given for comparability (Wells et al., 2000; Stang, 2010).

Seven quality indicators were used to gauge the quality of cross-sectional studies: appropriate research design, appropriate recruitment strategy, response rate reported, sample representative of similar population, objective and reliable measurements used, power calculation and appropriate statistical analysis. A cross sectional study was deemed moderate quality when it scored 3-5 out of the seven indicators (Duffy, 2005).

The National CASP Appraisal Tool was used as the assessment tool for qualitative studies. Three broad issues were considered while appraising the qualitative study: rigour (of appropriate approaches applied to key research methods in the study), credibility (meaningful and well-presented findings) and relevance (the value and usefulness of the findings to organisation) (Briggs J 2006; Dixon-Woods, Shaw, Agarwal & Smith, 2004; Thijs et al., 2012). There were a total of ten items in the assessment tool, and a score between 4 to7 was considered moderate while 8-10 was high quality (Dixon-Woods et al., 2007). The tools used to assess the quality of the selected articles are attached in Appendix A, B and C.

The quality assessment was carried out independently by the researcher and supervisor. In the event of disagreement, the second supervisor would be consulted to decide which score was more appropriate.

The RTW framework developed from the systematic review reveals the various factors (environmental, personal, work demand, work ability, health status and financial factors) including non-medical factors associated with RTW upon cancer diagnosis (Figure 3.1). This framework was used in developing the topic guide for the subsequent phase of study, Phase II, a qualitative study.

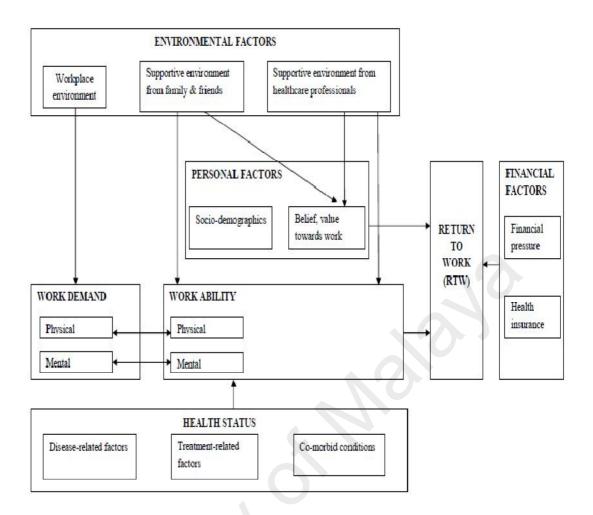


Figure 3.1: Return to work framework among cancer survivors

The detailed findings of this RTW framework are presented in Chapter four.

# 3.2 Phase II: Qualitative research

# 3.2.1 Study design

This phase of the study was a continuation from the Phase I, which revealed many stakeholders are involved in assisting cancer survivors' RTW process. The RTW framework developed in Phase I identified fourteen factors associated with the RTW process after cancer, and involved four main stakeholders (cancer survivors, employers, healthcare professionals and insurance organisations).

To answer the research questions on the motivators, barriers and challenges faced by colorectal cancer survivors in resuming work after cancer, a qualitative study method was used as a method of choice. Qualitative methods have been shown to be helpful for researchers to understand particular people, problem or issues in great depth and detail (Patton, 2005). Since the research conducted on RTW among colorectal cancer is scarce, this qualitative method is useful to explore a new area of research in greater depth and detail. Qualitative research can investigate the key informants' attitudes, beliefs, and preferences, and the value of qualitative methods lies in their capacity to pursue systematically the kinds of research questions that are not easily answerable by quantitative research methods.

A key informant interview is a qualitative in-depth interview carried out with an individual, who is knowledgeable, expressive, willing to help in understanding the situation, able to provide insight into the nature of the problems, and can give recommendations for solutions. By conducting key informants interviews, this study managed to obtain important and useful information during a short period of time without requiring a large sample size (Patton, 2005).

There are various research approaches in qualitative studies. In this study, the pragmatic qualitative research involving using an eclectic approach, without holding rigidly to a single paradigm or set of assumptions, and was employed to best match the research question at hand, that is to understand the factors associated with RTW after cancer.

The study was approved by the Medical Research and Ethnics Committee from University Malaya Medical Cenre (MEC Ref No 883.9).

## 3.2.2 Study participants

A total of four stakeholders identified from the conceptual framework (Figure 3.1), namely cancer survivors, healthcare professionals, employers and insurance organisations that have direct or indirect influence on cancer survivors resuming work after cancer. The study participants were the key informants for this qualitative study, recruited from these stakeholders except insurance organisations. Focusing on modifiable factors and targeting on relevant stakeholders are the keys in developing a work-directed intervention on RTW for colorectal cancer survivors. However, insurance organisations have existing policies pertaining to claims on medical treatment fees. Such policies are not easily modified as compared to the roles, support and advocacy by other stakeholders.

Key informants from colorectal cancer survivors, healthcare professionals and employers who are knowledgeable, expressive and could offer insights into the facilitating factors and barriers in returning to work were identified and face-to-face interviews were conducted. Hence, important, useful and relevant information were gathered during a short period of time in this study (Patton, 2005).

In-depth interviews were used as a method of data collection in this qualitative study to explore the motivators, barriers and challenges faced by colorectal cancer survivors in resuming work after cancer. Colorectal cancer survivors, who were diagnosed with Stage I to Stage III colorectal cancer, diagnosed during paid employment, aged between 18-60 years and had completed primary treatment, were recruited. This is a worthwhile group to study given that colorectal cancer survivors are underrepresented in existing employment or work related research, despite it being the commonest cancer affecting the Malaysian male population. Keeping in mind that the advanced stage of colorectal cancer is associated with a poor prognosis, poor QoL and returning to work is not the top priority for this group. Many Stage IV colorectal cancer survivors may be receiving palliative care, have permanent colostomy bag, still undergoing treatment, may have been diagnosed after retirement age and could be self-employed. Therefore, colorectal cancer survivors with Stage IV or advanced disease were excluded.

The management and care of cancer patients involves healthcare professionals from various disciplines. Cancer care begins even before a diagnosis is made and the cancer care continuum continues to palliative care. The perspective and views of healthcare professionals involved in cancer care and management are crucial in designing intervention to help RTW among cancer survivors. The inclusion criteria for healthcare professionals were those who have at least 10 years experience and are currently in practice and their service involves direct care for cancer survivors. These healthcare professionals are from the field of oncology medicine, surgery, rehabilitation medicine, occupational health, clinical psychology or primary care.

The exclusion criteria for healthcare professionals were those who have no experiences or current practice, and their service does not involve direct care for cancer survivors.

Different organisations have different policies with regards to employees' medical leaves and RTW. Civil servants in Malaysia are bound by the General Orders (G.O) with issues pertaining to leave. To have a better understanding on the RTW process practised by government organisations and private sectors, apart from their perspective on factors related to resuming work by their employees, in-depth interviews were carried out.

The inclusion criteria for these key informants representing employers in this study were those with clear knowledge of the organisations' policy on leave and RTW, having the authority to scrutinise employees' medical leave and carry out recommendations to assist employees' resumption of work.

## 3.2.3 Study setting

There were considerations taken into account when deciding on the sites for this study. Based on the availability of the resources on cancer treatment and the cancer registry, the researcher chose Penang and Kuala Lumpur as the study sites.

Penang is situated in the northwest region of Peninsular Malaysia, and consists of an island and a strip of mainland with a total land area of 1,149 square kilometres. Penang has five health districts-Timur Laut and Barat Daya districts on the island; and Seberang Perai Utara (SPU), Seberang Perai Tengah (SPT) and Seberang Perai Selatan (SPS) on the mainland.

The Penang Cancer Registry (PCR) was set up in 1994 as a collaborative effort between the Penang State Health Department and the National Cancer Society of Malaysia, Penang Branch. It was the first regional population-based registry in Malaysia, now covering a population of nearly one and a half million.

Kuala Lumpur is defined within the borders of the Federal Territory of Kuala Lumpur and is one of three Malaysian Federal Territories. It is an enclave within the state of Selangor, on the central west coast of Peninsular Malaysia (Jeong & Fadzlina, 2012). Commonly known as KL, Kuala Lumpur is the federal capital and most populous city in Malaysia. The city covers an area of 243 square kilometres and has an estimated population of 1.6 million as of 2012. There are many tertiary healthcare centres in the city, being the national referral centres for treatment and research. Hence, it is an excellent choice of study site for this study; especially as Kuala Lumpur has a combined cancer registry with the Putrajaya Cancer Registry.

## 3.2.4 Study samples and sampling methods

Unlike in quantitative methods, sample size calculation is not required in qualitative research. However, it is about exploring new issues, ideas and new understandings that can be used by the society (Rajesh, 2005). An appropriate sample size for a qualitative study is the one that adequately answers the research question. The depth and detail of data is considered to be more important than number of participants in qualitative research (Sandelowski, 1995). The validity, meaningfulness and insights generated from the qualitative data are concerned with the richness of the data obtained. The process of data collection is continued until saturation point is reached, when no new information is found after interviews or focus group discussions or themes continually repeat (Dongre, Deshmukh, Kalaiselvan & Upadhyaya, 2010; Mason, 2010).

A maximum variation sampling method was used to reach out to key informants from the stakeholders of colorectal cancer survivors (Figure 3.2), healthcare professionals (Figure 3.3) and employers (Figure 3.4) in both public and private sectors (Patton, 2005) who met the inclusion criteria. Employees from the private sector face different challenges and issues related to work resumption as compared to those in public sectors. Hence, it is important to take their perspectives and input into consideration when designing a work-directed intervention on RTW.

The sampling of colorectal cancer survivors was drawn from the larger sample of colorectal cancer survivors which was based on the epidemiology of colorectal cancer in Malaysia. Colorectal cancer affected men slightly more than the women (1.1:1) and the Age-Standardised Rate (ASR) was highest among Chinese men (31.5 per 100,000), in whom it is more than twice of that in Indian (15.7 per 100,000) and Malay men (12.3 per 100,000) (Lim, 2014). Attempts were made to get near this representation from the colorectal cancer registry: 30 Chinese, 15 Indian and 12 Malay.

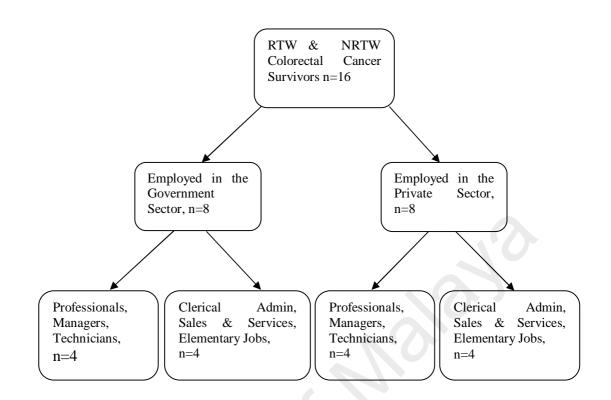


Figure 3.2: Maximum variation of colorectal cancer survivors (RTW and NRTW) recruited via purposive sampling method, n=16

Other key informants were recruited by using a criterion-based, purposive, maximum variation sampling method. The relevant criteria to be used prior to recruiting the key informants were identified. Such a sampling method was found to be the most appropriate in obtaining the richest possible source of information to answer the research question (Patton, 2005). The maximum variation sampling method was used in order to help the researcher understand the issue under study from the perspectives of individuals from various backgrounds and settings. The selection bias was minimised, since the researcher went directly to the participants rather than selection of participants from a pool of respondents.

Contact points for the recruitment of colorectal cancer survivors were in two different settings, namely hospitals and cancer support groups. In Penang, one government hospital and five private hospitals which offer cancer treatment were identified as the sites for subject recruitment. Penang General Hospital (HPP) is the referral centre for cancer treatment from the northern states of Peninsular Malaysia. Private medical centres in Penang are pioneers in health tourism. Thus, besides treating local patients, these medical centres also offer their services to foreigners, mainly patients from Indonesia. However, only local colorectal cancer survivors were recruited in this study. Apart from hospitals in Penang, the recruitment of colorectal cancer survivors was also carried out in the Oncology Unit of the University Malaya Medical Centre and two private medical centres in Kuala Lumpur. All colorectal cancer survivors who met the inclusion criteria were recruited by using purposive sampling.

The oncologists and colorectal surgeons of all the medical centres were briefed separately on the study objectives and methodology. A purposive recruiting method was used to recruit Stage I to Stage III colorectal cancers survivors who were diagnosed during paid employment and completed primary treatment. Posters were distributed to all the participating medical centres and cancer support groups in Penang and Kuala Lumpur. Contact number and email address of the researcher were shown in the poster for survivors to get more details about the study. At the same time, those potential subjects screened by the treating oncologists or colorectal surgeons, were asked to leave their particulars in order for the researcher to contact these survivors for further information and arrangement.

Besides posters, cancer databases in the hospitals were used as a source to trace the cancer survivor's case notes. From the database in the hospital, colorectal cancer survivors who met the inclusion criteria were identified. Subsequent efforts were made to retrieve their medical record from the either oncology or surgical department depending on the mode of treatment received.

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Purposive recruitment was done in various activities organized by cancer support groups or other Non-Government Organisations (NGOs). Relay for Life is an annual international activity held in various states like Penang, Melaka and Kuala Lumpur to celebrate cancer survivorship, motivate cancer patients who are fighting the illness and also to raise the awareness on early detection for cancer to the public. Various cancer support groups from different regions met to share and celebrate life. Flyers with information about the study were given out to cancer survivors during the event.

The Colorectal Cancer Survivorship Society Malaysia (CORUM) is a new cancer support group started in Kuala Lumpur that offers the survivors, caretakers and health care providers health education, support and care for colorectal cancer survivors. The support group also organises programmes related to cancer awareness and shares information about topics related to colorectal cancer survivorship.

In order to minimise the selection bias using a purposive sampling method, a maximum variation of the sample was selected. The occupational classification used in this study is based on the Malaysia Standard Classification Occupations 2008 (MASCO, 2008) where the professionals, managers and technicians were grouped in the same group while clerical admin, sales and service as well as elementary jobs were grouped in another group in the study. Figure 3.2 illustrates the purposive sampling used in order to achieve equal number of key informers (n=8) in both RTW and Non-Return to Work, (NRTW) groups. Recruitment and interviews were carried out at the same time until the data collected reached the saturation level for the RTW group. The same process was repeated for the NRTW group.

Healthcare professionals from the field of oncology medicine, surgery, rehabilitation medicine, occupational health, psychology and primary care were identified in the public hospitals and private hospitals in Penang and Kuala Lumpur. Invitations to take part in the qualitative study as key informants were sent out to these healthcare professionals through the hospital or the professional associations or societies. The purposive sampling method was also employed in recruiting these healthcare professionals through conferences and scientific meetings on treating cancer and helping cancer survivors.

Twelve healthcare professionals were recruited; six from the civil service and another six from private practice for this study (Figure 3.3).

university

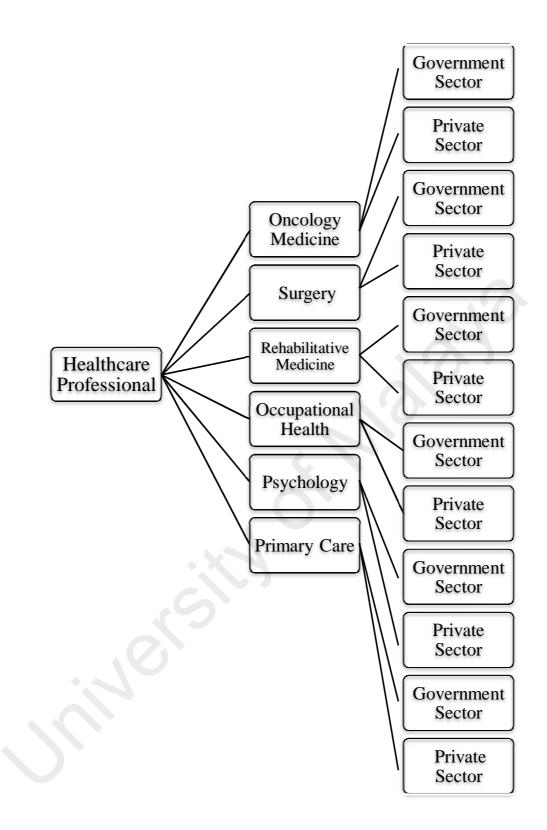


Figure 3.3: Maximum variation of healthcare professionals recruited via purposive sampling method, n=12

Key informants from the civil service and private sectors representing employers in this study must have clear knowledge of the organisational policy pertaining to leave, RTW and have the authority to scrutinise employees' medical leave and carry out necessary recommendations to assist employees' resumption of work. Attempts were made to contact the employers or Human Resource (HR) managers of the colorectal cancer survivors to get their input on issues concerning helping survivors return to workforce. Organisations from multinational companies (MNC) to small medium industries (SMI) which took part in National RTW conference and Flexiwork conference and exhibition were identified and invited to participate in the qualitative studies using a purposive sampling method.

To have a better understanding on the RTW process and factors related to resuming work by their employees, in-depth interviews were carried out with a total of nine informants from government organisations and those from private sectors (Figure 3.4).

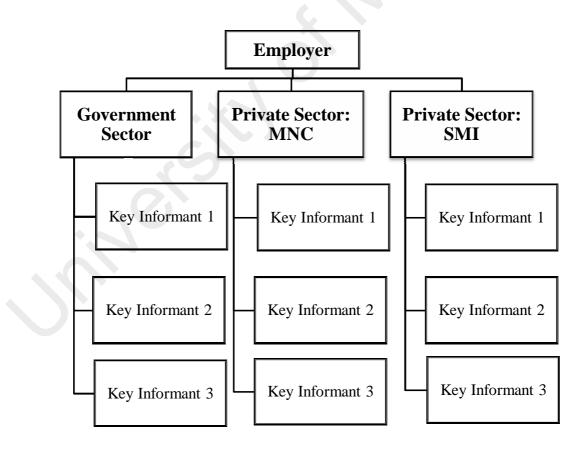


Figure 3.4: Maximum variation of key informants representing employer recruited via purposive sampling method, n=9

#### **3.2.5 Study instrument**

Study instruments are used in order to gauge some quality or ability of study subjects. The objective of instruments is to elicit data for study. In a qualitative study, the study instrument is the researcher, which is categorised as a human instrument. In the concept of a human as the research instrument, the researcher is involved in every step, being responsive, flexible, and adaptive besides being a good listener. When conducting the qualitative study, the researcher played a major part in the process of the interview or observation (Adler & Adler, 1987; Farber, 2006; Kvale & Brinkmann, 2009). Hence, the researcher became part of the process and potentially affected the process. This is different from quantitative research that aims to be objective instead of subjective by utilizing study instruments that have been tested on a previous study population. A qualitative study generally develops the questions before the study begins as the aim of the study is to explore the individuals' perceptions, ideas and opinion on the subject, or subjects being studied.

Only one interviewer carried out the interview sessions with all the respective key informants. The credibility of the qualitative method depends extensively on the researcher's skill, competence and rigor in performing fieldwork. Effective qualitative field researchers are those that build relationships easily, are sensitive to their surroundings, and who have few reservations about asking questions that enable them to learn more about new things; however, without transgressing the social norms of the community. Researchers also should be able to separate stereotypes, and personal opinions and judgements from accurate observations and effective recording of wording, meanings, and opinions of participants in the research (De Clerck et al., 2011).

This study was carried out by the researcher, who is a qualified healthcare professional and had undergone extensive training in conducting qualitative study methods. Additional lessons were taken up from online courses and from published qualitative journal articles. Besides that, the researcher was also involved in qualitative research data collection from other research projects as an observer prior to conducting this study. In the course of the study, the researcher received constant support and guidance from both supervisors who had skills and experience in carrying out qualitative studies.

Interviews can be carried out in both structured and unstructured ways. A set of questions that the researcher formulated beforehand is used in structured interviews while unstructured interviews allow the researcher and subject to talk with one another and share information in an informal atmosphere.

To facilitate the interview, semi-structured interview topic guides with open-ended questions were used (Appendix E, F and G). The questions in the topic guides were based on the themes generated from the RTW framework in Phase I of the study and were tested for content validity by the members of research team prior to the collection of actual data.

The interview topic guide used was fundamentally different from a questionnaire as it helped to ensure the right degree of consistency in data collection while still allowing flexibility to pursue details that were salient to each individual participant. As a guide to a dynamic conversation, it also freed the researcher to interact in a responsive way and pursue unexpected but nonetheless highly relevant themes that emerged (Ritchie, Lewis, Nicholls & Ormston, 2013).

The interview topic guide was an important document for data collection during fieldwork, and was prepared on a single sheet of paper for two reasons. First, it allowed researchers to focus attention on the key informant and what was being discussed. Second, such semi-structured interviews always require researchers to be well prepared and know the questions so they do not have to keep referring to the paper.

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The interview topic guide for the colorectal cancer survivors, healthcare professionals and employers mainly covered two sections. The first interview section focused on participants' perceptions and experience on RTW after colorectal cancer treatment by exploring the various barriers, challenges, facilitators and motivating factors associated with RTW among colorectal cancer survivors. The second section meant to explore the potential area for improvement and recommendations from key informants in relation to assisting colorectal cancer survivors in returning to workplace.

## 3.2.6 Data collection

The qualitative study was carried out over ten months, from June 2012 to March 2013, covering two different sites, Penang and Kuala Lumpur. The technique used for data collection in this qualitative study was in-depth interviews as it was the most appropriate method in exploring perception and experience of those key stakeholders in building up evidence in the development phase of the work-directed intervention on RTW.

Data collection process began by the researcher sending out invitations to all the stakeholders who met the inclusion criteria, recruited from a purposive sampling method. In addition, the participants were also given the participant information sheet informing them the purpose and expectation of the study (Appendix D).

On the agreed date given by the participants, the interviews with colorectal cancer survivors were carried out in a seminar room in the hospital setting or in a meeting room of the centre for a cancer support group. Healthcare professionals were interviewed in their respective consultation rooms. The interviews with Human Resource (HR) managers or leaders of those organisations were carried out in their respective offices. The purpose of the interview was outlined to all the participants and they were assured that information gathered would be handled confidentially and would be used solely for the research purpose (Appendix D: Patient Information Sheets and Consent Forms in both languages). The interviews were mainly conducted in English, lasted no more than 45 minutes and were audio recorded, after participants signed the informed consent form (Figure 3.5). Only a few key informants spoke in mixed Malay language with English and required minimal assistance in conversing in English with the help of a translator.

The researcher started the interview by introducing himself to build rapport with the key informants. Colorectal cancer survivors were first questioned about their personal and medical history. Then, they were asked to share their perception and experience in returning to work after cancer diagnosis. The aim of the qualitative phase of the study was to explore the participants' account of motivating factors, challenges and barriers in the transition stage of reintegrating to the workplace. At the same time, the work problems that the participants encountered in the workplace before, during and after colorectal cancer diagnosis and treatments were explored and gathered from the employers and healthcare professionals. The participants were asked questions based on the interview topic guide. However, they were encouraged to discuss other related issues on RTW and cancer that underlined the study objective. Despite having the interview audio recorded, some important notes were jotted down during the interview by the researcher. These notes recorded information on the socio-demographic characteristics of the key informants and responses by the informants on the topics discussed. Certain socio-demographic characteristics of interviewee may potentially influence the interview (Frances, Michael & Patricia, 2009; Karen, 2001) along with the age and gender of interviewer characteristics, are relevant in achieving higher cooperation rates during the interview (Lipps, 2013). The "similar-to-me" effect is a common manifestation of interviewer bias, characterised by higher interview ratings given towards interviewees who possess similar attitudes and demographics as the interviewer (Sears & Rowe, 2003). One explanation for this effect is through sheer similarity. These potential influences were acknowledged as they are part of the research and yield in themselves interesting research results. Taking notes during the interview helped the researcher to guide the interview besides assisting the preparation of transcript. During the interview, key informants were given the choice of using their real name or a pseudonym to maintain confidentiality.

At the end of each interview session, key informant was reminded to express any additional matters that they thought of later to the researcher. A summary was prepared by the interviewer at the end of the interview to verify the perception and experience of the topic under study and as a conclusion. The summary was member checked with the respective key informants, which served as a validation process of the interviews. About 15 minutes was spent soon after the interview to note a few points regarding the interviews. All the audio recording was then fully transcribed verbatim.

After four successful interviews with the colorectal cancer survivors, five interviews with healthcare professionals and five key informants representing employers, the data was analysed to identify similar thoughts and gaps that needed to be addressed and required more focus in the subsequent interviews. Thereafter, interviews were continued until the data became saturated, the point at which there are no new ideas and insights emerging from the data (Patton, 2005). Instead, the researcher discovers strong repetition in the themes that have been observed and articulated. In total, thirty seven (37) interviews were carried out and achieved the data saturation stage.

# I) Introduction of the study's objectives and background

- In-depth interview aims to understand the issues pertaining to RTW among local colorectal cancer survivors.
- Various issues on RTW among cancer survivors have been reported in the literature. Researcher intended to explore if local colorectal cancer survivors are facing the similar challenges in work resumption.

