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Die Fähigkeiten von Krebspatient(inn)en bei der Suche nach krebsbezogenen Online-Informationen und ihr Vertrauen in diese Informationen

Dissertation

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1 Einleitung

1.1 Internetnutzung unter Krebspatient(inn)en

Anwendungen der elektronischen Gesundheitsdienste und das Internet ermöglichen es Krebspatient(inn)en, die Gesundheitsversorgung aktiver in Anspruch zu nehmen, und erleichtern es, den Informations- und Unterstützungsbedarf zu erfüllen (Eysenbach, 2003; C. J. Lee, Gray, & Lewis, 2010; van Uden-Kraan et al., 2020). Krebspatient(inn)en können (1) auf Webseiten und in sozialen Medien nach gesundheits- oder krebsbezogenen Informationen suchen oder ihre(n) Arzt(in) per E-Mail um medizinischen Rat bitten, (2) virtuelle Kommunikation und virtuelle Gemeinschaften zur sozialen Unterstützung nutzen, und (3) E-Health-Programme als eigenständige Behandlungsmaßnahmen oder zur Verbesserung oder Unterstützung von Gesundheitsdiensten in verschiedenen Phasen der Krebsbehandlung nutzen. Im Rahmen dieser Dissertation beschäftigen wir uns ausschließlich mit der Suche nach gesundheits- und krebsbezogenen Informationen im Internet.

1.1.1 Informationssuche im Internet

Unerfüllte Informationsbedürfnisse gehören zu den am häufigsten genannten unerfüllten Bedürfnissen von Krebspatient(inn)en (6-93 %) in der Behandlungs- und Nachbehandlungsphase (Harrison, Young, Price, Butow, & Solomon, 2009). Krebspatient(inn)en bevorzugen es, so viele Informationen wie möglich über ihre Krankheit zu erhalten (Davies, Kinman, Thomas, & Bailey, 2008; Jenkins, Fallowfield, & Saul, 2001). Im Vergleich zu anderen Informationsquellen hat das Internet den Vorteil der ständigen Verfügbarkeit. Online können Krebspatient(inn)en jederzeit und von fast überall auf das Internet zugreifen (Ziebland et al., 2004), auf Wunsch auch anonym (Maddock, Lewis, Ahmad, & Sullivan, 2011; Ziebland et al., 2004). Über die Prävalenz der Internetnutzung von Krebspatient(inn)en wurde bisher nur in kleinen Studien berichtet, aber es gibt keinen Grund zu der Annahme, dass sie sich von der Prävalenz in der gesunden Bevölkerung derselben Altersgruppe unterscheidet. Die Prävalenz der Krebspatient(inn)en in einer niederländischen Stichprobe, zwei amerikanischen Stichproben und einer schwedischen Stichprobe, die das Internet nutzten, lag zwischen 60,2 % und 79,8 % (Castleton et al., 2011; Mattsson, Olsson, Johansson, & Carlsson, 2017; Shahrokni, Mahmoudzadeh, & Lu, 2014; van de Poll-Franse & van Eenbergen, 2008). Die Ergebnisse der schwedischen Studie zeigten außerdem, dass ca. 20 % der teilnehmenden Krebspatient(inn)en gesundheitsbezogene Diskussionsforen oder Blogs besuchten und 34 % gaben an, soziale Medien zu nutzen (Mattsson et al., 2017). In Industrieländern nutzen 87 % der Bevölkerung zumindest gelegentlich das Internet (Poushter, Bishop, & Chwe, 2018). In Deutschland nutzten im Jahre 2019, selbst in der Altersgruppe 65 Jahre und älter, in der sich mehr als die Hälfte aller Krebspatient(inn)en befinden, 70 % täglich das Internet. In dieser Altersgruppe suchten 68 % innerhalb der letzten drei Monate nach gesundheitsbezogenen Informationen im Internet (Statistisches Bundesamt, 2020). Es gibt verschiedene Gründe für Krebspatient(inn)en, im Internet nach Krebsinformationen zu suchen. Die Patient(inn)en berichteten, dass sie sich online informieren wollten, um Fragen zu entwickeln, die sie mit ihre(r)m Arzt(in) besprechen wollten, um die von ihre(r)m Arzt(in) gegebenen Informationen zu überprüfen oder um nach alternativen Behandlungsmöglichkeiten zu suchen (Castleton et al., 2011), und weil sie das Gefühl hatten, dass die Informationen, die sie von ihre(r)m Arzt(in) erhielten, nicht ausreichen (Chen & Siu, 2001). Die am häufigsten im Internet gesuchten krebsbezogenen Informationen sind Informationen über die Diagnose, die Prognose, das Krankheitsstadium, die Behandlungsmöglichkeiten oder die Nebenwirkungen der Behandlung (Castleton et al., 2011; Maddock et al., 2011). Die Suche nach krebsbezogenen Informationen im Internet ist positiv mit Patient(inn)en berichteten Endpunkten (PROMs) und sozioökonomischen Merkmalen der Patient(inn)en assoziiert**.** Krebspatient(inn)en, die im Internet nach krebsbezogenen Informationen suchen, sind stärker in die medizinische Entscheidungsfindung einbezogen (C. J. Lee et al., 2010), fühlen sich besser über ihre Krankheit informiert (van de Poll-Franse & van Eenbergen, 2008), haben einen höheren Grad an selbstberichteter Gesundheit (Chou, Liu, Post, & Hesse, 2011) und Lebensqualität (Shahrokni et al., 2014), haben eher einen Partner (Mattsson et al., 2017) und sind jünger und gebildeter (Castleton et al., 2011; Mattsson et al., 2017; Shahrokni et al., 2014) als Patient(inn)en, die nicht im Internet suchen.