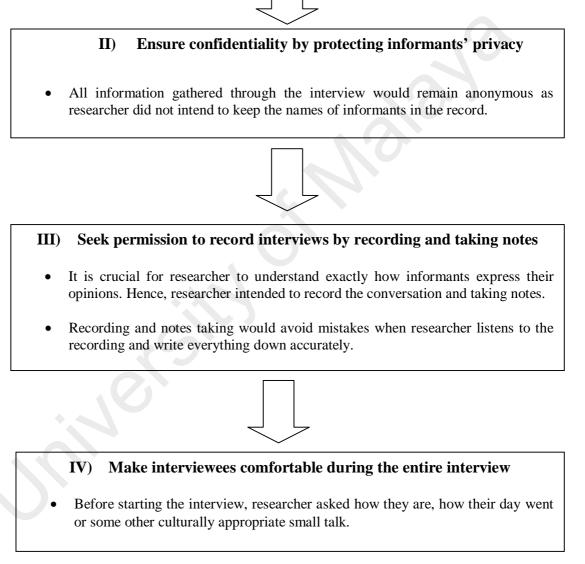


Figure 3.5: Steps taken before conducting the in depth interview

#### **3.2.7 Data management and analysis**

Data management and analysis were conducted with the support of QSR NVivo software Version 8.0. A thematic analysis was applied as a framework in data management and analysis. Such an approach emphasised the steps and procedures for connecting induction and deduction through the constant comparison method, comparing research sites, doing theoretical sampling, and testing emergent concepts with additional fieldwork (Patton, 2005). In this approach, data collection and data analysis occurred simultaneously, the management of which was done in systematic manner.

All data collected from the interviews were transcribed verbatim. Using the notes taken during the interviews, the textual data was compared and combined in order to ensure the summaries and conclusions made at the end of interview sessions were similar to the information given by the key informants. NVivo software version 8.0 was used for entering, organizing and integrating the data once the full version of textual data was completely acquired.

In thematic analysis, the researcher reviews the data, makes notes and begins to sort it into categories. Such data analytic strategy helps researcher move their analysis from a broad reading of the data towards discovering patterns and developing themes. Boyatzis (1998) describes thematic analysis as a process of "encoding qualitative information" that begins with the researcher developing "codes", words or phrases that serve as labels for sections of data. A set of codes may be a list of themes, indicators, and qualifications that are casually related; or something in between these two forms (Figure 3.6). The emerging themes developed from a set of codes are helpful in answering the research question besides bringing the researcher closer to their data and developing some deeper appreciation of the content (Boyatzis, 1998).

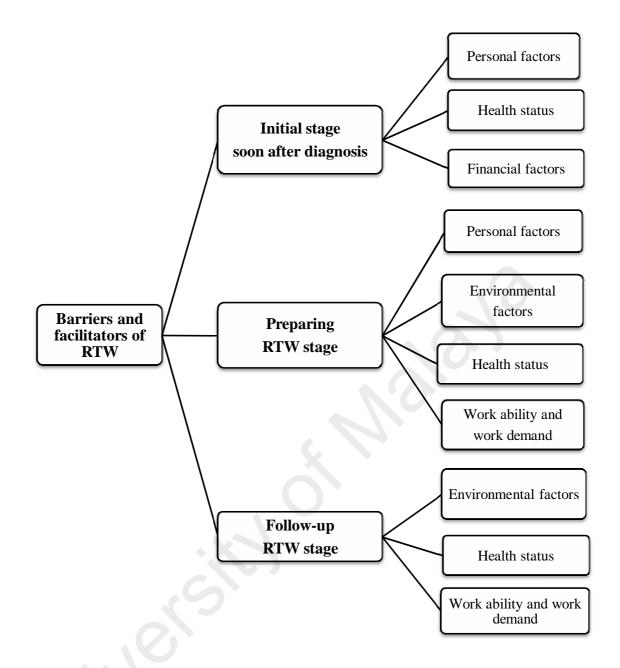


Figure 3.6: The development of coding procedure

# **3.3** Phase III: Feasibility study of the proposed pathway for work-directed intervention

In this section, the researcher describes the methodology used in developing and evaluating the feasibility of the proposed pathway for work-directed intervention on RTW for people living with colorectal cancer. This phase of the study focused on feasibility and can be differentiated from a pilot study of the proposed pathway for intervention as there is uncertainty regarding the components, design and flow processes to be used within a follow on study subsequently (Arain, Campbell, Cooper & Lancaster, 2010).

Parallel combinations of mixed-method evaluation methods were being employed in this phase of the study using different data collection and analysis methods (quantitative and qualitative methods) to answer the same research question on the feasibility of the proposed pathway for intervention.

Feasibility studies are studies designed to build the foundation for the planned intervention study. The United Kingdom's National Institute for Health Research Evaluation, Trials and Studies Coordination Centre (NETSCC, 2012) defined feasibility studies as pieces of research done before a main study in order to answer the question 'Can this study be done?'. They are useful to estimate important parameters that are needed to design the main study. For instance: willingness of clinicians to recruit participants, number of eligible patients, characteristics of proposed outcome measure, follow-up rates, response rates to questionnaires and adherence/compliance rates. According to the NETSCC, a feasibility study differs from a pilot study as the former tests out the component of an intervention programme, while the latter is a small scale version of the main intervention programme that is run to test whether the components of the programme can all work together, besides helping to design a further confirmatory study (Arnold, Burns, Adhikari, Kho, Meade & Cook, 2009). Unlike an external pilot study, a feasibility study does not evaluate the outcome of interest, as that is left to the main study. However, both types of studies play a preliminary role in the design stage of a subsequent larger trial, and do not themselves address the efficacy or effectiveness of the intervention to produce a desired or intended result (Shanyinde, Pickering & Weatherall, 2011).

The work-directed intervention is similar to a complex intervention characterised by multiple components which have separate modes of action, but the effects of the components depend on other components (Medical Research Council, 2006). Campbell et al. 2007 described it as interventions that are built up from a number of components, which may act both independently and interdependently. The new guidance by MRC states that the process from development through to implementation of a complex intervention may take a wide range of different forms. However, it also outlines the key elements of the development-evaluation-implementation process and outcomes in the development phase while focusing on testing the procedures, estimating the recruitment or retention and determining the sample size, amongst many other activities in the feasibility or piloting phase (Medical Research Council, 2006).

At present only a few interventions targeting employment outcomes among cancer survivors have been published (Bouknight, Bradley & Luo, 2006; Hoving, Broekhuizen & Frings-Dresen, 2009; Spelten et al., 2003a; Verbeek, Spelten, Kammeijer & Sprangers, 2003). Most of the interventions have evaluated the overall body function using QoL instruments that assess activities at work, at home, and in the community within each role function question (Frazier, Miller, Horbelt, Delmore, Miller & Averett, 2009). Evidence from clinical trials have shown that physical functioning can be improved using single-component interventions, such as physical exercise, or multicomponent programmes, such as individualised cancer rehabilitation (Speed-Andrews & Courneya, 2009). Those findings are useful, however, they do not specifically address how front-line healthcare workers may assist cancer survivors in preventing or managing common employment issues after cancer, such as coping with treatment related effects at the workplace and providing timely RTW guidance. Findings from Phase I, the systematic review suggested that there are various factors associated with RTW among cancer survivors, and they are not entirely medically related. The researcher also identified factors which are potentially modifiable, like environmental factors (e.g. employer's support), awareness, and beliefs about returning to work, health status and the balance between work demands with the work ability.

Findings from Phase II of the study suggested that barriers and facilitators for RTW encountered by local colorectal cancer survivors were quite similar to that in the RTW framework in Phase I, in terms of the categories of themes. The lack of awareness and guidance on RTW opportunities, delay in communication in preparing to RTW, being unable to cope with treatment effects and poor work performance were the recurrent barriers identified. As for the facilitators, all key informants agreed on good communication being needed between healthcare providers and employers, and appropriate education on what to expect after cancer treatment and support from workplace facilitated the timely RTW.

The work-directed intervention for RTW takes into consideration of all the findings gathered from the early phases of the study, as part of the sequential combination of a mixed-method research methodology. It emphasises promoting and enhancing the facilitators identified and at the same time removing or minimising the barriers at different stages of RTW process. This is made possible through detailed descriptions of the stakeholders' roles at different stages of RTW process, after colorectal cancer is diagnosed.

According to the MRC new guidelines on developing and evaluating complex interventions, a mixture of qualitative and quantitative methods is likely to be needed when it draws upon the strengths of both qualitative and quantitative paradigms whilst recognising the limitations of each. Such methods allow researchers to understand the

barriers to participation in the research. Hence, a mixed-method of parallel design was used in gaining the perceptions of key informants about the potential feasibility of the proposed pathway for work-directed intervention in current practice, with a survey used as the quantitative component, and in-depth interviews as the qualitative part of the assessment (Fonteyn & Bauer-Wu, 2005; Bowen et al., 2009; O'Cathain et al., 2015). Using these two data collection methods, data were analysed separately and then combined during critical discussion with both supervisors and interpretation, seeking differences, convergence and corroboration between the two data sets. Most importantly, the barriers and facilitators were identified from the qualitative component of the research work.

# 3.3.1 Participants for the feasibility study

Feasibility and pilot studies are not expected to have the large sample sizes that are needed for statistical testing. The majority of feasibility and pilot studies often do not show statistically significant findings and rarely lead to larger trials to adequately power the hypothesis testing (Arain et al., 2010; Shanyinde et al., 2011). Likewise, this study is concerned with generating descriptive statistics that will be used to evaluate the potential feasibility of the proposed pathway for the intervention on RTW and not to establish the effectiveness or generalisability of the intervention. After examining over three thousands papers described as pilot or feasibility studies, Shanyinde et al., 2011 concluded that there is no definite sample size for pilot/feasibility studies (ranging from 34 to over 100 participants) as it is very much depends on circumstances and direction of the study.

However, efforts have been made by the researcher to ensure key informants groups: colorectal cancer survivors, healthcare professionals (colorectal surgeon, oncologist and occupational health doctor) and employers were recruited from similar backgrounds with the same inclusion criteria that applied in Phase II. All the stakeholders in RTW were identified and recruited from those who had missed the opportunity to participate or those who refused to take part in our qualitative study in Part II, due to time constraints. The main advantage using this approach is that the feasibility component of this study could be tested on the participants sampled from the same study population. However, key informants who had participated in the second phase were not recruited for this phase of the study.

Findings in the exploratory phase, Phase II suggested that colorectal cancer survivors from the government sector were not keen for early RTW given that they were entitled to two years full paid leave following a cancer diagnosis. The provision of sick leave, the process of RTW or applying for medical board out are all outlined in the General Orders (G.O) for public servants in Malaysia. Therefore, in this feasibility study, colorectal cancer survivors from the government sector were excluded.

A similar purposive, maximum variation sampling technique was employed in Phase III. Such a sampling strategy aimed to capture a broad range of key informants, with minimal selection bias, from the stakeholders across the demographic spectrum.

All eligible participants were given the participant information sheet upon being explained the objective, flow and the methods used (survey and in-depth interview) for this feasibility study. They were given about one week to go through the material before the researcher contacted them to get their consent. They were allowed to clarify any doubts on the feasibility study before the commencement of the data collection.

## **3.3.2** Procedure of the intervention

This work-directed intervention aimed at assisting colorectal cancer survivors in returning to work after cancer treatment. Figure 3.7 illustrates the flow of the

intervention on RTW involving all the stakeholders. Facilitators and barriers identified from stakeholders in the second phase of study forms the basis of the intervention. In order to assist timely RTW among these colorectal cancer survivors, the intervention must take into account enhancing those facilitators, such as communication between treating physician, occupational health doctors and supervisors of the survivors. At the same time, correct information about work and cancer must be delivered to dispel myths attached to cancer survivorship in workplace. The safety aspect of the survivors, colleagues and working environment must not be neglected in drawing up the RTW plan, especially among survivors who had prolonged sick leave and delay in resuming duty at work.

Barriers such as lack of awareness among colorectal cancer survivors about RTW assistance available in the workplace could be minimised by early contact with the employer. For those organisations without an organised RTW programme, early contact with the colorectal cancer survivors would allow them to plan and organise ahead prior trialling RTW. By engaging the occupational health doctor in the event of an unsuccessful trial of RTW, the subsequent RTW process could be facilitated and followed-up. At the same time, the occupational health doctor could facilitate the RTW meeting at the workplace to address the relevant RTW issues for the colorectal cancer survivors, which would help in dispelling all myths associated with cancer and work. A better understanding of working again after cancer among colleagues in workplace could also avoid workplace discrimination.

Most of the literature advocated early RTW intervention but not many authors specified the right time to execute the work-directed intervention (Bains, Munir, Yarker, Steward, & Thomas, 2011). However, the researcher agrees that discussion on work issues and the RTW process should be incorporated early into current multidisciplinary clinical practice. The researcher discovered from Phase II that the most common employment topics brought up during consultations with treating physicians were about extending medical leave and applications for compensation from SOCSO or insurance claims. This is not surprising as many physicians are not aware of their potential role in assisting survivors' RTW processes (ACOEM, 2006; Chow, Loh & Su, 2014). Therefore, they may not assess employees in terms of their ability to RTW and may not effectively communicate with employers. However, physicians, especially those with occupational health training could take a more proactive role in the entire RTW process (Chow et al., 2014).

The work-directed intervention for RTW consists of three main stages and it begins after the colorectal cancer diagnosis is made on an employed individual with curative intent, before the commencement of cancer treatment. It may end at different stages of the intervention, depending on how well the survivors adapt to the work environment. The three main stages of RTW are: i) soon after diagnosis identifying initial work issues, ii) preparing RTW (after treatment) and iii) follow-up RTW. It involves the participation of the colorectal cancer survivors and also the commitment of the employer at the workplace, coordinated by the treating physician (oncologist, colorectal surgeon) initially and subsequently taken over by the occupational health doctor in the event of unsuccessful trial of RTW. Timely RTW is crucial as prolonged absence from work can potentially harm an individual's overall well-being, as well as their personal relationships (ACOEM, 2006; Orslene, 2013). The percentage of employees who successfully return to full employment drops to 50 percent after 6 months of absence from work, as reported by ACOEM (2008).

Since the treating physicians are the first healthcare professionals approached by colorectal cancer patients, the work-directed intervention would be initiated by them as part of the clinical consultation. Apart from explaining and planning for cancer treatment, treating physicians would be discussing potential treatment effects on daily activities, including work and encouraging the patient to keep contact with their employer and to assist RTW as much as possible. These colorectal cancer patients would be provided a "*Brochure on RTW*" (Appendix H) from the cancer clinics (oncological and surgical clinics) which comprises the roles and tasks played by employer and the survivors throughout the RTW journey. The colorectal cancer patients are asked to read through their roles in the brochure and submit the sections involving the employer and healthcare professionals to the Human Resource department along with the letter to notify their employer about their medical status.

The colorectal cancer survivor understands what to expect before and after the cancer treatment from the "educational leaflet" (Appendix J) provided by the treating physician, apart from the "*Brochure on RTW*". The educational leaflet serves as a tool to assist the treating physicians during the consultation, addressing the usual concerns related to treatment and side-effects. As for the colorectal cancer survivor, it may be more helpful eventually during the decision making process to RTW after treatment.

Upon the consultation with the treating physician to discuss the plan for the treatment regime, the colorectal cancer patient needs to inform the employer as early as possible with the letter from physician as well as a copy of *"Brochure on RTW"*. Such early contact ensures the employer is given sufficient time to plan and make arrangements in preparation for the absence of an employee during treatment. The employer and the immediate supervisor would also be able to plan for a trial of the RTW programme if the employee is scheduled to be away for cancer treatment for a certain period of time.

Those colorectal cancer survivors who are able to RTW after cancer treatment without extended medical leaves and are able to perform the usual work after a trial of RTW are considered as successful RTW. In Malaysia, civil servants enjoy up to two years full time paid leave for cancer as stated in General Order (G.O) while in private sector, 60 days paid leave is assured, if hospitalisation, irrespective of length of service.

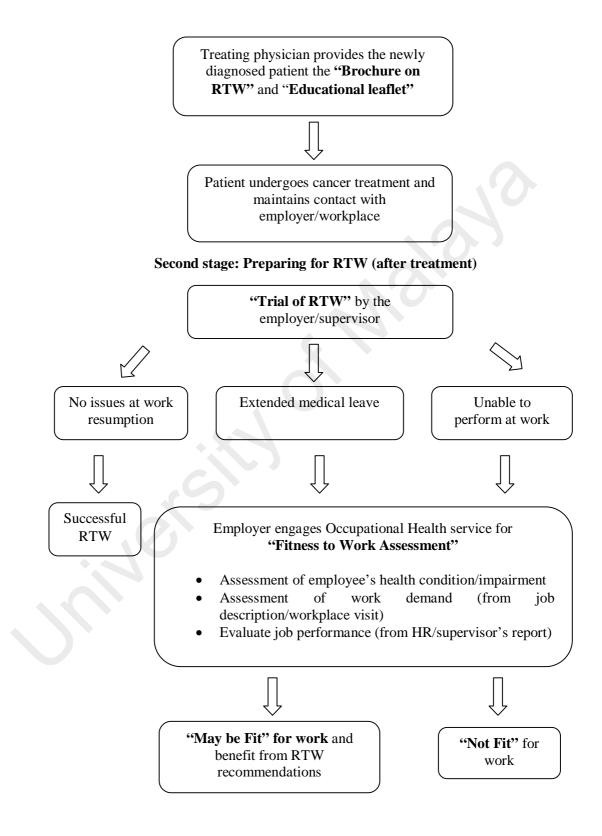
The HR department or immediate supervisor should monitor the medical leave of the employee. In the event of extended medical leave and inability to perform at work following a trial of RTW, the employer would alert occupational health doctor to proceed with the next stage of intervention, which is preparing RTW. It is during this stage of intervention, the colorectal cancer survivor is being assessed by the occupational health doctor on fitness to work, exploring the barriers to RTW, intention to RTW and the perceived work ability.

The occupational health doctor carries out the workplace visit with the supervisor of the survivor to understand the job scope and working environment, taking into consideration any safety issues if the survivor RTW. Potential workplace hazards must be identified and avoided as much as possible during the RTW process. For example, if the colorectal cancer survivor complains of poor concentration and has been operating machinery, it is important for the occupational health doctor to identify the hazard and risk involved before allowing the survivor to RTW.

To ensure the commitment from the employer and to improve communication between the stakeholders involved, the occupational health doctor facilitates the RTW meeting at workplace with survivor and employer. The meeting is meant to outline the RTW plan with recommendations on work adjustments based on the findings from fitness to work assessment and workplace visit. The supervisor for the survivor will be reminded off the tasks to avoid for a period of time in the written RTW plan. Such meetings also aim to achieve consensus on work recommendations as part of the RTW plan and address the respective roles and assistance to achieve the RTW goal. The outcome of assessment for fitness to work is either "May be Fit" or "Not Fit". The former would be followed by recommendations on work adjustments: phased RTW, altered hours, amended duties and workplace adaptations. For those colorectal cancer survivors with "Not Fit", additional support or referral may be indicated depending on the needs. The occupational health doctor and employer would explore all possible resources to assist RTW before considering compensation as an alternative.

The last stage of RTW is the "Follow-up RTW". This is scheduled at one month after the RTW meeting to evaluate the progress of RTW plan. Assessments of the RTW barriers, intention and perceived work ability would be carried out and compared with the findings at the "Preparing RTW" stage. Necessary referral is arranged to facilitate RTW, for example if the colorectal cancer survivor shows signs of cognitive impairment or depressive symptoms, psychologists would be consulted. If the participant is able to adapt to the work adjustment, then follow-up is scheduled at 3 months until full RTW has been achieved. However, if the employer is unable to provide work adjustments as recommended, then the participant is deemed as "Not Fit" and additional resources and supports would be sought to keep the participant in employment before subjecting the colorectal cancer survivor to insurance compensation.

# First stage: Just after diagnosis



# Second stage: Preparing RTW (after treatment) (con't)

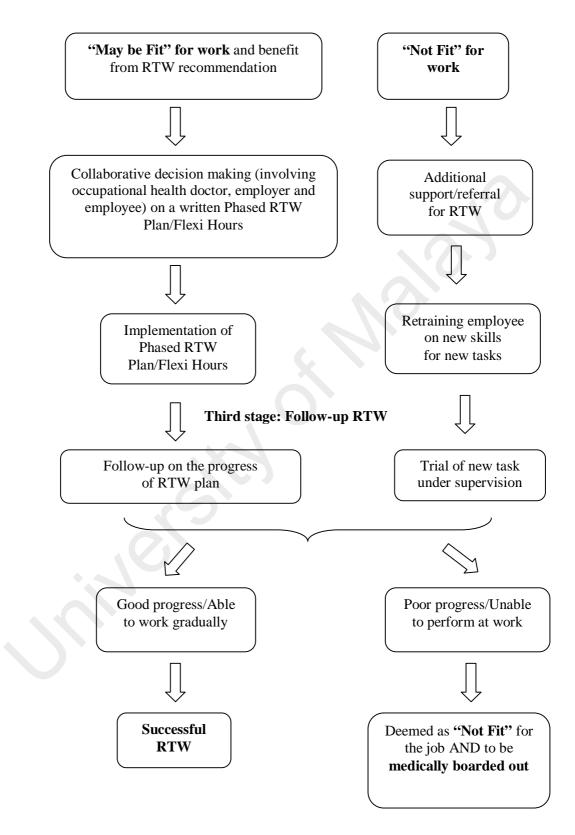


Figure 3.7: The flow of intervention on RTW

#### **3.3.3 RTW** Consultation and assessment of fitness to work

Colorectal cancer survivors who are able to perform at work after the trial of RTW are considered to have achieved successful RTW. However, those who have extended medical leave or were found to be unable to perform at work would be referred to the occupational health doctor for consultation and evaluation of fitness to work. The purpose of having the one-to-one RTW consultation is to explore the barriers and intention for RTW as well as the survivor's perceived work ability in terms of physical and mental (Appendix I).

The occupational health doctor is to be engaged by the employer through their associate panel doctor service or as an outsourced health service. Depending on the organisation, some companies have RTW programmes as part of their Employee Assistance Programme which may be headed by an occupational health doctor who is well trained in health promotion at workplace.

Work ability is assessed using the top three items taken from the Work Ability Index (Tuomi, Ilmarinen, Jahkola, Katajarinne & Tulkki, 1998) as part of the fitness to work assessment in this intervention for RTW. Such a method of assessment has been adopted by previous researchers in primary cancer patients who were treated with surgery, chemotherapy and/or radiotherapy (de Boer, Verbeek, Spelten, Uitterhoeve, Ansink, De Reijke & Van Dijk, 2008). Participants were asked to rate their work ability at each time point on a 10-point Likert scale (0=cannot work at all to 10=work ability at best), work ability in relation to the demands of the job (Range 2-10) and also the number of current diseases diagnosed by physicians (Range 1-7).

During the consultation, the colorectal cancer survivor would discuss the issues pertaining to RTW processes after treatment, the intention and motivation to work again and also the importance of work for the survivor. Apart from that, the current health status would be reviewed by the occupational health doctor while planning the phased RTW.

A workplace visit follows the RTW consultation, and allows the occupational health doctor to understand the nature of the job and the working environment involved. During the workplace visit, the occupational health doctor would interview the survivor's supervisor to explore the potential work adjustments as part of RTW process, if the need arises. Safety aspects of the working environment are also a cause of concern and potential occupational hazards are recorded to facilitate decision making in the RTW meeting with employer.

Care must be taken by the occupational health doctor and supervisor while planning for RTW, as planning is more than just matching an individual's physical restrictions to a job accommodation. The occupational health doctor should acknowledge RTW as a socially fragile process where co-workers and supervisors may be thrust into new relationships and routines (Nordqvist, Holmqvist & Alexanderson, 2003). If other co-workers are disadvantaged by the RTW plan, it can lead to resentment towards the returning worker, rather than cooperation with the RTW process (MacEachen, Clarke, Franche & Irvin, 2006).

# 3.3.4 RTW guidance and educational leaflet

The RTW guidance in the "*Brochure on RTW*" (Appendix H) outlines the tasks to be undertaken by colorectal cancer survivors, employers and healthcare professionals in order to facilitate the RTW process and enhance the communication between these stakeholders. The "*Brochure on RTW*" has different copies for colorectal cancer survivors, employers and healthcare professionals. Except for colorectal cancer survivors, the employers and healthcare professionals have specific tasks throughout the RTW process; from the point after the diagnosis until RTW follow-up. Essentially, the core component of the RTW guidance in the "*Brochure on RTW*" is to initiate early contact between colorectal cancer survivors and employers. With such contact, the employer is in better position in making arrangement and delegating the workload in the absence of employee due to the medical condition. The supervisor in the workplace is also aware of the survivor's absence and would be ready for the trial of RTW for the survivors upon completion of treatment.

Besides communication, the RTW guidance also directs the colorectal cancer survivors to seek the right information about treatment effects on work and strategies to cope with these effects. Such guidance is crucial in addressing evidence based treatment and would help them in making informed decisions on the choice of treatment. During the consultation with treating physician, colorectal cancer survivors would be given the educational leaflet (Appendix J) besides the "Brochure on RTW". Basic tips on managing colorectal cancer and work in the educational leaflet serves as a reminder to the survivors on what to expect following different types of treatment, coping strategies and dismissing the myths about not working again after cancer. Findings from the second phase of the study revealed that work issues were not discussed regularly during clinic consultations. One of the reasons is due to the fact that the colorectal cancer survivors were not ready to think of work issues soon after diagnosis. They preferred to complete treatment prior to considering or planning to resume work. As such, treating physicians may find it premature to bring up work related issues soon after diagnosis with their patients. Hence, the researcher advocates the provision of educational leaflets to the survivors for future reference, in addition to the usual clinical consultation.

It has been found that the lack of awareness about support for RTW delayed the RTW process. This barrier is modifiable and could be minimised. Therefore, one of the tasks related to initial work issues is to find out the organisations' policy on RTW, medical leave and the various supports available, for example the EAP prior to the treatment.

Survivors should be able to get such information from the Human Resource Department once the early contact is initiated.

With the early contact with employer and addressing the treatment effects on work, it is anticipated that colorectal cancer survivors could attempt a trial of RTW after treatment, with minor issues. However, such a trial of RTW should be monitored by the immediate supervisor. Cases of failure in the trial of RTW, inability to perform at work would warrant referral to occupational health doctor for further assessment.

Once the occupational health doctor is involved, the RTW process has entered another stage, aimed at preparing for RTW. In this stage, the RTW guidance focuses on the constant communication and involvement between occupational health doctor and the employer. The role of occupational health doctor at this stage is mainly to identify the RTW barriers, assess the fitness to work and work ability of the survivors before carrying out the workplace visit, weighing the safety issues before coming to the recommendation of RTW. The supervisor in the workplace must facilitate the process of assessment of survivor and also the workplace. All RTW progress is monitored and shared among the occupational health doctor and supervisor.

#### 3.3.5 Data collection and analysis

This section of study is concerned with generating descriptive statistics that would be used to evaluate the feasibility of the proposed pathway for work-directed RTW intervention. Descriptive statistics were also used to summarise characteristics relevant to participant flow, compliance with assessments and questionnaires. It is however, not used to evaluate the effectiveness or generalisability of the interventions.

Being a mixed-method, parallel approach, the data collection and analysis for both qualitative and quantitative methods were both carried out independently. A survey using an evaluation form to collect quantitative data served as a data collection while indepth interviews which aimed at exploring the facilitators and barriers in carrying out the work-directed intervention on RTW was used for qualitative method.

All participants were given a participant information sheet and a brief introduction on the objective and methods used to collect data. The researcher contacted these participants after one week to get their consent in taking part in the study. The participants were also assured of confidentiality prior to giving the written consent.

To assess the feasibility of the proposed pathway for intervention, the flow of referral, the tasks involved in the RTW guide (*Brochure on RTW*) and contents of the educational leaflet, participants from all stakeholders involved in the feasibility study were requested to complete a brief evaluation form. The aims of this approach are to gauge their level of agreement (1-strongly disagree, 2-disagree, 3-uncertain, 4-agree, 5-strongly agree), level of helpfulness (1-not helpful at all, 2-slightly helpful, 3-somewhat helpful, 4-very helpful, 5-extremely helpful) and level of priority (1-not a priority, 2-low priority, 3-medium priority, 4-high priority, 5-essential) on the tasks outlined in the RTW guidance. They were asked to respond in citing the number, from 1 to 5, according to the Likert Scale. As for the flow, timing of intervention, content of the educational leaflet and fitness to work assessment report, they were required to grade between 1 (very poor) to 10 (very good). While collecting the evaluation form, the response.

In order to explore more on the facilitators and barriers in carrying out the intervention, all participants were encouraged to share their views and their feelings besides focusing on the issues, challenges, potential resources required in the intervention. At the same time, the researcher also welcomed participants' suggestions about where the

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intervention could be further improved. Their concerns on the timing of the intervention, logistics and economic issues were documented. They were allowed to discuss these topics freely as the researcher asked open ended questions during the indepth interview.

Quantitative data were analysed descriptively based on the scores given by the participants from different stakeholders. Measures of mean and variance including CIs and SD were used to describe the full range of data collected in the survey.

There was no systematic guidance on how to categorise and explore issues that have arisen in a feasibility study. However, the views from the participants collected via the in-depth interviews were analysed and grouped into various themes under the flow of intervention (operational), logistics, timing of the intervention (schedule) and economic concerns. Apart from that, researchers selected pertinent methodological issues from the list of 14 issues, as advocated by Shanyinde et al. (2011) which need to be evaluated in feasibility studies. Among the relevant methodological issues that have been identified in this feasibility study were issues pertaining to recruitment, eligibility of the participants and acceptability of the intervention to the participants.

### **CHAPTER 4: FINDINGS AND RESULTS**

In this chapter, the findings and results of the study were presented according to phases of the study. The findings from each phase were used to inform and implement the design of the subsequent phase of the study in order to answer all the research questions.

Thus, the first phase of the study revealed the number of articles searched and identified systematically, and it was illustrated by using a flow chart (Figure 4.1). The end result of the Phase I was a RTW framework which describes eleven factors associated with RTW after cancer treatment. All these factors were then grouped into five main categories which were used to develop the topic guide for the subsequent phase of this study, the qualitative part (in depth interview).

In the Phase II of the study, findings from the in depth interviews of the key informants: colorectal cancer survivors, healthcare professionals and employers were described as barriers and facilitators associated with RTW.

The relevant evidence and model were identified through Phase I and Phase II and subsequently combined in developing the work-directed intervention on RTW. Phase III of the study explored the perceptions of the stakeholders on the flow and timing of the proposed pathway for intervention, the contents of the materials used in the intervention and their opinion on applicability and feasibility of the intervention developed.

# 4.1 Phase I: Systematic review

The literature search using electronic databases yielded a total of 1836 articles and after excluding for duplications, 1668 articles were identified. A total of 1615 articles were excluded based on title and abstract because these studies did not include work-related outcomes or employment status. Of the 53 remaining articles, 20 articles were included

after reading the full text. The other 33 articles were excluded because 25 articles focus only on quality of life while the other eight articles discussed physical disability associated with cancer. Of the 20 articles, two articles were review papers and were not included; thus, leaving 18 articles. Nine additional articles were identified through the references of the selected articles and the review papers. Thus, this resulted in total of 27 articles that were included in this review (Figure 4.1).

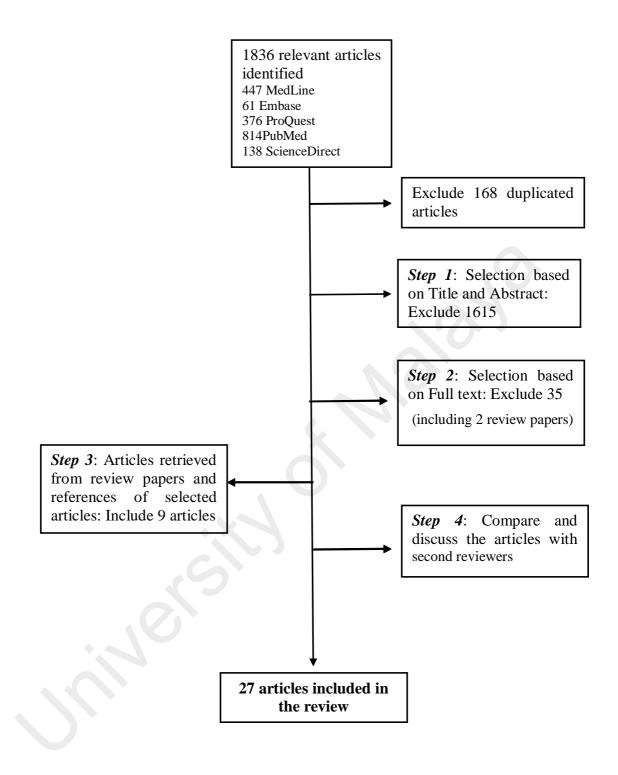


Figure 4.1: Flow chart of articles selection process

Study and patient characteristics

Table 4.1 summarises the first author, publication journal and year, country, study design and patient characteristics of the 27 selected articles. Eighteen articles (66.7%) were published in the last five years. Nine articles (33.3%) were cross sectional studies, one randomised trial (3.7%), nine longitudinal studies (33.3%) and eight qualitative studies (30%). Six articles (22.2%) recruited participants from cancer registries while three articles (11.1%) identified participants via cancer support groups. Two articles (7.4%) focused only on male patients with cancer of stomach, liver and colorectal, while nine articles (33.3%) focused only on female patients, among which eight articles (30%) exclusively studied breast cancer. Breast cancer alone was the most studied type of cancer (30%), colorectal cancer (7.4%), and cancer of various types (55.5%).

Author(s), Journal & Year	Study Setting/ Country	Study Design	Number of Subjects (N)	Age of subjects (years)	Cancer Type
Sanchez et al AAOHN Journal (2004)	Los Angeles, USA. Population based cancer registries	Cross sectional Using questionnaire (person, disease and work related factors)	N=250 Men: 46.5% Women: 53.5%	30-59	Colorectal
Ahn et al Breast Cancer Res Treat (2009)	Korea, Hospital based breast cancer registries	Cross sectional Using questionnaire (employment status, demographic data and clinical variables)	N=1594 Women	20-60	Breast
Grunfeld et al Occupational Medicine (2010)	UK	Cross sectional Using Brief Illness Perceptions Questionnaire (perceived impact of cancer and its treatment on work)	N=194 Men (40%) Women (60%)	51 (Mean Age) 22-69 (Range of Age)	Breast Urological Gynae Head and Neck

Table 4.1: Summary of included studies and participants' characteristics

Fantoni et al Journal of Occupational Rehabilitation (2010)	Northern France	Cross sectional Using questionnaire (on personal, disease- related and occupational characteristics)	N=379 Women	18-60 (Average age at diagnosis: 48.3)	Breast
Bouknight et al Journal of Clinical Oncology (2006)	Detroit, US Metropolitan Detroit Cancer Surveillance System	Longitudinal Using telephone interview (12 and 18 months post diagnosis)	N=416 Women	30-64 (Mean age of diagnosis: 50.8)	Breast
Choi et al Psycho- Oncology (2007)	Korea National Cancer Centre	Longitudinal Prospective Cohort Using employment questionnaire (every 3 months for 24 months)	N=305 Men	≥18	Stomach (32%) Liver (38%) Colorectal (30%)
Gordon et al Australian and New Zealand Journal of Public Health (2008)	Queensland, Australia Colorectal Cancer and Quality of Life Study (CRCQOLS) Queensland	Longitudinal Population-based Using telephone survey	N= 975 Men: 64% Women: 36%	20-80	Colorectal
de Boer et al British Journal of Cancer (2008)	Cancer Registry Hospital in Netherlands	Longitudinal Follow up (6, 12 and 18 months after 1 <sup>st</sup> day of sick leave)	N=195 Men:40% Women:6 0%	18-58	Breast (26%) Haematological (12%) Gastrointestinal (12%) Female genitals (22%) Genitourinary (22%) Others (6%)
Earle et al Journal of Clinical Oncology (2010)	Ontario, Canada. Population- based	Longitudinal Telephone interview (4 and 15 months after diagnosis)	N: 2422 Men: 53% Women: 47%	≥21	Lung (34%) Colorectal (66%) (Non-metastatic)
Johnsson et al ActaOncologi ca (2007)	Stockholm, Sweden Breast Cancer Study Group	Randomised trial (Follow up for 24 months)	N=222 Women	29-54	Breast

Johnsson et al European Journal of Cancer Care (2010)	Sweden	Qualitative: In-depth interview, Retrospective narration	N=16 -recurrent- free women -50% women RTW -50% women not yet RTW	44- 58	Breast
Kennedy et al European Journal of Cancer Care ( 2007)	6 Cancer support groups, UK	Qualitative: Individual interview (n=19) Focus group (n=4,n=6)	N=29 Women:9 3% Men: 7%	52.6 (mean) At diagnosis :47.2	Breast (83%), Non-Hodgkin's lymphoma (7%), Uterus (7%) Larynx (3%)
Nachreiner et al AAOHN Journal (2007)	Hospital in metropolitan Minnesota, US	Qualitative: Focus group	N=7 women	18-55	Breast (57%) Lung (14%) Acute Myeloid Leukemia (14%) Ovarian cancer (14%)
Main et al Psycho- Oncology (2005)	Colorado, US Colorado Central Cancer Registry (CCCR)	Qualitative, Face to face structured interview	N=28 Men: 50%; Women:5 0%	24-63 (Age at diagnosis) 42.6 (Mean) 45 (Median)	Gastrointestinal (17.9%) Brain (10.7%) Leukemia/ Lymphoma (10.7%) Lung (10.7%) Thyroid (10.7%) Breast (7.1%) Urinary tract (bladder) (7.1%) Male genital tract (7.1%) Skin (7.1%) Head and neck (7.1%) Female genital tract (3.6%)
Yarker et al Psycho- Oncology (2010)	National Cancer Support Group affiliated to NHS Trusts. UK	Qualitative, Semi-structured telephone interview	N=26 Men:38% Women:6 2%	31-61	Breast (35%) Prostate (15%) Lymphoma (12%) Ovaries (12%) Oesophageal (4%) Renal (4%) Bladder (4%) Brain tumour (4%) Colon (4%) Thyroid (4%) Pancreatic (4%)

Roelen et al Psycho- Oncology (2011)	Arbo Ned Occupational Health Services (OHS) Netherlands	Longitudinal study (sickness absence and full RTW after 2yrs post diagnosis)	N=5074 Men: 35.5% Women: 64.5%	18-60 47.7 (Mean)	Breast (31.1%) Female genitals (16.9%) Gastro-intestinal (14.2%) Lung (8.8%) Male genitals (8%) Skin (6%) Blood (5.8%) Other (9.12%)
Roelen et al Journal of Occupational Rehabilitation (2011)	Arbo Ned Occupational Health Services (OHS) Netherlands	Longitudinal study	N=5234 Men: 36% Women: 64%	18-60	Breast (31.1%) Female genitals (16.9%) Gastro-intestinal (14.2%) Lung (8.8%) Male genitals (8%) Skin (6%) Blood (5.8%) Other (9.12%)
Nilsson et al European Journal of Oncology Nursing (2011)	Urban area of Sweden	Qualitative Focus group (x4)	N=23 Women	20-63	Breast
Tiedtke et al BMC Public Health (2012)	Province of Limburg, Belgium	Qualitative In-depth interview	N=22 Women	42-55 46 (Mean age at surgery)	Breast
Grunfeld et al Health Psychology (2013)	Outpatient department of hospitals in three U.K Health Care Trusts	Qualitative Semi-structured interview	N=50 Men	18-65 59 (Mean)	Prostate
Mehnert et al Scandinavian Journal of Work Environmenta I Health (2012)	Cancer rehabilitation facilities Germany	Longitudinal Follow up at end of rehabilitation, t1(3weeks) and t2(12 months after rehabilitation)	N=750 Men:14.3 % Women: 85.7%	18-60 48.7 (Mean)	Breast (59.5%) Gynaecological (14.5%) Head and neck cancer (8.9%) Skin (6.1%) Colorectal (5.6%) Lung (3.1%) Haematological (2.3%)

Ross et al Cancer Epidemiology (2012)	Hospital departments treating cancer patients (Ringkoebing, Funen and Copenhagen) Denmark	Cross-sectional		N=1490 Men: 36% Women: 64%	18-80	Breast (37%) Gastro (8%) Lung (3%) Gynaec (12%) Prostate (3%) Urinary (2%) Head and neck (4%) Lymphoma (12%) Leukaemia (6%) Other (15%)
Hansen et al Occup Environ Med (2008)	USA	Cross-sectional reference group	with	Cancer survivors, n=100 Non cancer, n=103	45	Breast
Taskila et al Eur J Cancer (2007)	Finland	Cross-sectional reference group	with	Cancer survivors, n=591 Women:7 4% Men:26%	25-57	Women Breast cancer (90%) Lymphoma (10%) Men Lymphoma (41%) Prostate (30%) Testicular (29%)
Lee et al Bri J Cancer (2008)	Korea	Cross-sectional reference group	with	Cancer survivors n=408 General population N=994	18-65	Stomach cancer
Park, Park JH & Kim SG Psycho-Oncol (2009)	USA	Population-based longitudinal		Cancer survivors n=4991 General population n=1334	25-55	Oral (2.1%) Stomach (26.3%) Colorectal (11.7%) Liver (16.3%) Pancreas (2.3%) Lung (8.4%) Breast (8.3%) Cervix and uterus (3.7%) Kidney (3.3%) Bladder (2.4%) Brain & CNS (3.1%) Thyroid (7.0%) Non Hodgkin's (2.3%) Leukaemia (2.7%)
Tunceli et al Inquiry (2009)	USA	Cross-sectional reference group	with	Cancer survivors n=7531 Men: 47% Women: 53%	55-64	Mixed

Identified factors associated with RTW or employment status among cancer survivors

I) Personal related factors

Socio-demographic characteristics of the cancer survivor

None of the qualitative studies reported personal related factors in relation to the RTW while twelve out of the nineteen (63%) quantitative studies did mention personal factors as part of the factors identified associated with RTW after cancer. Among the personal related factors reported were age, gender, ethnicity, marital status, educational level and income were the common themes reported in the studies.

Grunfeld et al. (2010) reported older cancer patients (more than 55 years old) had more difficulties than younger patients in coping with physical symptoms, level of performance at work, emotional distress and continuing hospital appointments. The RTW rate was reported as lower among older women (more than 55 years old) compared to the younger women throughout the period of follow up (Fantoni et al., 20010). Similarly, the RTW rate was dependent on age as shown in a longitudinal study in Detroit where older cancer patients were less likely to return to workplace at 18 months following cancer diagnosis (Bouknight et al., 2006). However, cancer survivors between 40-49 years were more likely to keep their job after treatment compared to those younger than 40 according to a study done in Korea (Ahn et al., 2009). A study done in Denmark looking at various types of cancer agreed that older survivors were at higher risk of losing employment (Ross, Petersen, Johnsen, Lundstroem, Carlsen & Groenvold, 2012). However, a follow up study among 5074 cancer patients in the Netherlands found no association of age and gender to full RTW except for blood malignancy and genital cancer (Roelen, 2011).

Educational level and household income consistently determined the employment outcome of cancer patients after cancer treatment (Ahn et al., 2009). High school graduates were 1.86 times more likely than university graduates to lose their jobs (Choi et al., 2007). Higher educational level correlated with higher RTW rate (Fantoni et al., 2010) while less educated and lower income patients were particularly at risk of departing from the workforce (Ahn et al., 2009; Earle et al., 2010). Mehnert and Koch, (2013) suggested that individuals from higher educational background and social class are more likely to work in a better working environment, earn and lead a better living condition. As a result, these groups of employee achieved a higher rate of RTW and absence of sick leave.

Marital status was associated with employment rate after cancer diagnosis. A higher employment rate correlated with single women and women who were separated, divorced or widowed (Ahn et al., 2009). Similarly, among lower income women with lung cancer or colon cancer, those who were married were more likely to leave the workforce as compared to those who were unmarried (Earle et al., 2010).

Race and ethnicity factors were only reported in two studies (Bouknight et al., 2006; Sanchez et al., 2004). In a study on correlates of RTW for breast cancer survivors by Bouknight et al. (2006), African Americans were found to be less likely to RTW.

Personal beliefs and values towards work

Personal beliefs and values towards work were crucial determinants in the decision to RTW. For those cancer survivors who RTW, they perceived the value of having a job, work was part of their identity (Grunfeld et al., 2013; Johnsson et al., 2010; Nachreiner et al., 2007) and served as a healthy distraction from their illness or treatment to regain the sense of normality (Grunfeld et al., 2013; Kennedy et al., 2007; Main et al., 2005; Tiedtke, 2012), and was an essential part of healing process (Nachreiner et al., 2007).

The cancer journey changed the survivors' perception of work, helped them to reexamine their priorities and rethink the meaning of work and life. Some chose to lower their professional ambitions and devote more time to their family, friends and to themselves. Besides that, many cancer survivors also reported that the cancer experience changed how they reacted at the workplace as they chose not to allow themselves to get stressed at work (Grunfeld et al., 2013; Kennedy et al., 2007; Nachreiner et al., 2007; Tiedtke, 2012 ). However, continuing employment was often necessary for financial reasons despite their altered attitude and perceptions, following the changes in outlook and priorities as a whole (Roelen et al., 2011; Sanchez, Richardson & Mason, 2004).

#### II) Health status

#### Colon cancer treatment-related factors

Seven studies (Sanchez et al., 2004; Bouknight et al., 2006; de Boer et al., 2008; Gordon et al., 2008; Fantoni et al., 2010; Grunfeld, Low, & Cooper, 2010; Roelen et al., 2011) included the effects of chemotherapy as part of cancer treatment. Except for Bouknight et al. (2006), all studies reported negative effects of chemotherapy on RTW. The duration required by survivors to RTW was significantly influenced by chemotherapy as shown by Sanchez et al. (2004). Survivors who received chemotherapy were three times more likely to delay their RTW beyond two months of diagnosis and perceive problems due to fatigue, continuing hospital appointments and lack of understanding from colleagues (Grunfeld et al., 2010) compared to those who did not undergo such treatment. Chemotherapy was also reported to limit the RTW among breast cancer survivors in France (Fantoni et al., 2010) and was associated with work cessation among women colorectal cancer survivors (Gordon et al., 2008). Cognitive dysfunction, also termed as "chemo brain", as a result of long term effects of chemotherapy, is also associated with fatigue, distress and depression and has been associated with delay in full RTW in mentally demanding jobs (Roelen et al., 2011). Surgery as part of cancer treatment was only mentioned in studies among breast cancer survivors (Ahn et al., 2009; Johnsson et al., 2007) and prostate cancer (Grunfeld et al., 2013). Mastectomy is an extensive surgery and was associated with unemployment among breast cancer survivors, and surgery for breast cancer could also cause arm morbidity (Johnsson et al., 2007). Post surgery side effects like urinary incontinence, affecting prostate cancer patients was a concern due to effects on daily life, decisions to resume work and also perception of masculinity (Grunfeld et al., 2013).

Radiotherapy was found to limit RTW (Fantoni et al., 2010) and adjuvant radiotherapy to the regional lymph nodes significantly increased arm morbidity as compared to radiotherapy only on the breast parenchyma(Johnsson et al., 2007). Radiation therapy in men with colorectal cancer was found to be strongly associated with work cessation (Gordon et al., 2008).

#### Colon cancer disease related factors

Advanced and terminal stages of cancer had unfavourable employment outcomes (Ahn et al., 2009; Bouknight et al., 2006; Mehnert & Koch, 2013) and were negatively associated with RTW as well as reemployment among stomach, liver and colorectal cancer patients, due to the poor treatment outcome (Choi et al., 2007).

Overall, colorectal cancer survivors enjoyed a better employment outcome as compared to survivors of lung cancer and head and neck cancer as the latter are usually diagnosed at late stage (Earle et al., 2010; Mehnert & Koch, 2013; Ross L, 2012). However, in comparison with survivors of breast cancer, with smaller tumour size (Johnsson et al., 2007), testicular cancer and skin cancer (Roelen et al., 2011), the RTW prognosis among colorectal cancer survivors were noted to be much lower.

## Colon cancer co-morbid conditions

Health status was affected by the numbers of co-morbid diseases present and the effect of the cancer along with its treatment. The decisions about RTW were greatly affected by health status and symptoms associated with co-morbid conditions. Some patients experienced fatigue, sickness or increased vulnerable following cancer treatment, and some even went on to develop some form of disabilities. As a result of the difficulty coping with these physical symptoms, some chose early retirement (Kennedy et al., 2007; Main et al., 2005).

Poor health status was negatively associated with RTW as reported by Bouknight et al. (2006). Breast cancer patients with more than two co-morbid diseases were two times more likely to be unemployed (Ahn et al., 2009). Studies among colorectal cancer patients suggested that fatigue symptoms were more likely to delay RTW for more than two months (Sanchez et al., 2004) while among breast cancer patients, RTW was delayed for more than two years as a result of physical exhaustion and deterioration upon cancer and its treatment (Johnsson et al., 2007).

The time taken to RTW was longest for those with complications of breast cancer treatment like scar tissue pain and severe lymphoedema (Fantoni et al., 2010). More time off from work was required for minor illnesses as a result of increased susceptibility to infections along with fatigue and tiredness symptom that lasted for months or even years were disruptive and difficult to manage at work making transition back to workplace a real challenge (Kennedy et al., 2007).

#### III) Financial factors

#### Financial pressure

Financial pressure, the fear of being fired from the workplace after long periods of sick leave and being too old to get a new job were primary reasons to RTW after cancer (Grunfeld et al., 2013; Kennedy et al., 2007; Main et al., 2005). Some cancer survivors, despite having received temporary disability pensions, still hoped to remain in the labour market due to their perception that it was difficult for them to get employed again given their age and having retired early (Johnsson et al., 2010; Tiedtke, 2012).

## Health insurance

The interaction of cancer survivorship with health insurance was significant in predicting labour force exits, job changes and transitions to part-time employment for both genders. Tunceli (2009) found that job-related health insurance represents an additional economical and psychological burden on survivors. Maintaining health insurance coverage upon cancer diagnosis was a challenge for most cancer survivors as many were denied a new insurance policy after cancer. Two qualitative studies mentioned economic or health insurance factors as prime reasons for returning to work (Main et al., 2005; Nachreiner et al., 2007). Many cancer survivors also understood that it was not easy to get insurance again after a cancer diagnosis, thus the pressure to secure their current health insurance affected their decisions to continue working (Main et al., 2005). Such pressure was more intense when the cancer survivors were the breadwinner in the family and the only person having health insurance in the family (Nachreiner et al., 2007). Such a scenario was not reported in Denmark as the healthcare system was publicly financed and employees do not depend on employer to pay for health insurance to get treatment. As such, employees in Denmark could take time to recover without the fear of losing their health insurance (Ross, 2012).

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Gordon et al., 2008 found that having no private health insurance was a factor predicting work cessation for both genders with colorectal cancer. However, some senior cancer survivors ( >65 years old) could still benefit from other forms of health insurance, for example the public insurance or insurance through a family member (such as spouse), thus making them more likely to leave work (Earle et al., 2010).

Married women of lower incomes had more flexibility to leave the workplace compared to unmarried women; possibly they have a spouse who was the primary source of health insurance or income in the family (Earle et al., 2010).

#### IV) Environmental factors

#### Supportive environment from family and friends

Support from family and friends at the end of the treatment period was a crucial factor related to RTW among women cancer survivors (Fantoni et al., 20010). Support from family and friends for cancer patients was addressed by Main et al. (2005). Patients were encouraged to RTW for various reasons by their family and friends: as a part of the healing process, being productive in life again and being social with friends again. By disclosing their cancer diagnosis, cancer patients received advice and support from friends, especially those who had undergone a similar experience or had useful resources on process and outcome of the illness. Many reported that interactions from family and friends to be supportive and informative and were therefore positive about their decision to disclose their own diagnosis (Grunfeld et al., 2013).

#### Workplace environment

Various work related factors were studied in both qualitative and quantitative studies: types of occupations, physically demanding job, duration of working, workplace support from employer and colleagues. Work that involved heavy lifting was associated with a lower likelihood of RTW among women with breast cancer (Bouknight et al., 2006). Compared to sedentary workers, manual workers were 2.4 times more likely to experience job loss after cancer diagnosis (Choi et al., 2007). As a result of the problems in the working environment and/or the nature of the work, some cancer survivors were unable to perform to the same extent as previously and thus did not RTW within two years (Johnsson et al., 2007).

The work related characteristic that increased the time until RTW was the existence of psychological or organisational constraints rather than the physical constraints (Fantoni et al., 2010). Support from the workplace (employers and colleagues) was of great importance for successful RTW (Johnsson et al., 2010; Kennedy et al., 2007; Nilsson, 2011; Main et al., 2005; Mehnert & Koch, 2013; Nachreiner et al., 2007). Vocational rehabilitation initiated by the employer (Johnsson et al., 2010), frequent contact from the employer during sick leave (Kennedy et al., 2007), and work accommodation and adjustments offered by employer based on flexibility, gradual assimilation and changes in work tasks (Kennedy et al., 2007; Nilsson, 2011; Main et al., 2005; Mehnert & Koch, 2013; Nachreiner et al., 2007) were helpful for cancer survivors returning to workforce.

Less support from colleagues coupled with a hostile working environment, changes in the work situation, such as change of employer or work duties, and difficulties with the employer or with colleagues did not favour early RTW (Johnsson et al., 2010), while a strong relationship with co-workers support could compensate for an employer's inadequate response to transition back to work and help employees be better equipped to handle their situation (Nachreiner et al., 2007; Nilsson, 2011). The sense of responsibility to work, especially in smaller workplaces that struggle to cope with extra workload was a prominent factor in deciding to RTW. This feeling of loyalty involved added pressure for cancer patients to get time off from work for frequent hospital appointments, and fearing that colleagues and employers do not understand the longterm effect following cancer treatment, like fatigue (Kennedy et al., 2007; Tiedtke, 2012).

Skilled employees of larger companies started working earlier after cancer than those who were unskilled in smaller companies. This could be attributed to the establishment of written RTW policies in larger companies which is not common in smaller organisations. Furthermore, it is easier for large companies to accommodate appropriate work tasks and working hours to the work ability and vulnerability of cancer survivors.

Employees of the public sector (regardless of occupation) and senior employees were more likely to fully RTW later than those from private sectors and junior employees. Cancer survivors employed less than five years had full RTW earlier compared to those employed for many years (Roelen et al., 2011b).

Supportive environment from healthcare professionals

Physicians and health care provider teams play a critical role in the employees' positive evaluation of their recovery process and offer encouragement to RTW among survivors (Nachreiner et al., 2007). Many employees acknowledged that they did not receive much guidance and advice on work issues and rehabilitation from healthcare professionals (Nilsson, 2011), while some reported they had a different point of view on work issues from the physicians. Hence, doctors allowed the patients to decide for themselves whether to RTW or not (Kennedy et al., 2007; Main et al., 2005).

Provision of evening treatment sessions by healthcare personnel helped in reducing sickness absence from work for patients undergoing treatment (Nilsson, 2011).

Early communication and discussion on potential RTW issues, by the treating physicians after cancer with the employers helped in planning the initial phase of RTW. Such communication during sick leave strengthened the relationship and confidence in

line managers and occupational health staff which facilitated the provision of helpful guidance and advice from occupational health upon RTW (Yarker et al., 2010).

#### V) Work ability and work demand

The work ability of patients must match their work demands in order to delay loss of employment. Impaired work ability as a result of chemotherapy or presence of comorbid conditions does not favour employment outcomes. Survivors working in stressful jobs reported more difficulties when RTW (Kennedy et al., 2007; Tiedtke, 2012).

Many survivors were concerned about their work capability and performance following treatment and period of being absent at workplace (Grunfeld et al., 2013; Tiedtke, 2012). Gender, treatment related factors and disease related factors were found to be related to their work ability score (Gudbergsson, Fosså & Dahl, 2011; Lindbohm, Taskila, Kuosma, Hietanen, Carlsen, Gudbergsson & Gunnarsdottir, 2012). In a study done in the Netherlands, men scored higher than women on work ability until one year after the first day of sick leave, while haematological cancer patients had lower scores compared to those with cancer of urogenital tract or with gastrointestinal cancer. Among the treatment factors, those who underwent chemotherapy consistently showed lower work ability scores (de Boer et al., 2008).

Work ability scores among cancer patients improved significantly over the time, but the score at six months was a strong predictor of later RTW. Therefore, self-assessed work ability is an important factor in the RTW process of cancer patients regardless of age and clinical factors (de Boer et al., 2008).

#### **4.2 Phase II: In-depth interview (Qualitative Research)**

Findings from the Phase II, in-depth interviews with the relevant key informants were reported as barriers and facilitators associated with RTW, to contribute in developing the work-directed intervention on RTW. These key informants were: 1) colorectal cancer survivors who had returned to work (RTW) and non-return to work (NRTW), 2) healthcare professionals and 3) employers were recruited using purposive sampling method and maximum variation technique. The researcher reported the response rate for each group of the key informants. Findings and input from interviews are described based on barriers and facilitators associated with RTW.

## 4.2.1 Findings from colorectal cancer survivors

The colorectal cancer registry database in the hospitals started around 2009 and is relatively new. Until the beginning of 2012, there were a total of 58 colorectal cancer survivors from the databases that met the inclusion criteria. Out of the 58 contact numbers, 14 (24%) were unreachable, 5 (9%) had died, and the remaining 39 were reachable but 31 (53%) were not interested in the study. Thus, a total of 8 (13%) agreed to take part in the interview.

A further eight subjects were recruited from various cancer support groups making a total of sixteen cancer survivors for the study. Colorectal cancer survivors from both RTW and NRTW groups reported different experiences in reintegrating back to workplace after cancer. Some were successful in returning to the same workplace, some had left the workplace, while few had yet to resume work at the time when the interview was carried out. Table 4.2 shows the characteristics of colorectal cancer survivors who participated in our in depth interview as key informants.

Table 4.2: Characteristics of colorectal cance	r survivors
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	Return-to- Work (RTW) n (%)	Non Return- to-Work
		(NRTW) n (%)
Ethnicity		
Malay	3 (18.75)	2 (12.5)
Chinese	3 (18.75)	4 (25)
Indian	2 (12.5)	2 (12.5)
Age		
Mean	50.6	58.1
Gender		
Male	4 (25)	4 (25)
Female	4 (25)	4 (25)
Marital status		
Single	2 (12.5)	1 (6.25)
Married	6 (37.5)	7 (43.75)
Stay with		
Spouse, kids	5 (31.25)	4 (25)
Parents and brother/sister	3 (18.75)	3 (18.75)
Friends	0	1 (6.25)
Occupational status		
Government	4 (25)	4 (25)
Private sector	4 (25)	4 (25)
Medical sick leaves		
Range	12-104 wks	12-104 wks
Mean	38	64
Willingness to return to work		
Yes	8 (100)	3 (18.75)
No	0	4 (25)
Uncertain	0	1(6.25)
Return to work status		
Same employer + job title +		
job description	6 (37.5)	-
Same employer + job title		
but different job description	2 (12.5)	

# recruited as key informants, N=16

A total of nine themes emerged from the interview with colorectal cancer survivors on the barriers and seven themes for the facilitators to RTW.

#### Barriers for RTW

Among the colorectal cancer survivors interviewed, four (25%) were medically retired from their respective organisations, two (12.5%) had retired and the other two (12.5%) were still on extended unpaid leaves at time of interview.

One of the common themes that emerged from these colorectal cancer survivors who had RTW and NRTW was the side effects of the treatments as well as the symptoms of the disease (Figure 4.2). Those side effects and disease related symptoms affected them in every aspect of their lives from physical and psychosocial aspects. Symptoms like fatigue, tiredness, lack of strength and stamina to work were reported.

"...I feel really tired during the cancer treatment and even after it...I had problems working long hours." (Male, colorectal cancer survivor, NRTW, private sector)

"When I feel tired even walking for a short distance, I knew that going back to my work is out of the question." (Male, colorectal cancer survivor, NRTW, government sector)

Fatigue and tiredness were further worsened by poor oral intake as a result of chemotherapy while others still experienced changes in bowel habits despite the completion of cancer treatment.

"I find the frequent visit to toilet as a result of the cancer is extremely disturbing and the odour due to cancer drugs was very unpleasant to me and those people around me." (Female, colorectal cancer survivor, NRTW, private sector) "During the treatment phase, I had sore mouth...poor intake of food as I experienced nausea and vomiting almost everyday...it is not easy to overcome those symptoms." (Female, colorectal cancer survivor, RTW, government sector)

Cognitive impairments such as forgetfulness and slowness in thinking were attributed to the chemotherapy by the key informants.

"It is not easy to focus at the work task when the chemo effects set in. I was told that the effect is called Chemo brain." (Female, colorectal cancer survivor, NRTW, government sector)

"My job requires me to think fast and analyse accounting reports...with the chemo... I feel kind of slow...even my supervisor noticed that too." (Male, colorectal cancer survivor, RTW, private sector)

Few colorectal cancer survivors developed anxiety and depression after diagnosis and took some time to consider starting cancer treatment. Symptoms like insomnia, loss interest in daily activities, including routine work did not promote RTW.

"I felt very down, a sense of helplessness and difficulties to fall asleep even before starting chemotherapy. So, I was not interested in usual daily activities, including going to work also." (Female, colorectal cancer survivor, NRTW, government sector)

The constant fear of cancer recurrence also prevented colorectal cancer survivors to RTW and sustain work performance. Such fear was commonly shared by survivors who know someone having cancer recurrence after treatment.

"The fear of the cancer coming back really disturbed my working life...the thoughts of what if it returns was not good at all." (Male, colorectal cancer survivor, NRTW, private sector) "Can't really focus and enjoy the usual life...as I tend to worry about the cancer may come back." (Female, colorectal cancer survivor, NRTW, private sector)

Following the diagnosis of colorectal cancer, participants described a paradigm shift in their priority in life. Work itself was no longer being considered as the top priority to them especially when they had spent most of their life working. They chose not to RTW as they wanted to pursue their dreams doing something they always wanted to do or spending quality time with family given that they are uncertain about the future following the cancer diagnosis.

"Somehow, I manage to see things from different perspectives...no longer that ambitious about climbing the corporate ladder...something I used to believe in." (Male, colorectal cancer survivor, NRTW, private sector)

"Having worked in the organisation for almost 15 years, I think it is good time to take a break from work and enjoy my retirement with family and grandchildren." (Male, colorectal cancer survivor, NRTW, private sector)

"I like my job but I feel I shall spend my remaining years doing something more meaningful with my life which I always wanted to do." (Male, colorectal cancer survivor, NRTW, government sector)

Negative attitude, perception and value were identified as barriers. Two of the participants had the perception that work is a stressor which could cause the cancer development and may also cause cancer recurrence. Thus, they chose not to RTW and wanted to avoid working at all.

"You know...work is the source of the stress and anxiety...This negative energy would cause cancer in the long term." (Male, colorectal cancer survivor, NRTW, government sector) "I want to change my lifestyle and work...Stress from daily lifestyle and work pattern are unhealthy and can lead to cancer." (Female, colorectal cancer survivor, NRTW, private sector)

More than half of the survivors had special diets upon being diagnosed with colorectal cancer. Five of them (31%) also believed some faulty myths attached to diet for colorectal cancer survivors. They believed and advocated that colorectal cancer survivors needed to prepare special diets to maintain health, prevent accumulation of toxins and hence cancer recurrence.

"Talking about food intake...there is a long list of food to avoid...supplement for maintenance of health is not an option..." (Female, colorectal cancer survivor, NRTW, private sector)

"Not only have I become a vegetarian...I am also very particular about the type of vegetables...organic is also preferred..." (Female, colorectal cancer survivor, NRTW, private sector)

"Besides the conventional cancer treatment, I took advice from traditional complementary medical practitioners and was advised to follow a special diet and consume some herbal products..." (Male, colorectal cancer survivor, NRTW, government sector)

The survivors also commented on the demanding nature of their job as an obstacle for them to RTW upon completing cancer treatment. Work related factors like a physically demanding job, exposure to chemicals and smoke during work were among the crucial issues to consider in making the decision to RTW. "Unlike those working in the office, I work in workshop and am exposed to the dust... chemical fumes which are not good for my health despite having completed my treatment." (Male, colorectal cancer survivor, NRTW, government sector)

"It is my job to climb up the store to arrange the stocks every week...and to record in the computer system. It is a challenge for me to arrange those stocks now..." (Female, colorectal cancer survivor, NRTW, private sector)

"Working in a manufacturing industry... supervising the duty of my subordinates requires me to walk from one block to another...It is mentally and physically demanding job to supervise so many staff at one shift." (Male, colorectal cancer survivor, NRTW, private sector)

Lack of awareness of RTW opportunities among the colorectal cancer survivors and healthcare professionals also hindered them from a smooth RTW. This could be due to the lack of promotion and advocacy on RTW program and policy in the organisations.

"I was not aware of the Employees Assistance Programme of the company at all...I thought they will contact me...only to find out that I was required to update them about my leaves and treatment progress." (Male, colorectal cancer survivor, RTW, private sector)

"I asked the doctors on RTW plan for me after treatment...but they did not seem to know how to plan that...nor who can assist me." (Female, colorectal cancer survivor, RTW, private sector)

"My employer did not know anything about RTW plan...they were dependent on the recommendations from my doctors...but doctors usually give a very vague plan like light duty...or go back only when you are ready." (Female, colorectal cancer survivor, RTW, private sector)

"I have never heard of RTW programme or policy for that matter, neither from my workplace nor from the hospital." (Male, colorectal cancer survivor, NRTW, government sector)

Compensation either from Social Security Organisation (SOCSO) or private insurance indirectly prevents the colorectal cancer survivors from timely RTW. The Social Security Organisation is an agency under Malaysia Ministry of Human Resources responsible for administering two types of social protection schemes: The Employment Injury Insurance Scheme and the Invalidity Pension Scheme. The Employment Injury Insurance Scheme provides protection to employees who are involved in accidents arising out of and in the course of his employment occupational diseases and also commuting accidents. The Invalidity Pension Scheme provides twenty four (24) hours coverage for workers from invalidity or if they die irrespective of the cause of death. Compensation from private insurance is helpful for insured survivors during the critical period of medical leave. However, such privileges have been abused by some insured individuals who took the opportunity to avoid RTW at all.

"I would try to appeal for invalidity pension from SOCSO while having my medical leaves." (Female, colorectal cancer survivor, NRTW, private sector)

"This is a privilege for us as SOCSO contributors, it only makes sense...for us to submit and try applying for the compensation after cancer." (Male, colorectal cancer survivor, NRTW, private sector)

Sick leave is meant for employees to undergo medical treatment and recuperate from illness. However, long sick leave given to the colorectal cancer survivors could delay the RTW and in some cases could be a barrier to RTW. Civil servants in Malaysia are entitled to a maximum of two years full paid medical leave. All civil servants who did not RTW shared similar barriers upon getting two year medical leave.

"I knew being a civil servant...I am entitled to have up to 2 years paid medical leaves...it is all written in the General Orders (G.O) Thus, there is no hurry to get back to my work even though my treatment is complete." (Female, colorectal cancer survivor, NRTW, government sector)

"The sick leave is a special benefit for civil servants...I am using it up to the maximum period...I have not thought of returning back to my workplace...honestly." (Male, colorectal cancer survivor, NRTW, government sector)

"I would not complain about the duration of sick leaves given to me...for me it is more than enough but somehow I have lost the motivation to work again...I am not sure if that is a good thing." (Male, colorectal cancer survivor, NRTW, government sector)

Two of the colorectal cancer survivors from the private sectors attributed their non-RTW to the change of organisation's policy despite their motivation to resume work. Organisation policy renewed periodically and is beyond the control of its employees.

"After my cancer treatment, I went back to work for 6 months...then my contract is due for renewal. Then, I was told that...they would not consider renewing my contract under the new policy." (Male, colorectal cancer survivor, NRTW, private sector)

"May be is my age close to retirement, they offered me a part time position instead of a full time...when I asked why? They told me that is a new policy from the management." (Male, colorectal cancer survivor, RTW, private sector)

"Organisation was going through downsizing...only young employees get to keep the job...I am much older and was just recuperating from cancer." (Female, colorectal cancer survivor, NRTW, private sector) Unsupportive employers and colleagues are a commonly reported barrier to RTW after cancer. Such a theme is the most important obstacle under the category of environmental factors which could prevent RTW among colorectal cancer survivors.

"My boss repeatedly asked me to apply for SOCSO invalidity pension...he did not make any effort to help me to get back my work." (Female, colorectal cancer survivor, NRTW, private sector)

"Some of my colleagues may be unhappy having to do my work...though they were aware that I was in the hospital. When I had exhausted my medical leaves, I requested for extended leaves...but the supervisor was not happy." (Female, colorectal cancer survivor, RTW, private sector)

"I wish they could be more understanding...not so demanding towards my performance...After all, I had just finished my treatment...and it would take some time for me to get back to my usual pace." (Female, colorectal cancer survivor, RTW, private sector)

"Though I have given my employer all the medical reports and doctor's recommendation letter to modify the job hours ...I did not see any changes at the workplace...still the same routine and working hours." (Male, colorectal cancer survivor, RTW, private sector)

"It was a challenge to get back to work...how much should I reveal to my fellow colleagues so that they could understand that I was not looking for excuses to avoid working...I feel that I was not welcomed..." (Female, colorectal cancer survivor, RTW, private sector)

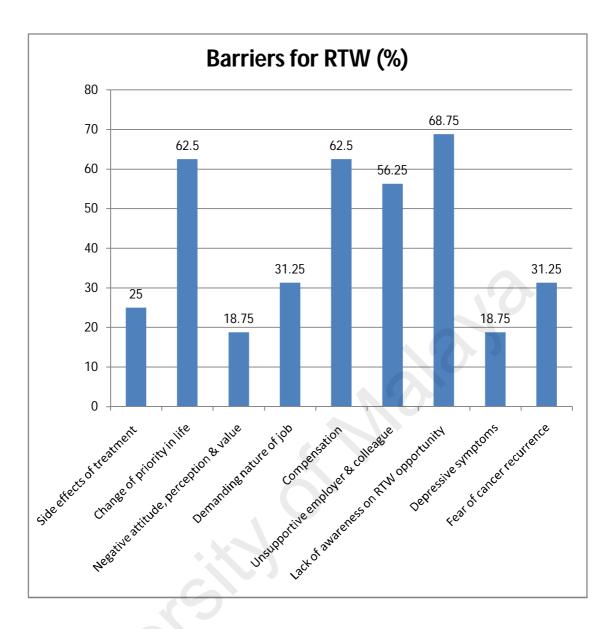


Figure 4.2: Barriers for RTW as reported by colorectal cancer survivors, n=16

#### Facilitators for RTW

Six out of eight participants who had RTW had successfully resumed their initial job and worked on full time basis while the other two managed to secure their initial job but on part time basis. Three colorectal cancer survivors (18.8%) had a phased RTW, two of them (12.5%) had modified their job, another two had flexible working hours (12.5%) and one of them (6.3%) worked from home as part of their RTW plan. Those colorectal cancer survivors who successfully RTW were motivated to resume a normal life as early as possible (Figure 4.3). They wanted to continue their working life despite the diagnosis. The usual comments were that they wanted to avoid boredom and to socialise with working colleagues.

"I want back my normal life...being able to work again is a good thing. It is something not related to cancer at all." (Female, colorectal cancer survivor, RTW, government sector)

"It is just a natural thing to RTW for me...having undergone the operation and completed my follow up...there is only so much one can do sitting at home." (Female, colorectal cancer survivor, RTW, private sector)

"I would probably go crazy or succumb to depression...staying at home and do nothing with my mind. Thus, work is important and going back to work can be viewed as part of healing process too...at least, I feel I am healthy." (Male, colorectal cancer survivor, RTW, government sector)

For others, work was part of their status and identity which they would not want to give up. The desire to keep that identity and status was the motivation to RTW.

"I enjoy my status and my work in the organisation...I am not prepared to give up that status...just because I had a brief illness." (Female, colorectal cancer survivor, RTW, government sector)

"It took me so long to reach my current position...of course, I love my job and I want to keep that job as long as I could...I had returned to my office before finishing my medical leave entitlement." (Male, colorectal cancer survivor, RTW, private sector) To have a source of income was the second most common reason for colorectal cancer survivors to RTW. This theme emerged from both male and female key informants. The desire to be financially independent was a motivating factor to resume work.

"Though my spouse is working, I could not afford to burden him more for my medical bills...especially I have exhausted the insurance coverage. I want to be able to independent financially." (Male, colorectal cancer survivor, RTW, private sector)

Key informants also reported the various financial commitments as a motivating factor to work again despite the cancer.

"The family basically is dependent on my salary...though my spouse is employed. We have quite a lot of financial commitments...from car loans, mortgage to children's education fund. I can't afford not to work." (Male, colorectal cancer survivor, RTW, private sector)

"Going back to work ensures I have a steady pay check monthly to support my family...the steady income kind of offered me the financial security to certain extent...it is not easy to get a new job especially after cancer." (Female, colorectal cancer survivor, RTW, private sector)

In order to maintain the health insurance offered by the organisation, some key informants decided to continue working. Such organisational health insurance would pay for the employees' medical expenses and is considered as a benefit to stay in the organisation.

"My medical fees are not cheap as I got treatment from a private medical centre... Fortunately, the medical bills were all paid up by the insurance from my organisation." (Female, colorectal cancer survivor, RTW, private sector) "RTW means I could continue enjoying the medical benefits from the company's insurance coverage...that also means I could save up a lot for my medical follow up and cancer surveillance...for example the colonoscopy." (Male, colorectal cancer survivor, RTW, private sector)

"Honestly speaking, the company has a very good medical benefit for the employees...that is something everyone would acknowledge...So, why not go back and work to enjoy that medical benefit...right?" (Male, colorectal cancer survivor, RTW, private sector)

A supportive workplace that made accommodations was one of the crucial factors under the environmental related category. All key informants testified that the supportive role played by the employer was helpful in the process of resuming their duty at the workplace.

"I got back to my office after treatment...but my head of department suggested me to work from home for some time since I had to drive to office from a far distance...I am thankful for that accommodation by the department." (Female, colorectal cancer survivor, RTW, private sector)

"I was given some flexi working hours...especially during the initial stage of work resumption...Basically, I could take some time off and getting back to the usual routine slowly with the flexi hours...In that way, I let my body decide if I should stop to take a rest or continue working for the day." (Female, colorectal cancer survivor, RTW, private sector)

"My job requires me to check and arrange the stocks in the store...but after I RTW, I was assigned to station at the computer section to key in the data...That was a kind of modified job for me." (Male, colorectal cancer survivor, RTW, private sector) "To have paid time off to attend clinic follow up after treatment is very encouraging to me...as a junior staff in the company." (Male, colorectal cancer survivor, RTW, private sector)

Key informants working in multinational companies acknowledged how they benefitted from the Employee Assistance Programme in their companies during and after treatment of cancer.

"As an employee in the multinational organisation, I am grateful for the assistance given to me during my treatment period as well as the RTW phase...We have Employee Assistance Programme in place which benefitted me personally. The staff was very friendly and helpful in providing me some information on the side effects of treatment and how it may affect my work." (Male, colorectal cancer survivor, RTW, private sector)

"The coordinators in Employee Assistance Programme have a clear idea on my job scopes...and that helped a lot when I explained to them my issues at work. Their understanding of the job nature helped in preparing me to resume my work duty eventually." (Female, colorectal cancer survivor, RTW, private sector)

Colorectal cancer survivors also attributed their successful RTW to the plan and constant advice on RTW by healthcare professionals. Healthcare professionals had influenced their decision in RTW as they recalled the advice and RTW plan outlined by these healthcare professionals.

"My treating oncologist has told me I could work after completing my cycles of chemotherapy...initially, I was not convinced, I requested for longer medical leaves. However, she told me that the longer I stay out of my job...the less unlikely I would eventually return to my workplace and function like usual. Thus, she counselled me on the various channels I could get help from as a survivor...like the support group for survivors. To her, I had no excuse to extend my leaves especially my young age and good prognosis of the cancer." (Female, colorectal cancer survivor, RTW, private sector)

"The occupational health doctor supported my RTW by outlining the RTW plan for me and all I needed to do was to pass the letter of recommendation for modified job to my manager...then I was followed up by the same doctor and he reviewed my work performance and progress report prepared by my manager. No doubt that the occupational doctor has helped me in the RTW period." (Male, colorectal cancer survivor, RTW, private sector)

"During one of the reviews with my oncologist, she asked when I would be ready to work again...then I knew that she was there to talk to me on RTW plan...I was glad as I wanted to discuss more than just medical leaves or claiming for health insurance..." (Male, colorectal cancer survivor, RTW, government sector)

"There was a period when I felt down...I did talk to a clinical psychologist as recommended by my doctor. Overall, it was more on exploring the various issues I faced at workplace after cancer...and I was taught on some techniques on relaxation and focus while at work." (Male, colorectal cancer survivor, RTW, government sector)

Success in RTW requires the survivors' ability to cope with work demand and stress as the key informants pointed out. Such ability is essential for them in performing the duty without compromising its quality at work.

"I attended Qigong exercise and discovered that I could handle my stress level better even at work." (Male, colorectal cancer survivor, RTW, private sector) "It took me some time to get back my usual routine and pace... however, I am glad that I managed to cope with the assignments given to me...on time... of course, with the help of my team as well." (Female, colorectal cancer survivor, RTW, private sector)

"With the flexi hours and working from home once twice a week...I had managed to perform well and meet my deadlines." (Male, colorectal cancer survivor, RTW, private sector)

"Somehow...you need to just do your work and show them the result despite the KPIs and stress attached to it...especially when everyone is supporting you and expecting you to perform." (Male, colorectal cancer survivor, RTW, government sector)

Support and encouragement from family was found to be helpful in making the decision to RTW. All RTW colorectal cancer survivors acknowledged the support and encouragement given by family members throughout the journey of battling with cancer.

"I am thankful to have a loving wife who constantly by my side to support me from the time of diagnosis till completion of treatment...She encouraged me to RTW as that is a healing process and a way to celebrate life...according to her." (Male, colorectal cancer survivor, RTW, government sector)

"When I told my family that I miss my working life...they encouraged me to continue working after the medical leaves as they know I would enjoy my work like before." (Male, colorectal cancer survivor, RTW, private sector)

"My family is my avid supporter in this battle against cancer...in fact; they let me decide if I want to work again. Whichever decision I make, they would stand by me...I finally decided to continue working and they were very supportive of my decision." (Female, colorectal cancer survivor, RTW, government sector)

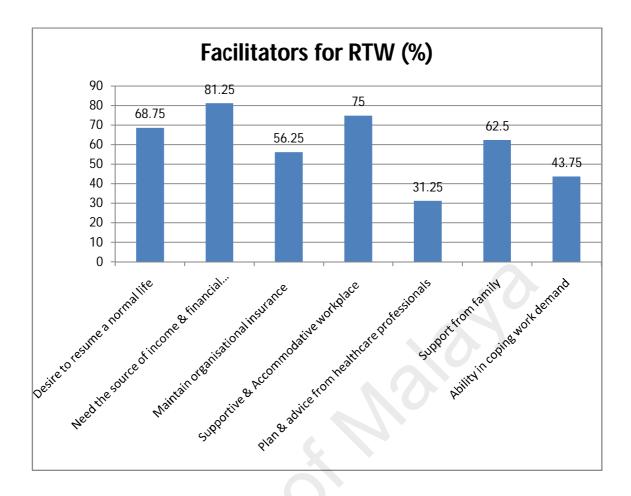


Figure 4.3: Facilitators for RTW as reported by colorectal cancer survivors, n=16

## 4.2.2 Findings from healthcare professionals

Healthcare professionals from the field of oncology medicine, surgery, rehabilitation medicine, occupational health, psychology and primary care were contacted in the public hospitals and private hospitals in Penang and Kuala Lumpur. The target number of key informants for healthcare professionals was twelve for the in depth interview with each field having key informants from both the public and private medical centres. The recruitment and interviews were carried out until reaching the saturation level, which were twelve key informants.

A total of five (41.7%) key informants were recruited among healthcare professionals through invitations to ten hospitals with oncological service in Penang and Kuala Lumpur. While four (33.3%) healthcare professionals agreed to take part in the interview after they were being briefed on the study in conferences and scientific meeting on cancer. Besides that, three (25%) key informants from health care professionals were recruited through the professionals' associations and societies (Table 4.3)

### **Table 4.3: Characteristics of healthcare professionals**

#### recruited as key informants, N=12

	Government Sector n (%)	Private Sector n (%)
Gender		
• Male	3 (25)	3 (25)
• Female	3 (25)	3 (25)
Postgraduate training		
• Local	2 (16.7)	2 (16.7)
• Overseas	4 (33.3)	4 (33.3)
Average years of service		
• <10	1 (8.3)	-
• 10-20	4 (33.3)	4 (33.3)
• >20	1 (8.3)	2 (16.7)
Perception on RTW		
• Not the role of doctor	4 (33.3)	5 (41.7)
• Follow patients' decision	4 (33.3)	6 (50)
Discussion on work issues		
during consultation	1 (22.2)	
• Often	4 (33.3)	5 (41.7)
• Sometimes	2 (16.7)	1 (8.3)
Seldom	-	-
• Never	-	-

From the in-depth interview with those key informants of healthcare professionals, there were eight themes for the barriers associated with RTW while seven themes were identified for facilitators in RTW.

Long medical leave policy in the employer organisations did not favour early RTW but may mean that rejoining the workplace is a real challenge, as most of the treating oncologists and surgeons stated in the interview. Laziness and being in the comfort zone were suggested as common obstacles and the result of colorectal cancer survivors having long medical leaves.

"Delayed in RTW and poor motivation to join back workforce...are the results of allowing the patients to have more than enough time to recuperate...it is certainly not productive for the organisations. That is the reason why I always push them to go back as early as possible to avoid them from trapping themselves in the comfort zone of medical leaves." (Oncologist, government sector)

"Frankly speaking, most of the civil servants whom I had treated were not motivated to go back to work. Somehow, they had told me their decision to avoid working indirectly even before completing the treatment...as they wished to enjoy the two years paid medical leaves...I could only help that much to encourage and guide them to RTW." (Colorectal surgeon, private sector)

"Quite a number of my patients developed the laziness syndrome after getting long medical leaves from their respective companies...I told them honestly that the longer they stayed out of job...the less likely they would eventually RTW...and studies from foreign countries also reported the same findings." (Occupational Health Physician, private sector)

"The duration of medical leaves may have certain effects on the motivation to RTW...Long sick leaves may be helpful for recovery process but may not have positive effect for RTW rate." (Rehabilitation Physician, government sector) Another barrier mentioned was the employers' lackadaisical attitude in helping colorectal cancer survivors to RTW. Besides the assistance and planning from healthcare professionals along with the motivated survivors, employers must play a part in the entire RTW process. Without the commitment from the employers, RTW of survivors would not be successful.

"It is very disturbing when the employer did not follow the recommendations given by my team in the phase RTW...Without implementing the recommendations, we are unable to comment if the job modification...would be helpful for the survivors. Hence, the process is delayed...loss of time and our effort." (Rehabilitation Physician, private sector)

"I understand the employer's aim is to make profit while my goal is to help survivors to return to their near to normal working life...Somehow, there were times when our goals do not meet...Very often, employers advised colorectal cancer survivors to apply for invalidity pension from SOCSO while my team and I had listed some potential recommendations to help the company to retain the employees." (Occupational Health Physician, private sector)

"May be the employers have the lack of awareness in helping survivors to RTW...or they chose to ignore that altogether...they were not keen in having the employees with cancer...hence they were not likely to give much effort to carry out whatever we suggested in the medical summary." (Occupational Health Physician, private sector)

There were some views among healthcare professionals suggesting that they lack knowledge and awareness in assisting RTW in their practice. Not every healthcare provider, who is involved in the treatment, considered helping their patients to RTW as part of their core duty given that they were not trained in that aspect. "Personally, I think the decision to RTW is not for us to make...survivors know they body better than us...thus, they are able to tell if they can cope with work load and stress after cancer. So, if they needed medical leaves...I would write for them as long as they still have leaves...if they requested my opinion for SOCSO invalidity pension, I would write according to their symptoms and complaints. The onus of approving the claim and certification of invalidity is on the medical board appointed by SOCSO...Treating physicians like myself are not qualified to comment on that." (Oncologist, private sector)

"Seldom had we discussed on work issues during clinic consultation...most of the time, our team review the symptoms of treatment...from there, we could have an idea when the survivors could work again. May be a word or two to encourage them to work again if they are fit...but on how to assist them to go back and achieve their usual level of work performance...that is not within my field." (Oncologist, government sector)

"Issue on returning to work is best to leave it for qualified, competent person like DOSH certified Occupational Health Doctors (OHD) to handle...to avoid all the unnecessary medico-legal implications, especially when dealing with patients with comorbid condition, working in challenging work environment." (Oncologist, private sector)

It is not uncommon that treating physicians were not aware of the roles played by other healthcare professionals in the RTW process. As a result, survivors who required further evaluation and assistance prior to RTW were referred later and therefore hampered the RTW journey.

"Sad to say...colorectal cancer patients like any other cancer patients would be referred to me only when they have signs or symptoms suggesting of anxiety, stress or depression. In fact, we can do more besides psychosocial aspect if they were referred to us earlier. We do work with rehabilitation team to prepare them functionally and mentally before discharging them to work. However, treating doctors must have high level of suspicion on survivors who are not motivated to work and refer them to us for immediate evaluation." (Psychologist, government sector)

"Our team of occupational therapist look at the working condition of the survivors and would suggest therapy to achieve the level of functions required for the work task...Till now, we do not receive much referral for cancer patients except for breast cancer patients with lymph-oedema after treatment. Majority of cancer patients are at risk of developing stress and depression...we have few screening tools to screen for the mental health which are still underutilised thus far." (Rehabilitation Physician, government sector)

"I am not sure what more I could help in RTW besides writing a summary of the survivor's treatment and the progress to the Human Resource manager...Isn't that considered part of RTW assistance?" (Primary Care Physician, government sector)

Poor understanding of RTW opportunities among the colorectal cancer survivors was blamed for not utilising the services and resources on RTW in their respective organisations. Two healthcare professionals also noticed that none of the colorectal cancer survivors aware of the RTW programme under SOCSO even though they are SOCSO contributors.

"Some of the patients under my care are not aware of the RTW programme conducted by SOCSO...all they know is the compensation from SOCSO. In fact, SOCSO has done quite a lot for rehabilitation to assist insured employees suffering from disability due to illness to recover and also rejoining the workforce." (Primary Care Physician, government sector) "I thought that those employees working in multinational companies would utilise the Employees Assistance Programme for their RTW programme. However, I was then being informed that some of the services are out sourced to different service providers and the employees were not being updated for such changes..." (Primary Care Physician, private sector)

"There were times when I had to inform the survivors that their company has Employee Assistance Programme for them..." (Rehabilitation Physician, government sector)

"Sometimes due to the poor communication between the survivor's immediate manager and the occupational health or human resource department, there was no contact among these two important departments at all. There should be a system to enhance the communication and notification among departments in the organisation on leaves and preparation to RTW." (Psychologist, government sector)

Disturbing symptoms related to treatment and disease were challenging obstacles for colorectal cancer survivors to RTW early. Fatigue, tiredness, numbress of the hands and feet besides frequent loose stool were among the common complaints and hurdles reported by the colorectal cancer survivors to healthcare professionals during clinic follow up.

"When I asked my patients why they needed longer medical leaves...almost all of them complained of the fatigue...tiredness disturbing their working life." (Colorectal surgeon, private sector)

"Patients have been informed about the potential side effects of the various treatments by our team before the treatment. Despite that, many of them still find it hard to battle against the symptoms like diarrhoea and the odour. Such symptoms were their main concerns going to public places as well as to workplace." (Colorectal surgeon, private sector) "Some patients had numbness of the hands...but that was not the real hurdle for returning to workplace...for them the real challenge was the gastrointestinal symptoms like nausea, vomiting...passing loose stool." (Oncologist, government sector)

Key informants specialised in occupational health and rehabilitation agreed that many of the colorectal cancer survivors encountered various psychological barriers rather than physical disability to resume work after cancer. All efforts by healthcare professionals to help colorectal cancer survivors to lead a normal working life must always focus on the psychological issues like anxiety, stress, depression and forgetfulness.

Healthcare professionals also believed that some survivors were in denial stage after being diagnosed with cancer and took some time to seek help for their depression.

"Depression is not a nice term to use but when the patient is found to have some signs suggesting of depression...they were referred to psychological department. Usually, it took some time for them to come to terms with that additional health issue following cancer diagnosis...that should explain why some cases were seen by us later than it was being scheduled." (Psychologist, government sector)

"Psychological issues are real issues for these cancer patients especially after knowing the diagnosis...until when these issues would stay in their mind...is hard to say. Until they face these issues and learn to manage a new life...they are not ready to RTW." (Psychologist, government sector)

"Besides fatigue and cognitive impairment associated with cancer treatment, I would say anxiety, stress and depression of varying degree are the commonest indications for medical leaves despite them having completed the entire cycles of chemo." (Rehabilitation Physician, private sector) One rehabilitation practitioner brought up other factors in the workplace which could add to the burden of a patient's health, especially mental health.

"Unable to adjust in working environment and the constant worries of discrimination at workplace could really take a toll on their mental health...so it is not always due to the cancer." (Rehabilitation Physician, private sector)

Having understood the working environment of the colorectal cancer survivors, some occupational health doctors and rehabilitation practitioners reported challenges in suggesting modified jobs for those survivors without higher education. They attributed this problem to the poor ability to multitask among certain individuals.

"Patients working in job that demands more physical effort than mental capacity are not trained to work in the office...like checking accounts and keeping documents. Such categories of staff with limited skills offer us a real challenge in planning RTW for them." (Occupational Health Physician, private sector)

"Patient's skills and level of education are both crucial in deciding what to recommend for them in the workplace. In such case, a jack of all trades may be of advantage...but the reality is not so ideal. Most employees are master at some specialised task...thus not easy to introduce new task to them." (Rehabilitation Physician, private sector)

Compensation from an organisation like SOCSO has been viewed as a hurdle to resume work by most healthcare professionals. Some survivors would try applying and appealing to the board several times just to get certified as an invalid and receive the pension for SOCSO.

"Some patients were planning how to get the invalidity pension since diagnosis...rather than RTW, they plan for applying invalidity from SOCSO." (Rehabilitation Physician, private sector) "SOCSO compensation is meant to help those who deserved it but sad to say, many insured employees would just try their luck hoping to be certified by medical board as invalid and need not work again." (Occupational Health Physician, private sector)

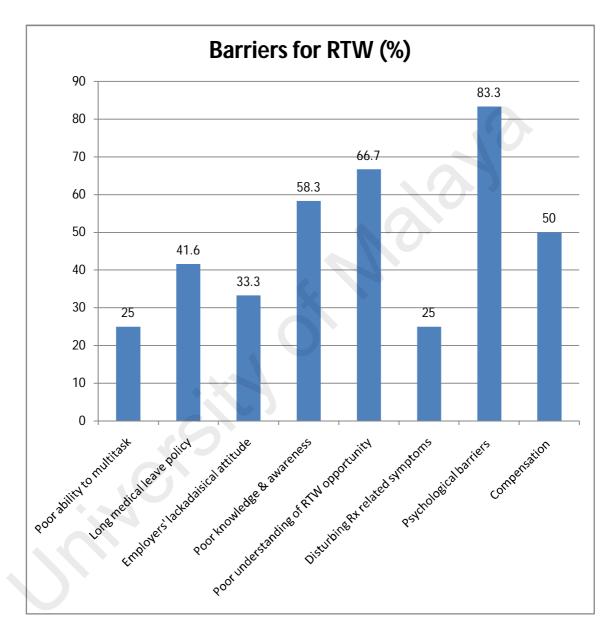


Figure 4.4: Barriers for RTW as reported by healthcare professionals, n=12

Facilitators for RTW

All interviewed healthcare professionals suggested that many colorectal cancer survivors wanted to move on with their life and going back to work meant regaining normal life. This was seen more in colorectal cancer survivors of younger age who were diagnosed with an early stage of disease.

"I would say some survivors consider working as part of their life... so to have a good quality of life means work resumption is a must for them." (Primary Care Physician, private sector)

"Once we told them treatment is over...we could sense the excitement in them to leave that chapter and move into a new one...that is to lead a new normal life. So, it is not too surprising that they wanted to work again." (Rehabilitation Physician, government sector)

"In the cancer support group, we have members who had successfully resumed their working life after cancer treatment...and active in work and social life like any other person. Thus, I believe those are good testimonies for new survivors who wish to overcome the fear of joining back the workforce." (Colorectal surgeon, private sector)

Very often healthcare professionals felt there was more than just the wish to return to normal working life, there was some level of desire to contribute to society, especially according to the key informants practising clinical psychology. This motivation could be guided by some spiritual values where colorectal cancer survivors wanted to do something for society having been given a second chance to live after a battle with cancer. Many colorectal cancer survivors value their work as an opportunity to pay back to the society.

"I would expect a lecturer to retire after the treatment given her age but she stayed on giving lectures for the students on part time basis. That is truly a calling...certainly teaching is more than a job for her." (Primary Care Physician, government sector) One of the key informants also believed that humans need something meaningful in life and more than just existing.

"I know someone who was going against the odds to work again simply because he sees his work as a way to help others in the nursing home...perhaps it is what Maslow termed as self-actualisation needs at the top of Maslow's hierarchy of needs. The needs to seek personal growth and self fulfilment could have motivated him to consider working again." (Psychologist, government sector)

Another reason reported by the healthcare professionals was the financial reason to RTW. In view of the inflation and increased cost of living, many colorectal cancer survivors had no choice but to continue working in order to support their families. Thus, this was a common reason for many survivors to RTW, regardless of the positions they held in the organisations.

"Financial pressure is evident more so among those sole breadwinners in the family...For them, it is crucial to get back their job and being employed to support the entire family." (Primary Care Physician, government sector)

"I notice everyone is being affected by the increased cost of living...regardless whether one is in government or in private sector. Hence, keeping the job is crucial to have a reasonable quality of life." (Oncologist, private sector)

"Monthly steady salary is a real motivation to RTW even if the survivor has a spouse who is working. Many of the survivors whom I have met in the support group wanted to be financially independent and hence keeping their job." (Colorectal surgeon, private sector)

Another push for RTW among colorectal cancer survivors according to the healthcare professionals was the health insurance coverage by the organisation. All employees working in the private sectors have certain health insurance coverage of varying amount from the employers. This is one of the basic medical benefits offered to the employees throughout their employment. Employees working in managerial levels enjoy higher health insurance coverage as compared to those working in the clerical, sales and marketing.

"They are aware that the medical bills are not cheap...thus before they make any decision on their employment, they would usually enquire the Human Resource on the limit of their health insurance coverage for cancer. After all, they do not need to pay if the company's insurance covers for their cancer treatment and follow up." (Oncologist, private sector)

"The bigger and more established a company, the better the health insurance coverage offered to its employees. My patients knew that it is hard for them to get insured after being diagnosed with cancer...thus, they wanted to maintain the health insurance." (Oncologist, private sector)

Strict organisational policy on medical leave and performance allowed no room for complacency among colorectal cancer survivors and was the reason for them to RTW as early as possible. Medical leave and employees' performance were under great scrutiny by the human resource department and the supervisors after survivors' RTW. Strict organisational policy like shorter medical leave among the private sectors and the employees' performance based assessment were commonly termed as a "shape up or ship out policy."

"Medical benefits are good in most of the private companies, especially those listed companies. However, this does come with a price...Once the medical leaves are over; patients need to take unpaid leaves to rest or recuperating." (Occupational Health Physician, private sector)

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"I call that shape up or ship out company's policy which expects you to perform and meet those KPIs as you have completed the cancer treatment and received support to RTW from the organisation." (Occupational Health Physician, private sector)

Employers who provided support at the workplace as recommended by the healthcare professionals played a crucial role in the RTW process. Supportive and accommodating employers worked along with the healthcare professionals in preparing the survivors' RTW to workplace. Such important communication between employers and healthcare professionals made RTW as early as possible.

Rehabilitation practitioners shared their experience in helping RTW of a colorectal cancer survivor by modifying their work.

"I am glad that the employer took the effort to modify the job task for the patient...they did contact me and update me on the patient's progress in the workplace. Such understanding and supportive employer really helped me a lot." (Rehabilitation Physician, private sector)

"One of the concerns the employer had was how long they should practise the recommendation for modified work...flexi hours. I assured them these recommendations would be evaluated and changes would be made to slowly return the job to the employees. Once they are aware of the aim...they are usually very supportive and ready to work with us." (Rehabilitation Physician, private sector)

"Those survivors who had contacted their coordinator of Employee Assistance Programme as well as the Human Resource department from time to time managed to RTW without much issue. Perhaps, the constant communications allowed the employers to prepare new task, working schedule for them prior to their RTW." (Rehabilitation Physician, government sector) Colorectal cancer survivors with less demanding jobs were believed to have a smooth RTW. Participants suggested that survivors with work that demanded more physical effort like climbing, lifting and carrying heavy objects had a lower RTW rate compared to those working in mentally demanding jobs.

"Same type of treatments was given but patients working in office tend to be more ready to RTW and managed to cope with their work compared to those in assembly...and manufacturing industries. The difference could be due to the job demands were different in both groups." (Rehabilitation Physician, government sector)

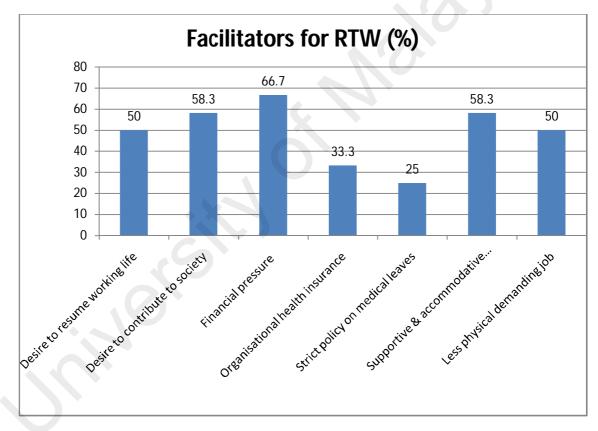


Figure 4.5: Facilitators for RTW as reported by healthcare professionals, n=12

#### 4.2.3 Findings from employers

We attempted to contact the employers of the colorectal cancer survivors to get their insight into the challenges and issues they faced while accepting the employees' back to work after cancer treatment. However, there were only four (25%) out of the sixteen

employers agreed to participate in the study conducted. Out of the four, two (50%) were from the government sector while the other two (50%) were from the private sector. The remaining five (55.5%) from the nine employers who had the experience of assisting employees' RTW after cancer, were recruited at the SOCSO National Return to Work Conference and Flexiwork conference and exhibition in Kuala Lumpur. The characteristics of those representing employers are shown in Table 4.4.

From the in-depth interview with those key informants of employers, there were seven themes for the barriers associated with RTW while five themes identified for facilitators in RTW.

	Government n (%)	Private sector: MNC	Private sector: SMI
		n (%)	n (%)
Field/Industries			
Services	3 (33.3)	-	-
Manufacturing	-	2 (22.2)	1 (11.1)
• Healthcare	-	1 (11.1)	-
Transportation	-	-	1(11.1)
• Education	-	-	1 (11.1)
Job title			
Administrative head	3 (33.3)	-	-
• Human resource	-	3 (33.3)	3 (33.3)
(HR)			
Existing RTW policy			
• Yes	_	3 (33.3)	1 (11.1)
• No	3 (33.3)	-	2 (22.2)
			_ ()
Experience in helping RTW			
• Yes	3 (33.3)	3 (33.3)	3 (33.3)
<ul> <li>No</li> </ul>	-	-	-
Employees' motivation			
to RTW			
after long medical leaves		- /	
• Highly motivated	-	2 (22.2)	2 (22.2)
Not motivated	1 (11.1)	-	1 (11.1)
• Uncertain	2 (22.2)	1 (11.1)	-

Table 4.4: Characteristics of key informants representing employers, N=9

Workplace support			
offered	1 (11.1)	3 (33.3)	3 (33.3)
Flexi hour	2 (22.2)	2 (22.2)	1 (11.1)
<ul> <li>Modified job</li> </ul>	-	1 (11.1)	-
• Work from home			

Barriers for RTW

Poor work performance was a barrier for RTW, according to two (22.2%) employers. They noticed the employees were not performing up to their organisations' expectation and target. However, they were unable to tell exactly what the reason was behind the change of work performance after the cancer.

"Despite all the supports given, some of them just didn't seem to be able to perform like before. That is very worrying especially when senior executive officers were involved and our group performance is affected." (HR manager, MNC)

"To be honest, we were not sure what could be the effect of chemo on his work performance. After few months, we still noticed the work is not as efficient as before. We just hope that he will be able to cope with all the work in the company." (HR manager, SMI)

Some of the employers complained that employees were more keen in getting SOCSO's compensation rather than planning and discussing on when to RTW. Quite a number of employees would prefer to get the pension from SOCSO instead of going back to work.

"...it is quite obvious. Many would try to apply for the pension from SOCSO. However, it is not easy to get such pension scheme, especially when SOCSO board thinks that you are still capable of earning your income by working." (Manager, SMI)

"SOCSO is not a charity or insurance company...that is what many don't understand. To them, it is their right to try and apply or even appeal when initial application got rejected." (HR manager, MNC) "From my experience, we had employee with long medical leaves and was not looking forward to work anymore as he was looking for financial assistance from agencies like SOCSO." (HR manager, MNC)

Long and paid medical leave is commonly associated with delay in resuming work among civil servants according to few participants. For civil servants, they get paid leave up to two years once diagnosed with cancer. Many key informants admitted that such long medical leave with paid salary are a hindrance for these civil servants returning to the workforce.

"For civil servants, we are entitled for two years paid leave. Thus, many employees would have chosen to rest during such long leaves." (Headmaster, government sector)

"When you are allowed to be away from work and get your salary for such a long time with no pressure to joining back work, I am not surprised when working again is not in the top priority." (Head of Department, government sector)

"It is not unusual for the staff to spend all the medical leaves entitled and just apply and wait to be medically boarded out." (Head of Department, government sector)

The attitude of some employees was considered as a barrier for successful RTW, based on comments from some key informants. Negative attitudes such as lack of motivation, commitment and responsibilities were associated with delayed RTW or extended medical leave. Such attitudes were not tolerable in most of the workplace, especially in high performing private organisations.

"We have good medical care for our staff. There are no reasons not to work again especially after the treatment and when there is no work restriction advice from the hospital. Hence, we take extended medical leaves very seriously. We do not want the negative attitudes of some staff affect the work culture." (HR manager, MNC)

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"All our staff with prolonged sick leaves need to report to respective supervisors who would then submit a report or summary to the human resource department. We do not tolerate poor attendance, bad working attitude among our staff especially when we have tried to help them." (HR manager, MNC)

However, there were times when employers felt helpless in matters pertaining to RTW after cancer treatment. They wanted to help their staff resuming work but they were not equipped with the right knowledge and skills required for that purpose. Very often, they did not find any useful guidance on workplace support nor assistance from the physicians' letter.

"We were hoping the treating doctor could comment on how long the staff should be away from work and the kind of support which we can offer once the staff enters workplace." (HR manager, MNC)

"We are not trained in such aspect...thus the lack of guidance is a major issue on how to really help them." (Manager, SMI)

"Among the common advice was light duty...personally, I think such advice is just too vague and it is hard to imagine how to help the staff by offering light work?" (HR manager, MNC)

The change of organisational policy could potentially ruin the chance to return to the same workplace for some survivors. From time to time, organisations undergo review and change of policy to meet their changing needs. This is true especially in private sectors which emphasis on productivity, efficiency and return of investment. As for the government sector, the main aim is to provide service to the public, rather than generating revenues from the services rendered.

"Sometimes it is about the timing. Some might just miss the boat to work again in the company soon after the management review its policy." (HR manager, MNC)

"When economic is not that good...many companies are downsizing their operations. So, chances are many might just lose their jobs...not because of the illness per se but the change of company's policy and direction." (HR manager, MNC)

While some key informants did not get guidance from healthcare professionals on helping survivors on work issues, there were others who reported they were unable to accommodate survivors as recommended by healthcare professionals.

"It is rather difficult to give a lecturer an alternative role in a university. The most practical step which we tried was flexi hours but then again for how long?" (Senior lecturer, government sector)

"We understand the purpose of job rotation and trial of modified job. But, it is not so easy and direct especially when our company is such a small scaled organisation. There is not much variety of jobs available for us to consider rotating on. It could be ideal in huge multinational companies with various departments...but just not ours." (Branch manager, SMI)

"When the staff is on sick leaves, the job is being taken over temporarily by the colleagues. Upon finishing the sick leaves, the staff returned and everyone was expecting some kind of relief of work burden rather than a continuation of job sharing." (Manager, SMI)

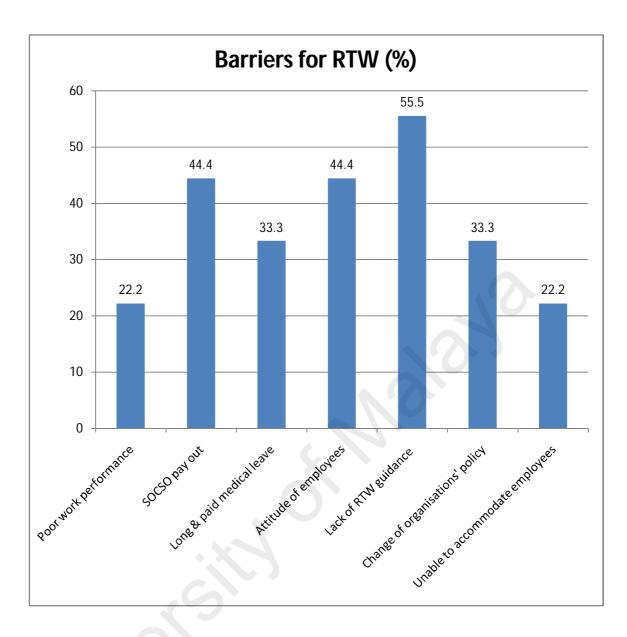


Figure 4.6: Barriers for RTW as reported by employers, n=9

#### Facilitators for RTW

Key informants from various organisations believed that one of the crucial facilitating factors for successful RTW was the motivation of employees who looked forward to resuming a normal life after treatment. A normal life to most motivated employees would mean going back to work, just like before being diagnosed with the illness. Such an intrinsic value of work for the employees helped in a smooth and timely RTW.

"Employees who are motivated and passionate about the work would return to workplace even before exhausting their medical leaves. We are very pleased to have such employees working with us." (HR manager, MNC)

"It is believed that self desire and motivation to work again after a brief period of illness helps in recovery. Perhaps, that was the reason why some of our staff joined back the organisation soon after the treatment. They were keen to work and gave no excuses due to illness in the workplace." (Branch manager, SMI)

Some private organisations have an Employee Assistance Programme (EAP) which aims to help employees handling work related issues. Such a service, at times is being given by a third party hired by the private organisations. Among the services offered in EAP, helping employees to get back to work at the right time by coordinating with all the stakeholders is part of their RTW programme.

"Our company has existing RTW policy and we do offer such RTW plan via our EAP, a programme which is rendered by a third party appointed by our company." (HR manager, MNC)

"All of our staff is aware of the line of reporting for medical leaves. We do not have issues on that. In fact, new staff are being briefed on the company's policy on medical leaves and return to work policy during the orientation." (HR manager, MNC)

"Big organisations certainly have some guidelines or policy on managing employees with long sick leaves. We have such policy that employee who has completed the medical leaves and still unfit to work to be referred for further evaluation and management via our EAP." (HR manager, MNC)

According to some key informants, the organisational benefits are the common facilitators to prompt RTW after a brief period of sick absenteeism. The benefits could

range from monetary like an annual bonus or some other forms, like the continuity of health insurance coverage.

"Some employees are very honest to admit that the benefit like health insurance motivates them to continue working with us." (HR manager, MNC)

"The yearly bonus and award for best employee are awarded to our much deserving staff. Good personalities, work performance and seniority in the workplace are taken into account." (HR manager, MNC)

"As long as the staff is capable of performing in the company, we do not penalise him or her by removing the benefits for our staff." (HR manager, MNC)

Feasibility to support and accommodate employees was a common comment among the key informants as well. Facilitating factors for successful RTW is much dependant on the size of the organisations, the variety of jobs available as well as the skills of the employees.

"Fortunately we could assign a office job for him after his cancer treatment which does not require him to work long hours and handle machinery." (HR manager, MNC)

"In order to introduce modified job, sometimes training is required. Thus, it is always best to let the staff carry out the same work. We monitor the work progress and performance either after the flexi hours or shorter working hours for these staff." (HR manager, MNC)

"There were times when we allowed employees to work from home for some time if travelling to work is not feasible after initial treatment." (HR manager, MNC)

Many key informants believed that good communication with healthcare professionals helps in planning a smooth RTW for the employees. The healthcare professionals must be able to identify the potential work issues before suggesting the employee to go back to work. Work issues can be safety issues given the hazards at the workplace and the ability for the employee to work in the same job again. Many employers appreciated the walk through survey carried out by healthcare professionals to understand the workplace.

"We have good experience working with the team from the hospital. Every referral was well written and good communication has been observed which helped in our planning for our staff." (HR manager, MNC)

"At times, the occupational safety doctor will carry out a workplace visit to understand the working condition before introducing any plan for the return of our staff." (HR manager, MNC)

"Good communication with the treating physician and team is a must to identify the potential areas that we need to look into when receiving our staff after illness. The common concerns are the hazards at workplace and the safety issue for the staff" (Branch manager, SMI)

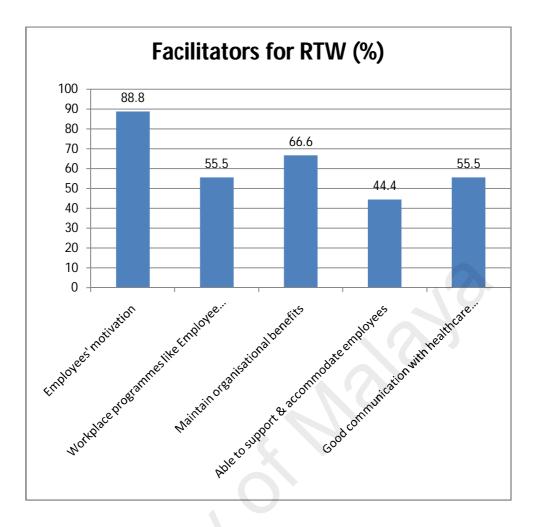


Figure 4.7: Facilitators for RTW as reported by employers, n=9

# 4.3 Phase III: Feasibility study of the proposed pathway for work-directed intervention

Feasibility assessment of this study was based on the findings from survey (quantitative) and in-depth interview (qualitative) with the key informants from the stakeholders. One of the important criteria for feasibility assessment is the acceptability of the flow and contents of the intervention by its stakeholders or users. Therefore, in this feasibility assessment, the researcher assessed the acceptability level using proxy indicators, which could be gauged by the Likert scales. At the same time, by carrying out in-depth interviews, the findings from the surveys could be supported and strengthened.

In this section, researcher reported the findings which included the participation rate, acceptability of the flow, material used and content of intervention (RTW Brochure, educational leaflet and fitness to work assessment report) which were gathered via the survey. The barriers, facilitators and areas of improvements for the work-directed intervention on RTW were emerged from the in-depth interview, as shown in Table 4.5 and Table 4.6.

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### Table 4.5: The perceptions of the work-directed intervention on RTW among the participants (n=42)

Participant's comments	n (%)
Comments on the flow and timing of intervention Essential effort in promoting continuity care for cancer survivors beyond the usual practice, which does not deviate from the current practice.	35 (83)
Offers the stakeholders a bigger picture and understanding their respective roles in RTW process through the algorithm.	25 (59.5
Emphasise on the importance of early contact with employer prior to medical treatment, allowing employer to make arrangements at workplace during survivor's cancer treatment.	38 (90.5
Good way to communicate and engage all stakeholders in assisting RTW process from the beginning till follow-up stage.	32 (76.2
Trial of RTW prior to engaging occupational health doctor is time and cost saving measures.	29 (69)
RTW meeting is an excellent platform to discuss the RTW plan among all stakeholders, prior to implementation. Specific goal, time frame for RTW plan is outlined and discussed in the meeting.	26 (62)
The intervention includes providing the right information, support and recommendations for RTW, allowing the colorectal cancer survivors to make informed decision and plan ahead after cancer diagnosis.	20 (47.6
Comments on the tasks outlined in RTW Brochure Tasks to be carried out by relevant stakeholders are clearly outlined in each stage of RTW.	15 (35.7
Important task in early stage of RTW is to enquire on the organisation policy on RTW as many are not aware of it.	11 (26.2
Treating physicians are not sure on the role of other healthcare professionals in assisting RTW process.	18 (42.9
Prefer the workplace visit to be carried out only if safety hazard is of concern during RTW process. Routine workplace visit as part of fitness to work assessment is not necessary and not cost effective.	25 (59.5
Referral to psychologist must be done without delay if survivor is found to have signs and symptoms of depression, anxiety as psychological barriers are common in RTW.	18 (42.8
The task to have new training and further assistance for survivor to RTW depends a lot on organisation resources and survivor's motivation.	10 (23.8

Comments on the contents of educational leaflet Educational leaflet is a useful tool and reminder for treating physician 15

	to discuss relevant topics during consultation.	(35.7)
	Information on myths about working again after cancer is informative, easy to understand and helpful as such information is usually not mentioned in other cancer related leaflets.	18 (42.8)
	Educational leaflet serves as a future reference for the survivors and also helps in equipping them mentally and physically throughout treatment and life after cancer.	11 (26.1)
Comme	ents on the contents of fitness to work assessment report Concern about confidentiality issues, especially in revealing the barriers to RTW, which may be perceived negatively by employers.	9 (21.4)
	Prefer the recommendations by occupational health doctor to be specific and well documented in the report, in terms of the expectation, time frame to achieve the RTW.	17 (40.5)
	Important findings and advice on RTW recorded in the report are essential for reference during follow-up to gauge the RTW progress.	28 (66.7)

## Table 4.6: Recommendations for improvement of work-directed intervention on RTW (n=42)

Participant's recommendations	n (%)
Comments on the flow and timing of intervention	
To consider integrating occupational health services as part of the care after treatment. This could be facilitated with early contact with occupational health doctor after diagnosis within the same healthcare facility providing cancer treatment.	10 (23.8)
Occupational health services could be a potential scope to be expanded in all tertiary medical centres in assisting RTW after treatment, as part of recovery process to improve Quality of Life (QoL).	17 (40.4)
To improve awareness on working again after cancer through the cancer resource centres. This could be done by furnishing relevant educational materials as well as inviting survivors who had successfully RTW after cancer as ambassador and motivator for others.	19 (45.2)
Comments on the RTW Brochure	
To list the relevant field of healthcare professionals who can assist in various stages of RTW after treatment.	8 (19.0
Comments on the educational leaflet To consider using pictures, infographics to describe the tips on managing colorectal cancer and work.	25 (59.5
Information in educational leaflet can be presented in visual form in CD or website. Certain information is best delivered with visual form, for example the types of exercises for cancer survivors.	23 (54.7
To include some basic physical activities (exercises) that could help survivors in coping with cancer related fatigue, as part of health promotion in cancer survivorship.	20 (47.6
To add in some testimonies from colorectal cancer survivors who had successfully RTW after cancer.	30 (71.4
Comments on the fitness to work assessment report	
To consider changing the term "barrier" to "motivation" as the former carries some negative connotations.	15 (35.7
	18

#### 4.3.1 Participation rate

From May 2013 until Feb 2014, healthcare professionals (colorectal surgeon, oncologist and occupational health doctor), colorectal cancer survivors and employers from private sectors were enrolled in this feasibility study. A total of forty three healthcare professionals, twenty three employers and twenty-five colorectal cancer survivors were eligible based on the inclusion criteria, identified during the recruitment period of time.

The participation rate among healthcare professionals was 46.5 percent, with a total of twenty among forty-three healthcare professionals took part in this study. Among the healthcare professionals, occupational health doctors made up half of the healthcare professionals who took part in this feasibility study while four colorectal surgeons (20%) and six oncologists (30%) were also involved. The researcher conducted the surveys and in-depth interviews with the twenty healthcare professionals in their respective offices. Out of the 23 healthcare professionals who did not participate, the common reasons gathered for non-participation were: too busy and unable to commit (34.8%), fear of medico-legal implications (26%), RTW is not within the scope of duty (17.4%), and could not be reached (13%).

A total of twenty-three employers met the inclusion criteria but only eleven of these employers agreed to take part in this feasibility study. Hence, the participation rate among employers was 47.8 percent, slightly higher than healthcare professionals (46.5%) and colorectal cancer survivors (44%). Employers from multinational companies, MNC (n=4) as well as small medium industries, SMI (n=7) showed mixed responses and interests in the RTW topic. Non-participation among employers was due to the beliefs that: existing policy is good enough (41.7%), it is the responsibility of the employee and treating physician to undertake the RTW process (33.3%), and having limited role in assisting the RTW process (16.7%).

Employed colorectal cancer survivors were recruited from oncological and surgical clinics in hospitals which offer cancer treatment, with a participation rate of 44 percent. Researcher encountered various challenges in recruiting employed or previously employed colorectal cancer survivors. Some of the common challenges faced were: reluctance to discuss cancer experience (42.8%), RTW is a personal choice (28.6%), not interested (21.4%), and unable to contact by phone (14.3%).

There was an indication that participants who entered this study were younger, they still had many years before retirement (colorectal cancer survivors), they appreciated the RTW process, were aware of the importance of work after illness, and were interested to learn more about RTW assistance (healthcare professionals and employers).

#### **4.3.2** Flow and timing of intervention

The participants were asked to grade the flow and timing of the proposed intervention between the score of 1 (very poor) to 10 (very good). Overall, the flow and timing of intervention proved to be feasible. The majority of the participants graded the flow and timing of intervention above average with a mean of 8.1 among healthcare professionals, 6.7 among employers and 7.3 among colorectal cancer survivors.

Healthcare professionals graded the flow and timing with a range of scores from 6 to 9. The majority of the healthcare professionals believed that the flow of intervention promotes continuity of the care for survivors from diagnosis to the end of treatment, covering aspects beyond usual treatment. An algorithm which depicts the flow of intervention allows participants to see the bigger picture and the significance of roles played by all the stakeholders in the RTW process. Some healthcare professionals also believed that the flow outlined in the intervention, the use of the RTW brochure and educational leaflet could improve the communication between colorectal cancer survivors, employers and the treating physicians. Some oncologists and colorectal

surgeons were of the opinion that their role is predominantly about treating the survivors, and discussion on RTW should be initiated by the survivors. However, they agreed to encourage survivors to consider working again when the survivors are ready. All healthcare professionals understood the importance of colorectal cancer survivors having early contact with their employer during medical leave. Early contact is feasible according to most healthcare professionals as the employer would be informed by the treating physicians before starting the cancer treatment, which is covered by the organisational healthcare insurance. Three occupational health doctors (15%) suggested that early contact with occupational health doctors after diagnosis could be very helpful and feasible, especially when such service is available within the same medical centre where the survivor is receiving treatment. Proper guidance could be introduced to the survivors in preparing for cancer treatment and coping with working life after therapy. Though occupational health services are not available in government hospitals, timely RTW could still be achieved for those survivors seeking cancer treatment there if early contact and trial of RTW was followed, according to some occupational health doctors.

"This kind of guidance ensures continuity in care, from diagnosis till after treatment, during the period of cancer survivorship." (Oncologist, government sector)

"Flow chart gives a general guideline in each stage of transition upon returning to work." (Occupational Health Physician, private sector)

"Using material like educational leaflet and brochure on return to work would help in equipping the survivors to prepare mentally and physically on work resumption upon treatment." (Colorectal surgeon, private sector)

"The discussion on work should be initiated by the patients as the decision is a personal choice. Only when they bring up the topic, then the flow of the intervention could begin." (Oncologist, private sector)

Employers who took part in the study also valued the flow and timing of the intervention, rating it between 5 to 8. They viewed such flow and timing of the intervention allowed the organisation to prepare in advance in the absence of survivors during cancer treatment. Such an arrangement is crucial to them in order to maintain the productivity of the organisation. Some of the participants shared their concern about a trial of RTW for the colorectal cancer survivors upon completion of treatment. For most of the employers, unless stated otherwise, a trial of RTW meant allowing the employee to resume their usual role in the workplace without restrictions. They believed the immediate supervisor for the employee is in the best position to monitor the trial of RTW. The trial of RTW must be carried out within a period of time (within one month) and should not disrupt the work of others in the workplace. Five of the participants (45%) believed that the trial of RTW before engaging occupational health services was time saving and may avoid unnecessary fitness assessments for RTW in cases with no issues about RTW at all. Besides that, a trial of RTW also gives these employers some time to engage the occupational health services in the event of an unsuccessful trial of RTW. The collaborative effort in the RTW meeting would help them in assisting the survivor's RTW, which would also consider any additional support or referral needed during the RTW process.

"For the organisation to prepare for a worker to go for long medical leaves, we need to be informed once the worker gets the diagnosis confirmed...This is to ensure the productivity of the workplace is not affected" (HR manager, MNC)

"Trial of return to work should be monitored by the direct supervisor, if it means doing the exact same task in the workplace" (HR manager, MNC) "This intervention suggests self-monitor the progress of trial of return to work...and this approach could potentially save time and effort in engaging occupational health services" (HR manager, MNC)

"The meeting to discuss on the return to work plan is excellent idea as all would be briefed on the recommendation on work resumption" (Manager, SMI)

Colorectal cancer survivors graded the score between 4-7 in terms of the flow and timing of the intervention. Overall, participants were able to appreciate and understand the flow and timing of the intervention; that is to contact employer prior to treatment, and maintain contact with employer during treatment. For many of them, the top priority after being diagnosed with colorectal cancer was to decide on the treatment regime and treatment centre. More than half of the colorectal cancer survivors (81.8%) admitted that they were seeking various second opinions from different medical centres before making the decision on treatment. While RTW may not be their priority soon after diagnosis, they agreed that early contact with the employer was able to be established as their cancer treatment was covered by the organisational health insurance. Hence, they viewed the objective of contacting employer before treatment was achievable, though they may not contact the employer by themselves. Psychological barriers were cited as a common obstacle for early RTW. Hence, participants valued the provision of a trial of RTW, the additional support, as well as referrals to assist RTW. Participants gave mixed responses on the duration for a trial of RTW, ranging from 4 weeks to 10 weeks for them to prepare resuming work after cancer. Some of them also voiced their safety and health concern during a trial of RTW and they hoped the employer would address those issues. Participants also noted the intervention encourages communication between treating physicians and the employer which also helps colorectal cancer survivors to gather information, support and recommendations for RTW throughout the RTW process.

"Usually cancer patients, like me would go around asking for second opinion on the treatment of choice...but employer would be informed prior to the treatment as they need to process the medical insurance." (Male, colorectal cancer survivor, RTW, private sector)

"Trial of return to work may not be that direct as I work in height and sometimes working in shift...so safety is a great concern, especially after the treatment." (Male, colorectal cancer survivor, NRTW, private sector)

#### 4.3.3 Perceptions on the tasks outlined in RTW Brochure

Perceptions of the participants on the tasks outlined in the RTW Brochure offered the researcher information about the practicality of the tasks recommended at various stages of RTW. Such perceptions were explored in various categories: level of agreement, and level of helpfulness and priority, using a Likert scale and an interview.

Agree (4) or strongly agree (5) means participant agrees to carry out the particular task. When a participant answers the recommended task is somewhat helpful (3) or very helpful (4) or extremely helpful (5), the participant believes that the task is helpful to achieve successful, timely RTW. Level of priority, ranging from medium (3) to essential (5) points towards the importance of the recommended task to achieve successful RTW according to the participant.

The work-related guidance outlined in the RTW Brochure for colorectal cancer survivors only covers the tasks to be carried out by survivors soon after diagnosis. These tasks are related to health, finance and early communication with employer. For health related tasks, all participants ranked obtaining a treatment plan before starting treatment and understanding the potential treatment effects, and impact on work as top priority, compared to enquiring about the expected duration to be away from work (36%). After diagnosis, they spent time to consider the treatment options available and were in no hurry to RTW as their medical leaves were sufficient for them to complete treatment. Despite that, more than half of the participants (55%) believed that enquiring about the expected duration to be away from work would facilitate the RTW process, especially if they had prepared mentally. However, only five participants (45%) agreed to find out more on the duration of treatment which would require them to be away from work. This was due to the duration taken for them to come to terms after being diagnosed with cancer and also to seek for second opinion on treatment options available. Enquiring with the employer on the financial implications following cancer was considered as a priority task which eight of them (73%) agreed to carry out, and believed it is helpful to achieve timely RTW. As for the early communication with employer, all participants agreed that informing the employer about the diagnosis could be facilitated with the medical report and RTW Brochure provided by the treating physicians. They also considered early communication with the employer was a high priority task; though some participants shared they would just inform their immediate supervisor by phone, then followed by sending all the medical report and documents required for insurance claim. Participants believed that finding out the organisational policy on RTW could be helpful in the RTW process (55%) and regarded that task as important (73%). However, four participants stated that not all organisations have a RTW policy as compared to an occupational and safety policy.

"Soon after the diagnosis, I spent most of the time considering what treatment to receive and from which treatment centre...That was my top priority, not so much concern on the medical leaves." (Male, colorectal cancer survivor, RTW, private sector)

"Frankly speaking, I took some time to accept the diagnosis and to decide what treatment to get...Thus; employer was only informed when I had made up my mind to start treatment. It would be better to keep them updated as suggested in the RTW Brochure as company need to prepare for my medical leaves." (Female, colorectal cancer survivor, RTW, private sector)

"Getting the detailed treatment plan and knowing the possible treatment side effects helped me to prepare myself mentally and also physically as I knew the treatment was meant to cure the cancer. The recommended tasks would be of help for survivors like me who want to resume working life after treatment." (Female, colorectal cancer survivor, RTW, private sector)

"The recommended task to find out the return to work policy is good, but not all companies have such policy in placed." (Male, colorectal cancer survivor, NRTW, private sector)

Tasks outlined for healthcare professionals start from after diagnosis being made, after primary treatment until the RTW follow up stage. Each of the stages involves healthcare professionals from different specialities. Hence, it is not surprising that only healthcare professionals from relevant specialities responded for "the level of agreement" for the particular tasks. Tasks involved in the early stage of RTW are related to the health of the survivors, and also early communication with employer. All healthcare professionals suggested that educating survivors on treatment effects, and coping strategies by using the educational leaflet was very helpful and included important tasks. While educating survivors on treatment effects has been part of their usual practice, not many treating oncologists or colorectal surgeons have used any particular educational tool for that purpose. However, they welcomed the use of an educational leaflet, which may help in answering most of the questions asked by the survivors. Discussing survivors' overall physical and mental health was quite a challenge to some treating physicians as many survivors did not open up on that topic. Hence, the task was not rated as important by some of the treating physicians. Physical rather than mental health was given more attention by physicians especially when it comes to considering a mode of cancer treatment. Healthcare professionals believed the use of the RTW algorithm is helpful to facilitate discussion on RTW and should be given priority. All of them considered the task to encourage survivors to keep contact with their employer during medical leaves is essential and most of them are doing that. The task of informing survivors on the role of the occupational health doctor, rehab physician and psychologist in the RTW process received mixed responses among treating physicians as some of them admitted that they are not too sure what services these professionals could offer in the RTW process. Therefore, they welcomed the RTW algorithm and guidance in the RTW Brochure which outlined who the survivor could seek help from in the process of RTW. While preparing RTW, not all healthcare professionals agreed upon the need to carry out a workplace visit as a routine task. However, they believed that if indicated, the workplace visit would be of help to the RTW process. Occupational health doctors strongly agreed on the need to identify barriers for RTW, assessment of fitness to work, and addressing safety issues with the employer while preparing the survivor's RTW. They could identify with their role in assisting RTW and using the fitness to work assessment report was helpful in documenting all the findings in an assessment and workplace visit, if any. Using the RTW meeting as a platform to engage the employer and survivor has been viewed as a cornerstone for a successful RTW, according to many occupational health doctors. They considered the RTW meeting as an avenue for all stakeholders to discuss the RTW in detail and commit to the agreed written RTW plan. Assessment of RTW intention, self perceived work ability and barriers to RTW at baseline and during the follow up stage is important and helpful as it gives the occupational health doctor an objective assessment on the progress of the RTW process. All healthcare professionals agreed that referral to

other healthcare professionals is essential during follow-up and it must be done without delay. According to them, a clinical psychologist or psychiatrist specialising in oncology would be of help when survivors face psychological barriers in RTW.

"Educational leaflets are not new but not many touch on the impact on work and also the myths of working again after cancer. So, I believe this is a useful and important educational tool during discussion on management of cancer, treatment and work." (Oncologist, private sector)

"The flow of this return to work intervention clearly outlines the various stages of work transition and at which stage the healthcare professionals could be of help. With this intervention, I understand the role of occupational health doctor in returning workers to workplace." (Colorectal surgeon, private sector)

"Workplace visit is not done routinely, but only when we need to assess the workplace, especially on the safety aspects of the working environment." (Occupational Health Physician, private sector)

Most of the employers agreed that successful RTW starts with early communication and planning. They gave emphasis on workplace productivity as well as the well-being of employees. Employers suggested that the onus to initiate and contact the employer lies with the newly diagnosed cancer employee who would require medical leave for treatment. The tasks of providing the information on medical insurance, organisational policy, and supporting employees with their RTW and making arrangements for a trial RTW after employees have completed treatment were considered the priority and important roles of the HR department once initial contact has been initiated. Depending on the size of the organisation, the support for employees varies. Some of the established organisations have Employee Assistance Programme (EAP) which is part of the support services for the employees. Employers from smaller organisations may not have a clearly written workplace support but they agreed on the importance and helpfulness of such assistance to employees who RTW after medical treatment. At the moment, there are no standards for assisting survivors RTW after colorectal cancer treatment, according to those employers who were interviewed. Many of them are dependent on the medical report and readiness of the survivors to RTW. Therefore, they viewed the RTW Brochure as a potentially helpful tool for them in improving the RTW outcome. Overall, all of the employers understood the importance and helpfulness of communication with occupational health doctors during and after drawing up the written RTW plan. However, not all of them agreed upon the need to carry out a workplace visit on the routine basis. To them, the medical report from the treating physicians or the fitness to work assessment report from the occupational health doctor should suffice to recommend the RTW plan. This is partly due to the fact that the employers do not see any potential safety hazards within the workplace which could hamper the RTW process. But, employers are aware of the Occupational Safety and Health Act (OSHA 1994) and agree to ensure the safety of the employees. As such, they strongly agreed the workplace visit should be carried out if there is real safety hazard concern prior to RTW. The task of considering new training for an employee if the initial work adaptation fails, received mixed responses from employers. Many believed that training and retraining depended on the employee's motivation as well as the resources available in the organisation. Assigning new tasks for survivors in the event of an unsuccessful initial RTW recommendation may not be feasible in small organisations where the choice of tasks is limited.

"Employee need to inform us in HR prior to receiving the company's medical benefit...It is certainly the responsibility of the employee to keep us updated prior to and after the treatment." (HR manager, MNC)

"I would strongly support the trial of return to work before engaging the occupational health services...Besides that, the workplace visit may only be necessary if there is a safety or hazard concern which would be highlighted by our safety health officer." (HR manager, MNC)

"For medium industries without established employee support programme, this intervention has provided a guideline to self monitor the initial trial of return to work. I would stay that is both cost and time saving measure." (Manager, SMI)

"There are not many tasks available in the job scope within our organisation. Hence, the limited resources may be a problem in introducing the new task for employee...Apart from resources, the employee's motivation in return to work is also an important factor." (Manager, SMI)

#### 4.3.4 Educational leaflet as an educational tool

Healthcare professionals and colorectal cancer survivors rated the usefulness of the educational leaflet between 6 to 8. Treating physicians acknowledged the usefulness of the educational leaflet in addressing various issues related to cancer and life after cancer. It serves as a reminder for treating physicians during the consultation to cover the most frequently asked questions by survivors. The section covering the myths about working again was very relevant for the survivors' journey through the cancer treatment and rehabilitation. Information found in the educational leaflet is easy to understand as it is in simple language. Suggestions to improve include using pictures or graphics to depict the basic tips on managing the colorectal cancer in workplace. Many healthcare professionals believed the use of graphics could reach more survivors in a more impactful manner. There were also recommendations to add in some tips on basic physical activities that could help survivors in coping with cancer related fatigue. Such basic tips on exercise could be added in the educational leaflet as well as presented in

the visual form in a CD or website, as part of the health promotion during cancer survivorship. Some healthcare professionals (45%) also suggested including some testimonies from colorectal cancer survivors who had successfully RTW in the educational leaflet too.

"Educational leaflet is informative and provides relevant tips for colorectal cancer survivors preparing to work again. Perhaps, the basic tips on management of cancer and work could be depicted with some pictures or graphics, rather than just words." (Colorectal surgeon, private sector)

"Some basic physical activities or exercises may be added in the educational leaflet, CD or even in the website promoting healthy lifestyle during cancer survivorship as well as a way to combat the cancer related fatigue." (Oncologist, private sector)

"Some good testimonies and case studies on successful return to work among members of cancer support group could be documented and shared in the educational leaflet as well." (Colorectal surgeon, private sector)

Among the colorectal cancer survivors, the educational leaflet was found to be very helpful (80% scored about 6 out of 10) in preparing them from the stage of being diagnosed until the actual RTW stage. They noted the relevant and important information on myths of working again, and the management of cancer and work, which are usually not covered in most of the educational leaflets. Some of the survivors also believed the educational leaflet could equip them to be mentally and physically prepared for treatment and life after cancer. Hence, it indirectly empowered them to relook at their lifestyle and adopt a more positive way of life after cancer diagnosis. Though many of the survivors preferred not to think of RTW issues during the treatment phase, they however perceived the importance of being briefed on those potential work-related issues and having a printed educational leaflet would serve the purpose well. Some of these survivors recommended the educational leaflet be made available online for future reference as they fear they might misplace the leaflet after the consultation in the clinic.

"The basic tips on working again after cancer are important though during the initial stage, work was not my top priority. So, it may be useful if such information is published online for future reference." (Female, colorectal cancer survivor, RTW, private sector)

"To me the educational leaflet serves as a reminder to live a healthier life after cancer...it gives some positive messages to face the survivorship." (Male, colorectal cancer survivor, RTW, private sector)

#### 4.3.5 Perceptions on the fitness to work assessment report

All participants understood the purpose of fitness to work assessment as a component of work-related RTW intervention. The report comes with recommendations for RTW, upon considering the survivor's physical, mental health status, intention, motivation, barrier to RTW along with the safety concerns in the workplace.

Colorectal cancer survivors rated the assessment report of average value, between 4 to 6 (mean=5.3), relatively lower than healthcare professionals' rating (mean=7.6). Three of the survivors (27%) were not comfortable with the column which states barriers to RTW. They were worried that those challenges related to RTW could be viewed by their employers negatively as excuses to extend medical leave. That would indirectly discourage them to openly share their perceived barriers in relation to RTW. There was also fear expressed about being discriminated or ostracised by the co-workers if their RTW was not well handled by management and supervisors. The advice on fitness to work with either "Not Fit" or "May be Fit" could be elaborated further, especially when the survivor is found not fit to perform the usual work. Though the plan for "Not Fit" is outlined in the algorithm, survivors believed that if the plan is written in the assessment

report, the employer would take it more seriously. They also would like the occupational health doctor to explain to them the various recommendations on RTW and the expectations from these recommendations within a specific time frame. Many of the survivors would like to know the outcome of the fitness to work assessment from the occupational health doctor who assessed them. They preferred not to get the report from their employer or supervisor without having been informed about the recommendation offered to RTW.

"It is a dilemma when it comes to opening up on the barriers for work resumption...The fear of the challenges faced by us could be interpreted by workplace as excuses and laziness to work again." (Female, colorectal cancer survivor, NRTW, private sector)

"I would prefer the occupational health doctor to inform me the outcome and the plan of return to work if I was found to be "Not fit" to perform my work...before it is being discussed in the meeting with my employer." (Male, colorectal cancer survivor, NRTW, private sector)

Healthcare professionals valued the fitness to work assessment report as an important document which states the advice on fitness to work. Occupational health doctors strongly agreed on the use of the form, which clearly outlines the important parameters in deciding the fitness to RTW. The self perceived work ability may need further explanation by the occupational health doctor before requesting survivors to rate the scores. Barriers to RTW are expected to be more psychological in nature. Therefore, the majority of the occupational health doctors prefer to mention the psychological status of the survivor in preparing to RTW. However, they were of a different opinion on how much to reveal about the psychological barriers, keeping in mind that such a revelation may lead to unnecessary worry in the workplace. For example, psychological barriers could be related to anxiety of working again, not being confident of work performance,

fear of workplace discrimination and poor concentration as a result of treatment effects. All occupational health doctors agreed that the main objective is to facilitate the RTW process and psychological barriers may take time to resolve. Therefore, there were some (55%) suggestions to replace the "barrier" with "motivation" as the latter carries a more positive connotation. "Motivation" would appear to many as a modifiable factor while barriers may be modifiable or otherwise. Comments such as "survivor has shown motivation towards RTW" or "survivor's motivation has been improving ever since RTW recommendation was introduced" would not put the employer in dilemma on what to do if the barriers identified are not fully understood by them. In addressing the potential hazards at workplace, it is thought to be more helpful for the occupational health doctor to specifically mention the tasks within the job scope of the survivor to be avoided, rather than listing the various categories of hazards. For example, if the survivor still complains of poor concentration and focus in the early stages of RTW, tasks like working at height, operating machinery must be avoided for safety reasons.

"This fitness to work assessment report can serve as an important document for followup and future reference. The concept of work ability must be explained by assessor before asking the survivor to score it." (Occupational Health Physician, private sector)

"The barriers for return to work most likely are due to psychological in nature and these barriers like anxiety, poor concentration and cognition will take time to resolve...Such information are sensitive and must be handled with caution to avoid unnecessary worry in the workplace." (Occupational Health Physician, private sector)

"Perhaps survivors will be more willing to open up if we were to ask about motivation rather than barriers in returning to work." (Occupational Health Physician, private sector) Employers were more concerned about the outcome of the assessment for fitness to work. More than half of them wanted to know their role upon receiving such a report from the occupational health doctor. They understood the recommendations were made based on the barriers identified and potential safety concerns at workplace. Despite that, they were looking for more specific recommendations beyond the four options outlined in the report. To avoid any miscommunication on that, they suggested the occupational health doctor to put it in words (preferably type) the expected roles played by the employer upon receiving that report. The RTW meeting, according to them is a good avenue to clear all the ambiguities pertaining to the survivor's RTW. Employers also emphasised the importance and need for the commitment of the survivors in implementing the RTW plan. Many of them voiced their concerns over the need to carry out the various types of RTW recommendations in the fitness to work assessment report. They could understand the "Phased RTW" and "Altered hours" but "Amended duties" and "Workplace adaptations" according to them would incur some degree of expense. Hence, employers preferred "Phased RTW" and "Altered hours" to be considered first. To them, both are feasible for survivors who were stationed in the office workplace and some of them had introduced working from home as part of "Phased RTW".

"We welcome this type of report especially when it comes with clear recommendation on return to work. It would be great if occupational health doctor could specifically outline our role in accommodating the survivor's return. That would be helpful as compared to "light duty" which we usually get." (HR manager, MNC)

"Workplace adaptation and amended duties are the two recommendations that would involve high costs and we might not be able to accommodate that in view of limited resources." (Manager, SMI)

#### **CHAPTER 5: DISCUSSION**

This chapter on discussion compares the findings from this study with other studies on RTW, regardless of study design. Many factors associated with RTW are neither tangible nor measureable, as reported from the Phase I of the study. This prompted the researcher to carry out the qualitative component in the second phase of the study, with the aim to explore more factors in relation to barriers and facilitators, which were not quantifiable in the quantitative studies. In Phase III, the feasibility study, the researcher also discussed the mixed-method approach employed in gauging the perceptions and recommendations from the stakeholders on the flow, contents of material used in the work-directed intervention on RTW.

The challenges encountered in carrying out the study are also highlighted in this section. Apart from that, the strengths and limitations of the research are also explored, based on

the research methodology employed in different stage of the study.

#### **5.1 Phase I: Systematic review**

Work reintegration upon cancer treatment is an important milestone and determinant of quality of life (QoL) under the category of level of independence. The World Health Organisation (WHO) defines QoL as the individual's perceptions of their position in life considering the value and culture system where they live and in relation to their expectations, goal, standards and concerns. It is a broad spectrum concept affecting an individual's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment in a complex manner ("WHOQOL Measuring Quality of Life ", 1997 ). Thus, QoL is relative, subjective and has intangible components such as overall wellbeing and happiness, being employed is no doubt part of it (Veenhoven, 2013).

Selected articles for the systematic review were characterised by a high degree of heterogeneity in terms of patients' characteristics, cancer sites, mode of treatment, the RTW rate which ranged from 45 percent to 89 percent, with an average of two years after the cancer diagnosis. Despite the advanced medical treatments that offer a good outcome for cancer patients, there are quite a number of cancer survivors who ended up unemployed, retired early or changed jobs more often than those without cancer instead of returning to their work (Bradley & Bednarek, 2002; Maunsell et al., 2004; Short et al., 2005). Very often, the reasons for not returning to work were not medically related, for example issues on health insurance, lack of understanding from colleagues at workplace and the physical nature of their work, and other problems that led to survivors leaving the job (Feldman, 1978). The loss of income as a result of unemployment could lead to a decline in standard of living of the individual or their entire house-hold which in turn affects both the physical and mental health of unemployed workers (Bjorklund, 1985). Being unemployed not only results in a drop in status among friends and family but the society at large which could potentially lead to a loss of self-esteem (Bjorklund, 1985). The loss of societal engagement and shrinking of social networks due to unemployment could bring about a decline in individual wellbeing as well (Helliwell & Putnam, 2004).

Most of the existing studies examined the factors in relation to RTW under three main themes: socio demographic or personal factors, disease related factors and work related factors (Spelten et al., 2003b; Taskila & Lindbohm, 2007). However, this review aimed at identifying various factors beyond these three themes from studies published in journals over a span of 23 years. A total of ten factors were identified from the 22 selected studies in terms of patients' characteristics, types of studies and methodology. To our knowledge, this is the first systematic review on cancer survivors and RTW that has examined both qualitative and quantitative studies, given that qualitative studies could offer an insight into areas which were not covered in quantitative research. Interestingly, all the quantitative studies mentioned three factors which were disease stages, socio-demographic and working environment, while qualitative studies explored many other factors which were not addressed and were unable to be measured in quantitative studies, for example support from friends and family (Main et al., 2005), priority and perception towards work (Johnsson et al., 2010; Kennedy et al., 2007; Nachreiner et al., 2007), advice from healthcare professionals (Kennedy et al., 2007; Nachreiner et al., 2007; Yarker et al., 2010) and self-perceived work ability (Kennedy et al., 2007).

Poor health status as a result of cancer, treatment and existing co-morbidities were consistently found to have a negative association with employment status. Cancer related fatigue is one of the most researched symptoms besides other equally relevant symptoms like depression, psychological distress, insomnia and cognitive impairment. Fatigue could be due to psychological (depression) and physical causes (insomnia). Thus, fatigue has been known to be the most common and debilitating symptom in cancer patients with an impact in various work settings given its long term effect (Curt, 2001), and the fatigue level independently predicts the duration needed for a cancer patient to return to the workforce (Spelten et al., 2003b). Therefore, cancer survivors must be aware of the likelihood of worsening fatigue levels following cancer treatment, which could put them at risk of extending their medical leave.

Different modalities of cancer treatment have been shown to have unfavourable employment outcomes in terms of delayed in RTW, limited RTW or even unemployment mainly due to the effects of the treatment like fatigue, scar pain and disability (Ahn et al., 2009; Fantoni et al., 2010; Sanchez et al., 2004). Long term effects of treatment and illness after RTW were only highlighted in one study (Yarker et al., 2010) while other studies were mainly cross sectional that reported negative associations between cancer treatment and RTW. Compared to other modes of treatment, chemotherapy has been frequently linked with symptoms like fatigue, cognitive impairment and treatment induced menopause (Fan et al., 2005; Stewart, Bielajew, Collins, Parkinson & Tomiak, 2006). It has also been suggested that patients who experienced the treatment-related symptoms reported poorer QoL significantly, though most studies focused mainly on fatigue symptoms (Fan et al., 2005).

The source of health insurance proved to be an important consideration in returning to the workplace. Having a private insurance coverage for cancer patients at work could motivate them to return to the organisation (Gordon et al., 2008), while those having an alternative source of health insurance from their spouse and/or public insurance were less pressured to resume work (Earle et al., 2010).

Most studies consistently reported positive associations of workplace accommodation and adjustment, along with supportive employers and co-workers with employment outcomes in cancer survivors. Only Fantoni et al. (2009) examined the work related factors in three different aspects: physical, psychological and organisational constraints. Physical demanding and manual labour work was frequently reported as negatively associated with RTW. However, the association between sedentary work and RTW was not reported. Discrimination at the workplace was not related to RTW and it did not appear to be a more prevalent issue among cancer survivors than those without cancer (Ehrmann-Feldmann, Spitzer, Del Greco & Desmeules, 1987). This could be due to the legal provision against discrimination at the workplace in countries like USA. Contrary to that finding, Bouknight et al. (2006) found that breast cancer patients in Detroit, USA who perceived employer discrimination at the workplace were three times less likely to RTW than those who did not perceive discrimination. Besides that, survivors in European studies performed better at returning to work than those in North American studies, suggesting that job discrimination in the USA may be higher than in Europe (de Boer, Verbeek, & van Dijik, 2006).

There was variation in responses to working life after cancer diagnosis as some did not report sick at all while some had never returned to workplace. Such variation could be due to different perceptions towards work. A change in the perceptions towards work is expected after cancer diagnosis. Some patients recognised work as part of their identity, part of normality, a healthy distraction, or valuable for accomplishment and self-worth (Johnsson et al., 2010; Main et al., 2005). Altered attitudes might suggest a change of outlook and priorities in life as a whole. Therefore, despite having recovered completely from cancer, work may no longer be the top priority for some, after re-evaluating their priorites and rethinking the meaning of life (Nachreiner et al., 2007).

Common methodological weaknesses were observed in most of the studies selected for the systematic review: no mention of power and sample size calculation, unjustified recruitment strategy and choice of location as well the issue of transferability of the research findings. Only a few studies included population-based follow up with a group of cancer patients and controlled potential confounders. In addition to that, the lack of common standardised measures has been reported in assessing work ability and employment outcomes in various studies. However, despite the limitations, factors that promote RTW are similar: a supportive work environment, support from family and friends, and financial pressure along with health insurance coverage. Poor health status, attributable to the illness or treatment characterised by fatigue, cognitive impairment and depression, apart from physical demanding jobs, are negatively associated with RTW.

The International Classification of Functioning, Disability and Health model by WHO describes work as a role which one can participate in society (WHO, 2001). It examines

how a person copes with disability which is related to the ability to perform activities, which in turn is dependent by the appropriate functioning of the body. This model emphasises health conditions (disease/disorder), environmental factors and personal factors in relation to work participation. From the systematic review, it has been shown that the decision to RTW was based on more than these three factors, more importantly; some of the factors were not medically related and not easily modifiable (Figure 5.1). The RTW framework was developed from systematic review on all types of cancer, except childhood and occupational cancer. The potential relevance of such findings on local colorectal cancer survivors may be further enhanced by exploring the various barriers and facilitators associated with RTW. The second phase of this study aimed at achieving this, in order to gather more evidences in developing the intervention on RTW.

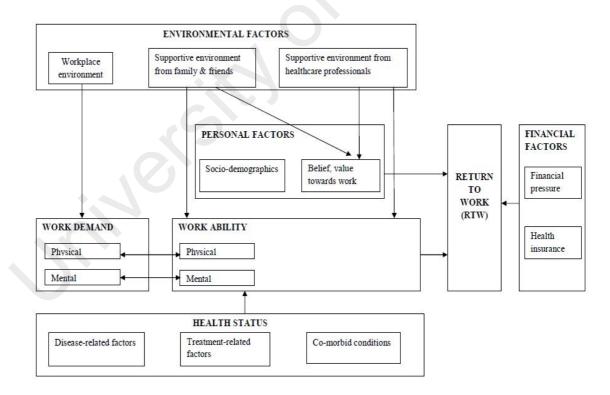


Figure 5.1: RTW framework identifies potential modifiable factors

# for RTW among cancer survivors

### **5.2 Phase II: In-depth interview (Qualitative Research)**

This section focuses on the findings from the qualitative study as compared to other similar studies. Four main themes that generated from the qualitative interviews with colorectal cancer survivors, healthcare professionals and employers were presented. These themes answered the specific research questions on barriers and facilitators associated with RTW among local colorectal cancer survivors. From the findings, the predictors for RTW and non-RTW were outlined and potential modifiable factors were identified.

The barriers and facilitators associated with RTW were found to be consistently different among those working in the government sector compared to those in private sectors. This is evident from the input from all the key informants of colorectal cancer survivors, healthcare professionals and employers, regardless of gender. All key informants agreed that intervention needs to be improved in order to assist employees to resume work after cancer. However, not many key informants offered insights into areas to be improved upon and recommendations on future intervention.

Findings from the Phase II qualitative study revealed that colorectal cancer survivors encountered various issues related to RTW, from preparing to RTW, during RTW and after RTW stages. Similarly, up to 73 percent of employed patients experienced work-related problems (de Boer et al., 2011). Gordon et al. (2014) reported that while many individuals were able to RTW by 12 months (some were working through their treatment regimes), many changes occurred among individuals who RTW, irrespective of genders. Among the work-related changes that took place were job losses, changes in job tasks, employer accommodations and reduced working duration.

Our qualitative study revealed several emerging themes on RTW which were grouped into four main categories-personal factors, environmental factors, financial factors and

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work related factors. These categories would answer the specific research questions on barriers and facilitators associated with RTW.

### **5.2.1 Personal factors**

The personal experience in coping with the side effects of cancer treatment exerts a strong influence on the survivors' RTW. These factors served as key barriers which hindered the early RTW among survivors, regardless of gender and ethnicity. Side effects affecting survivors' physical fitness and psychosocial well-being were expressed more frequently by the survivors themselves, followed by the healthcare professionals, as barriers to resuming work after cancer. Employers may not be aware of treatmentrelated effects affecting the survivors. That could be due to a lack of opportunity for survivors to voice their work issues after cancer treatment to their employers. Among the effects reported were fatigue, tiredness, cognitive impairments, anxieties and frustration which caused the survivors to be emotionally sensitive at the workplace. Similar findings had been widely shared by researchers from other countries (Du, Cai & Symanski, 2013; Vardy et al., 2014). It has been reported that cancer-related fatigue also had a significant emotional component as it contributes to a feeling of loss of control, lack of motivation, sadness, and an inability to lead a normal life, which includes working life. However, colorectal cancer survivors who had received peer support from cancer support groups were better able to cope with those treatmentrelated effects, compared to those who had not.

The fear of cancer recurrence is among the most commonly reported problems and imposes a substantial burden in cancer survivors before and after treatment (Mehta, Lubeck, Pasta & Litwin, 2003; Simard, Thewes, Humphris, Dixon, Hayden, Mireskandari & Ozakinci, 2013). The fear of cancer recurrence was worsen by family or friends' cancer recurrence experience as shared by some colorectal cancer survivors.

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Such influence by family was also reported among general cancer groups (Mellon, Kershaw, Northouse & Freeman-Gibb, 2007). Female (Davis-Ali, Chesler & Chesney 1993; ), survivors who had chemotherapy (Vickberg, 2003), younger age (Bowman, Deimling, Smerglia, Sage & Kahana 2003; Vickberg, 200) and high educated survivors (Gil, Mishel, Belyea, Germino, Porter, LaNey & Stewart, 2004) were among the risk factors associated with fear of cancer recurrence. Knowing these predictors of fear of cancer recurrence, treating physicians could identify those who need additional support during survivorship in order to refer and manage them accordingly.

Negative attitudes, beliefs and values of the survivors also influence the decisionmaking for RTW. It is likely that colorectal cancer survivors may not be well informed on life after cancer as they held various negative perceptions and beliefs towards work, citing work as a stressor which could cause cancer. It is not uncommon for local cancer patients to believe multiple myths on diet and lifestyles after cancer (Loh, Packer, Yip & Low, 2007). Some of the colorectal cancer survivors believed that they need to change their working environment and also prepare their special diet in order to lead a healthier life after cancer. These misconceptions and myths indirectly posed as barriers for timely RTW.

For some colorectal cancer survivors, not returning to work was a personal choice rather than a negative impact following cancer diagnosis. Their choice of redirecting their focus on living a better life, and spending more quality time with family members (Maunsell et al., 2004), may have improved the Quality of Life (QoL) for the survivors. However, the likelihood of retaining the survivors in employment at the workplace decreases. Employee motivation has been identified as a significant factor for RTW in other studies (Krause, Frank, Dasinger, Sullivan & Sinclair, 2001; Michie & Williams, 2003). Hence, it is crucial to recognise survivors' decisions on RTW and level of motivation to work again soon after treatment, when deciding if a work-directed intervention would be helpful and relevant in returning the survivor to workplace.

### **5.2.2 Environmental factors**

Many themes shared by colorectal cancer survivors, healthcare professionals and employers were under the category of environmental factors. Some of these factors are policy related and therefore, are beyond the control of the survivors as well as healthcare professionals. It is known that survivors from government sector enjoy up to two years full paid medical leaves to recuperate from the cancer. Such a long full paid leave may delay the timely RTW or discourage the survivors from resuming the working life at all. A company's disproportionate generosity of paid sick leave has also been reported as a risk factor in preventing RTW in United Kingdom (Barmby, Nolan & Winkelmann, (2001). Contrary to these findings, Veenstra et al. (2015) reported that paid sick leave was associated with a greater likelihood of job retention and reduced personal financial burden among individuals with stage III colorectal cancer. Employees with paid sick leave were twice as likely to retain their jobs compared to those without paid sick leave. Up to 40 percent of American employees do not have paid sick leave as it is not mandated under the Affordable Care Act or the Family Medical Leave Act. Such a policy affects younger patients working in low-income jobs (Phillips, 2004) and causes financial burdens incurred due to recommended cancer therapy, such as chemotherapy, follow-up care and unpaid time off or lose pay checks (Lovell, 2004; Veenstra et al., 2015).

The knowledge and awareness of RTW among colorectal cancer survivors, healthcare professionals and employers had a great influence in assisting colorectal cancer survivors in returning to work. Many of the survivors chose to work again because of the conducive environment which allowed them to lead a near to normal life during the

survivorship phase. The lack of knowledge and low awareness about RTW are some of the modifiable factors which must be looked into while developing a work-directed intervention on RTW. In fact, RTW processes can be facilitated through early contact with employers, good communication between healthcare professionals, collective effort in planning RTW and efforts to support and accommodate survivors in workplace as mentioned consistently by all key informants in this study. Hence, an intervention to assist survivors going back to workplace must involve the healthcare professionals and also the employers. Such a collaborative effort would ensure recommendations offered by healthcare professionals in view of the survivors' health status, work ability and work demand could be arranged and accommodated by the employers.

Awareness of RTW opportunity and support was rather low among the colorectal cancer survivors. Despite the availability of the Employee Assistance Programme and SOCSO RTW programme, many insured colorectal cancer survivors were not aware of this. This could be attributed to the lack of promotion on these programmes among the organisations and also the attitude of employees who look forward to compensation rather than RTW after treatment.

## **5.2.3 Financial factors**

Three recurrent themes emerged under this category: compensation, source of income and organisational insurance. While compensation is meant to help the survivors after being diagnosed with cancer, many survivors and healthcare professionals believed that it was also the barrier for them to work again. In fact, for some colorectal cancer survivors, receiving the compensation means they are no longer fit to work and required to be medically retired from work. Such survivors failed to RTW due to disability, impairment or poor work ability attributed to cancer. However, there were also some survivors who used such compensation by insurance to avoid working again. The scenario of going all out to obtain compensation from insurance and choosing not to work has been reported among breast cancer survivors in Malaysia as well (Tan et., 2012).

With financial pressure, most of the colorectal cancer survivors chose to RTW out of necessity rather than choice as they have financial commitments to meet. This reason was highly expressed among those who are married and are not near to retirement age.

Health insurance coverage by the organisations was one of the reasons for many survivors to return to the companies. This benefit allows insurance coverage for the survivors as long as they are still employed in the same organisation. However, colorectal cancer survivors employed by MNC were more likely to benefit from such organisational health insurance coverage as compared to those in SMI. Similarly, the threat of unemployment and no provision of workers' insurance at the workplace were among the risk factors that prevent timely RTW, as identified by Blank, Peters, Pickvance, Wilford & MacDonald (2008).

## **5.2.4 Work-related factors**

The common work-related barriers for RTW point towards an imbalance between work demand and survivors' work ability. Workplace accommodation helped colorectal cancer survivors in keeping their job by achieving a balance between work demand and their current work ability. Hence, supportive employers who provided time flexibility and accommodated survivors' limitations were able to promote survivors' timely RTW. Studies have also shown that psychological support at the workplace can contribute towards early RTW (Johnsson, et al., 2010) while poor support from colleagues resulted in delayed returning to work (Fantoni et al., 2010).

The fear of exposure towards hazards at workplace had delayed and hindered some colorectal cancer survivors in resuming their work. Some key informants, especially those from occupational health practitioners emphasised the safety aspects of the RTW process which must look into the safety of the survivor as well as those individuals working in the same working environment. Hence, the issue of fitness to work must be addressed prior to planning for timely and safe RTW.

Most of the colorectal cancer survivors from the private sectors wished that their employers could play a bigger role in facilitating them to RTW while some of the HR managers (employers) suggested that it was not easy to accommodate survivors based on the requests and recommendations. Similarly, the lack of accommodated work and the differences in managing work versus non-work-related absences were among the challenges highlighted in Ontario (Schweigert, McNeil & Doupe, 2004).

Healthcare professionals have mixed responses on the role and to what extent they are expected to help in survivors' work issues. The continuing role ambiguity, lack of knowledge and training of the treating physician on the RTW process are not new as they have been reported in other studies as well (Denne, Kettner & Ben-Shalom, 2015; Schweigert et al., 2004; Soklaridis, Tang, Cartmill, Cassidy & Andersen, 2011). As a result, the treating physicians in this study often relied on information provided by their patients to complete the functional-ability forms. Such findings concur with those of Pransky, Katz, Benjamin & Himmelstein (2002), who found that many primary care physicians often relied mainly on patient input even for a disability assessment, contributing to the considerable discordance among the various stakeholders involved. Treating physicians in this study voiced their concerns over the medico-legal issues if the RTW process is not handled by certified personnel. This concern however was not highlighted in other studies. Issues like privacy concerns, time constraints, possible conflicts with physicians' role as patients' advocates, and the complex nature of

physician-patient relationship, often put the treating physicians in dilemma when recommending RTW for the survivors (Beaumont, 2003; Denne et al., 2015; Schweigert, 2004). However, all healthcare professionals agreed that RTW would benefit the employers and survivors who are motivated to work. Hence, the workdirected intervention on the RTW plan must involve the employer and the healthcare professionals in planning and follow up phase (Gensby et al., 2012).

In short, the findings from this Phase II, qualitative phase of study have further strengthened the evidence gathered in Phase I, in developing the work-directed intervention on RTW. Those factors associated with RTW as outlined in the framework on RTW were mentioned by all the key informants in Phase II. Thus, it is evident that the RTW issues faced by colorectal cancer survivors in Malaysia are not unique but rather common among other survivors globally. Based on those findings, the identified modifiable factors associated with RTW must be included in the content of intervention. The key modifiable factors identified from the in-depth interviews were the awareness of the RTW opportunity among the colorectal cancer survivors and healthcare professionals, the support for RTW from healthcare professionals, workplace and family, and the work-related factors which determine the balance of work ability and job demands.

However, the work-directed intervention on RTW must be tailored according to local settings, taking into consideration the current healthcare practice in Malaysia. The initial component of the intervention must include encouragement, education using materials such as, educational leaflets, counselling or advice about RTW or work-related subjects, addressing the myths and misconceptions attached to cancer (Clark & Landis, 1989), should occur soon after diagnosis (Capone, Good, Westie & Jacobson, 1980; Cimprich et al., 2005; Korstjens, Mesters, van der Peet, Gijsen & van den Borne, 2006; Høybye et al., 2008), should maintain contact with employers, including a trial of RTW, gradual

RTW with limited works hours and workplace training (Heim & Schwerte, 2006). Though letters from treating physicians to occupational health physicians could enhance communication in the RTW process (Nieuwenhuijsen et al., 2006), this work-directed intervention on RTW allows employers to carry out a trial of RTW prior to engaging the occupational health service by the organisation. Hence, this approach filters out the uncomplicated RTW cases and save the cost and time in engaging occupational health service.

The occupational health physician would be engaged to assess the fitness to work and conduct a workplace visit (Sherer, Meyers & Bergloff, 1997) for those survivors who had extended medical leave and were unable to perform at work after cancer treatment. Self perceived work ability is part of the fitness to work evaluation used to gauge the mismatch of job demands and work ability during the RTW process (Van Weert et al., 2004). A written gradual RTW plan would be developed as a collaborative effort by the occupational health physician, employer and employee following the outcome of the assessment and recommendation on a RTW plan (Clark & Landis, 1989; Fismen et al., 2000).

# 5.3 Phase III: Feasibility study of the proposed pathway for work-directed intervention

The perception and opinion of the stakeholders involved, on the flow and materials used for the RTW process were carefully examined and the assessment of feasibility of the proposed pathway for intervention on RTW was exploratory in nature (Pope, Ziebland & Mays, 2000; Curry, Nembhard & Bradley, 2009). Besides that, the challenges and unanticipated problems encountered during the feasibility study would enable the researcher to respond accordingly, before embarking on the next full trial of the intervention. These are part of the discussions covered in this section besides the strengths and limitations of the feasibility assessment.

The perceptions of the key informants suggested that the overall flow and material used in the RTW process were feasible. Participants were able to understand the flow and contents of materials used in the intervention. Early contact with the employer is feasible after the diagnosis as the employer would be informed about the cancer treatment plan for the purpose of paying the medical bills with the organisational insurance, though RTW was not considered as a priority by most colorectal cancer survivors. Employers appreciate early contact from survivors with the aim of preparing the work flow in the workplace during survivor's treatment phase. With a work-directed intervention involving the workplace, the employer could play a bigger role in planning for a trial of RTW and carrying out subsequent RTW recommendations. Some of the employers are not aware of the role of occupational health doctor and were dependent solely on the medical report furnished by the treating physicians in accommodating the survivor's RTW. In fact, not all treating physicians are aware of the healthcare professionals who could be of help in the RTW journey. This prompted the idea of including such crucial and helpful information in the educational leaflet.

Routine workplace visits prior to recommending a RTW plan may not be necessary in all cases but they are indicated when safety hazards are of concern when a survivor resumes duty at the workplace. Employers are concerned about the economic implications if such a workplace visit is being carried out routinely, as it may cause some degree of disruption to work flow, to a certain extent. Besides that, such a workdirected intervention on RTW would be able to engage the involvement of employers if their role and expectations are clearly outlined. Recommendations on the RTW plan would also take into consideration the resources available as well as the commitment of the survivor to work again.

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This feasibility study has also yielded useful suggestions for improvement of the educational leaflet. The roles of the occupational health doctor, clinical psychologist, and rehabilitation physician could be added in the educational leaflet to inform the survivors on the team of healthcare professionals involved in care after cancer. As an effort to advocate a healthy lifestyle during cancer survivorship, some basic tips on exercise to combat fatigue may be helpful if shared in the educational leaflet. In order to deliver health related information with more impact, basic tips in managing life after cancer could be delivered in the form of infographics along with successful RTW testimonies among colorectal cancer survivors. There were also suggestions to share the educational leaflet and include relevant video clips on successful RTW stories along with promotion of healthy lifestyle during cancer survivorship using a website. In fact, information technologies like web-based interventions are increasingly popular and used in various chronic disease settings, including cancer, to enhance patient empowerment (Kuijpers, Groen, Aaronson & van Harten, 2013; Groen et al., 2015). Patient empowerment reflects the ability of the survivors to positively influence their health and health behaviour (Kuijpers et al., 2013), gain control, adapt and improve health outcomes when living with a chronic illness (Small, Bower, Chew-Graham, Whalley & Protheroe, 2013) as well as those interventions that aim to foster selfmanagement of chronic illness (Bravo et al., 2015). Information technology has contributed to patient empowerment by providing useful educational material which helps patients in improving their QoL (Husson, Mols & Van de Poll-Franse, 2011), reducing the depressive symptoms (Griffiths, Calear & Banfield, 2009; Duffecy et al., 2013) and bringing down the incidence of cancer-related fatigue (Yun et al., 2011), and to a lesser extent, enhancing autonomy and skills of the patients (Groen et al., 2015).

During the data collection, recruiting colorectal cancer survivors for the feasibility study was a real challenge. Essentially, many of the survivors were not ready to think of RTW issues as they placed cancer treatment as their immediate top priority. There were also elements of fear to work again after cancer, anxiety over changes of lifestyle and altered priorities in life upon cancer diagnosis which delayed their plan in initiating discussion on RTW with their treating physicians. This could be attributed to the common myths attached to significant change in lifestyle and quality of life after cancer, which include work.

The main strength of this work-directed intervention on RTW is that it was specifically developed to address the RTW barriers identified in the second phase of the study in local setting. Using mixed methods (sequential approach), the intervention was developed based on evidence from published literature, before proceeding with exploring the barriers and facilitators among local stakeholders. Input and opinion on RTW issues were sought from the stakeholders in the RTW process in developing the intervention. Similarly, the flow of the intervention and material used were also shared among the stakeholders to gauge its potential feasibility. Another strong point is its simplicity, as this work-directed intervention on RTW does not require any substantial deviation from the current usual care provided by the treating physicians. It enhances the communication flow between employer and healthcare professionals, empowering the survivors with the right information besides directing them to the right team of healthcare professionals during and after cancer treatment.

Like the second phase of the study, this feasibility component is not without its own limitations. As this is a feasibility study, a limitation is the relative small sample size that was used. This is consistent with feasibility studies in general; the sample size was modest about 10 to 14; too small for tests of statistical significant (Manke et al., 2001; Broadhead et al., 2002). However, the results suffice to answer the research questions and arriving at the research objectives. Further to this, the absence of a control group limits the researcher to draw definite conclusions about the usefulness of the intervention. However, the objective of this study was to test the feasibility of the proposed flow and content of the work-directed intervention on RTW instead. Therefore, the objective of this feasibility component has been achieved. This limitation may guide the direction of further research, which may include a full trial involving a control group to measure the effectiveness of the "work-directed intervention" on cancer survivors' RTW, particularly for colorectal cancer survivors. In addition to that, using a purposive sampling method in this study may lead to self-selection type of sampling bias. Such selection bias happens following the fact that those who chose to participate tend to have a strong desire to RTW and possess the positive perceptions of work ability as well as working again after cancer.

## **CHAPTER 6: CONCLUSIONS AND RECOMMENDATIONS**

This chapter presents the conclusions and recommendations based on the findings of this study. The findings from each phase of the study answered the specific objectives and were subsequently used to carry out the next phase of the study.

The conclusions are drawn concerning the raised issues, particularly on assisting RTW process among colorectal cancer survivors in our local setting. In addition to that, this chapter also highlights new approaches in tackling the related issues in light of the findings presented above.

Subsequently, some recommendations and potential direction for future research are also mentioned at the end of this chapter. Essentially, such recommendations should be taken up if the work-directed intervention on RTW is to be implemented on a larger scale as part of the healthcare service in Malaysia.

## 6.1 Conclusion

Firstly, the researcher answered the first research question on various factors and their interactions associated with RTW among cancer survivors with the findings from a systematic review on all published literature over the span of 23 years. The review on selected articles was characterised by high degree of heterogeneity, in terms of study designs, patients' characteristics, cancer sites and mode of treatment, with the range of RTW rate varied from 45 percent to 89 percent, with average of two years after diagnosis.

Despite the advanced medical treatments that offer good outcome for cancer survivors, there are still quite a number of cancer survivors who did not enjoy good employment outcomes following cancer diagnosis. Many ended up unemployed, in early retirement or having job changes more often than those without cancer (Bradley, 2002; Maunsell et

al., 2004; Short, Vasey & Tunceli, 2005). The systematic review revealed some important findings which suggested that the factors associated with RTW were not always medically related. Health insurance, lack of understanding from colleagues at the workplace, work demands, supportive employers (Feldman, 1978), self-perceived work ability (Kennedy et al., 2007), support from friends and family (Main et al., 2005), advice from healthcare professionals (Kennedy et al., 2007; Nachreiner et al., 2007; Yarker et al., 2010) and also a priority and perception towards work (Johnsson et al., 2010; Kennedy et al., 2007; Nachreiner et al., 2007) were among the non-medical related factors which were also important in determining the employment outcome of the cancer survivors after treatment.

The researcher showed that the decision to RTW is based beyond the three factors (health condition, environmental factors and personal factors) as described by the WHO's International Classification of Functioning, Disability and Health (ICF). From the development of the RTW framework, the researcher identified the relevant stakeholders and working on those potential modifiable factors in assisting RTW among colorectal cancer survivors. Hence, it is concluded from the first phase of the study that interventions should focus on modifiable factors like improving health status through healthy lifestyle, promoting work ability through work-directed rehabilitation, enhancing the involvement of employer and healthcare professionals, and creating a supportive working environment. Ultimately, this may lead to a better QoL and functioning, improve the RTW process, and prevent survivors from losing a job following cancer diagnosis and lead to better employment outcome for cancer survivors.

The second phase of the study used qualitative methods to reveal more or less similar findings to those found in the systematic review. Findings from the stakeholders were consistent on barriers and facilitators to RTW. Among the modifiable barriers targeted in developing the intervention were the ability to cope with treatment effects, negative attitude, beliefs (personal factors), awareness and knowledge of RTW (environmental factors), imbalance between work demands and work ability and the fear of exposure to safety hazards in workplace (work-related factors).

The facilitators of RTW identified through the qualitative study were the desire of the survivor to resume working life as part of recovery to normal life (personal factors), conducive working environment, supportive employer and working colleagues (environmental factor) as well as the commitment of employers in accommodating survivor's RTW and addressing the work demand, work ability and safety concern in the workplace (work-related factors).

The work-directed intervention should therefore focus on reducing, if not removing the modifiable barriers and enhancing the facilitators associated with RTW in order to achieve timely RTW. It is helpful to recognise those individuals who are motivated to work again after cancer diagnosis, especially when they belong to the young working population. Such individuals must be assisted so that the employment outcome for them is favourable, since they are motivated to work again. However, those who do not show interest in RTW may be furnished with the correct information on life after cancer, to address the myths attached to cancer, including their working life. This could be achieved by the treating physician having a brief discussion on cancer and work, prior to cancer treatment.

Awareness and knowledge about RTW is another potential barrier, which is modifiable. Established organisations may have an in-house Employee Assistance Programme (EAP) and RTW may be part of it. However, this may not be the case for Small Medium Industry (SMI) which often faces challenges in providing occupational health services to the staff (Black, 2008). In order to achieve timely RTW, engagement and commitment of the employer are crucial. In organisations with established RTW programmes or policy, healthcare professionals should encourage individuals to inform the employer as early as possible after cancer diagnosis and keep in touch with employer and colleagues during medical leave. Early contact with the employer ensures the RTW programme or policy would take place without delay. For survivors from organisations without an existing RTW programme or policy, early contact with the employer would allow the employer to plan ahead and prepare during the survivor's medical leave as well as during RTW. A structured guideline on tasks to be carried out by the employer in assisting the survivor's RTW may potentially enhance the support rendered to the survivor and hence improve the RTW outcome. The evidence based guideline does not only outline the tasks and roles of the employers but also the flow of referral to relevant healthcare professionals in the RTW process.

Essentially, employers are not left alone but activities are coordinated with relevant healthcare professionals in accommodating the survivor upon RTW. Health status, survivor's self-perceived work ability, work demands and potential safety hazards are elements to be assessed further in a fitness to work assessment prior to RTW. Employer engagement in the RTW intervention involves a partnership with the healthcare professional in arriving at an agreed workplace accommodation for the survivor, for a specific time frame. Such a partnership is based on continuous feedback on the RTW progress during follow-up in order to find ways to assist RTW with the existing resources and support.

The third phase of the study involved the feasibility component of the proposed pathway for work-directed intervention. Overall, the intervention was considered feasible in terms of the flow, and contents of the materials used in the intervention. However, interpretation of this conclusion must be done with caution as the entire work-directed RTW intervention has not been tested in a full trial with comparison with a control group. Therefore, no conclusion on the effectiveness of the work-directed RTW intervention could be made at this point. Despite that, the last specific objective has been achieved with this feasibility study.

The participation rate among colorectal cancer survivors was not encouraging for the second and third phase of the study. This could be attributed to the societal myths that cancer leads to poor QoL and employment outcomes. Besides that, many of the survivors were not ready to think of employment issues soon after diagnosis as they preferred to take one thing at a time, placing treatment as their top priority. Provision of full paid medical leave up to two years among Malaysian civil servants did not favour timely RTW compared to those in private sectors. In addition to that, administrative management of civil servants in Malaysia is clearly spelled out in the General Orders (GO), allowing limited room for intervention. In view of that, the work-directed RTW intervention was developed targeting survivors from private sectors.

It is also concluded that the occupational health doctor is the best candidate in planning and monitoring the RTW process while treating physicians are the frontlines who could start a brief discussion on coping with treatment effects with the survivors.

# **6.2 Recommendations**

One of the obvious findings from the systematic review is that majority of the studies are still focusing on common cancers like breast cancer. This could be due to the fact that breast cancer has been diagnosed at earlier stages given the active breast cancer screening programme via self-breast examination and mammography. Other cancers do not get screened as widely as breast cancer, thus diagnosing non breast cancers at early stage poses a real challenge to clinicians. Thus, to the researchers, getting sufficient non-breast cancers as participants in quantitative studies is not an easy task. Perhaps, future research on non-breast cancer should begin with qualitative studies, exploring the work related issues prior to, during and after RTW. Similarly, the perceptions from those stakeholders who are involved in treating and managing cancer patients should be taken into account in designing the intervention on RTW. It is recommended that Cancer Registries keep records of the patients' employment status before and after cancer, as well as any changes in income. The detailed information on job tasks should be described beyond the scope of manual and sedentary work or blue and white collar working classes. With this information, interventions may focus and plan to achieve the tasks that patients are expected to perform upon RTW.

Ideally, a common classification like the International Standard Classification of Occupations (ISCO) by the International Labour Organisation (ILO) should be used to categorise the patients in all cancer registries. Such a uniform classification does not only allow the researchers to gauge the much-needed prevalence of cancer in the respective working population, but also makes the comparison of prevalence of cancer among employees between countries possible.

Study on the employment status of cancer survivors can be expanded by using population-based follow-up to look at the impact of cancer on work status compared to people with no cancer. While the impact of cancer varies, the outcome measures for employment status can be examined beyond the RTW rate; such as changes of job/task, early retirement, unemployment and reemployment. Using standardised outcome measures on the impact of cancer and fitness to work assessment tools like the work ability index could improve reliability and validity of assessment.

The role of fit note has been documented and widely used in the UK. This proposed work-directed intervention on RTW highlighted the unique role of the fit note in focusing on the tasks an individual is allowed to do, and certain tasks to avoid. It does not label the individual as a sick person, hence removing the perception of necessity to avoid work at all. Therefore, fit note should be welcomed as a potential replacement for the existing medical certificate eventually by all stakeholders, as it avoids unnecessary work absenteeism and loss of work productivity following medical conditions.

Essentially, empowered colorectal cancer survivors who lead a healthy lifestyle during survivorship are likely to have a better health status and QoL. Therefore, the use of information technology (IT) as part of intervention on RTW would appear promising in preparing those IT savvy survivors for timely RTW. However, future studies should identify the perceived barriers for and facilitators of the use of web-based type of interventions on RTW.

This study also suggests the essential role played by occupational health doctors in RTW after primary cancer treatment. With the increasing disease burden of chronic diseases affecting the working population, occupational health services are looking at RTW assistance and workplace accommodation. This is now overdue in all tertiary hospitals in Malaysia. Integrated work-directed interventions on RTW would then be an extension of services available in current practice. Occupational health services should be viewed beyond the scope of preventing ill-health due to workplace exposure to hazards, but also as a facilitator to prevent pre-existing medical conditions affecting safe and effective work performance, besides improving general health among the employees. Establishing occupational health services in all organisations should be viewed as a profitable investment in the long run as it aims to retain the employees in the workplace after the onset of various health conditions.

A better understanding of the cancer survivors' needs, motivation to resume work, the role of healthcare professionals as well as the workplace accommodation and supports by employers would contribute to an increase in the labour participation of cancer survivors. This is done through comprehensive fitness to work assessment as part of the intervention on RTW. Such emphasis is in line with the concept of Total Workplace

Safety and Health (TWSH), a holistic and integrated system to manage workplace safety and health risk which is characterised by risk management approach and promotion of health and well-being of employees, the most valuable, important asset and the heart of any organisation.

In UK, allied health professions (AHPs) had developed an advisory fitness for work report which could stand alone as guidance if the employers choose to use it or as an additional report along with the fit note certified by treating physicians. The report outlines the functional difficulties in both clinical and workplace setting and offer the most appropriate solution for long-term. There is no such advisory fitness for work report in Malaysia and the involvement of allied health professionals in RTW process is limited at present.

However, findings from this study could be used to conduct a feasibility study on the actual implementation and flow of the intervention in hospitals with multidisciplinary team. The RTW rates, duration to resume work are among the potential outcome measures for the future study. Since this work-directed intervention involves many stakeholders, time taken to initiate workplace contact, outcome of trial of RTW by employers, adherence to the recommended tasks outlined in the RTW Brochure, number of referrals made to other healthcare providers (e.g. psychologists, occupational therapists) prior to full RTW could be further explored. These essential findings would be useful before researcher embark into a larger scale of study.

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## SUPPLEMENTARY SECTION

## LIST OF PUBLICATIONS AND PAPERS PRESENTED

## A) Journal publications:

- i) Chow Sze Loon, Anselm Su Ting, Tin Tin Su. Development of conceptual framework to understand factors associated with return to work among cancer survivors: a systematic review. *Iranian Journal of Public Health* (ISI-Cited Publication)
- Sze Loon Chow, Siew Yim Loh and Tin Tin Su (2015) Perceived barriers and facilitators for return to work among colorectal cancer survivors: Malaysian healthcare professionals' experience- a qualitative inquiry. J UOEH 37(2): 127-138
- iii) Sze Loon Chow, Tin Tin Su and Siew Yim Loh (2015) Role of GP in enhancing return to work (RTW) among cancer survivors. *Australian Family Physician* (Submitted on 25 Nov, 2015).

## **B)** Oral presentations:

- i) "Factors associated with return to work among cancer survivors: A systematic review" at the 2nd International Conference and Exhibition on Occupational Health and Safety on 21-22 May, 2013 in Beijing, China.
- ii) "Cancer and employment: Implications for cancer survivors and employers" at Coloproctology 2014 on 8 March, 2014 in Shangri-La Hotel, Kuala Lumpur.
- iii) "The role of human resource (HR) manager in return to work (RTW) programme" at FMM Safety Conference scheduled on 28 March, 2016 in Eastern & Oriental Hotel, Georgetown, Penang.