In Abhängigkeit davon, ob die Patient(inn)en die gesundheitsbezogenen Online-Informationen mit ihren Ärzten(innen) besprechen, kann die Suche nach Gesundheitsinformationen im Internet die Arzt(in)-Patient(inn)en-Beziehung bei Patient(inn)en mit akuten oder chronischen Erkrankungen verbessern (Tan & Goonawardene, 2017). 24% der teilnehmenden Krebspatient(inn)en in einer australischen Studie fühlten, dass die Online-Informationssuche die Arzt(in)-Patient(inn)en-Beziehung positiv beeinflusst, wohingegen nur 8 % der Meinung waren, dass sie sich negativ auswirkt (Newnham et al., 2006). Einige Krebspatient(inn)en, die an einer Interviewstudie teilnahmen, berichteten, dass sie vorsichtig sind, wenn es darum geht, Online-Informationen mit ihren Ärzt(inn)en zu besprechen. Diese Patient(inn)en befürchteten, dass sich ihre Online-Recherche negativ auf die Beziehung zu ihrem Arzt(in) auswirken und dazu führen könnte, dass sie von den Ärzt(inn)en als Problempatient(inn)en behandelt werden, oder sie hatten bereits schlechte Erfahrungen mit ihrem(r) Arzt(in) gemacht, als sie Online-Informationen besprachen (Broom, 2005; Chiu, 2011).

1.1.2 Qualität von krebsbezogenen Internetinformationen

Nur wenige Studien geben Aufschluss darüber, welche Art von Informations-Webseiten Krebspatient(inn)en besuchen. Krebspatient(inn)en bewerteten Webseiten mit Gesundheitsinformationen für eine wertvollere Quelle für Gesundheitsinformationen als Foren oder Blogs (Mattsson et al., 2017). Darüber hinaus berichteten Krebspatient(inn)en, dass sie verlässliche Informationen über Krebs lieber von Webseiten ihres Onkologen, des Krankenhauses oder der Krebsgesellschaft beziehen und weniger wahrscheinlich Webseiten mit kommerziellem Interesse besuchen. Dieselben Patient(inn)en besuchten jedoch am häufigsten Webseiten, die von der pharmazeutischen Industrie finanziert und erstellt wurden (van de Poll-Franse & van Eenbergen, 2008), die möglicherweise deren eigene Interessen fördern und von geringerer Qualität sein können als gemeinnützige Webseiten (Liebl et al., 2015). Eine mögliche Erklärung für diese Diskrepanz ist, dass die Gesundheitssuchenden die Quelle und das Datum der online gefundenen Gesundheitswebseite nicht überprüfen (Eysenbach & Köhler, 2002; van der Vaart, Drossaert, de Heus, Taal, & van de Laar, 2013).

Die Qualität der im Internet zugänglichen Informationen über Krebs ist sehr unterschiedlich. In mehreren Studien wurde die DISCERN-Skala verwendet, um die Qualität von Webseiten mit krebsbezogenen Informationen zu bewerten. Die DISCERN-Skala ist ein validiertes Instrument, das Nutzer(inn)en helfen soll, die Qualität gesundheitsbezogener Informationen über Behandlungsmöglichkeiten für ein bestimmtes Gesundheitsproblem zu bewerten (Charnock, Shepperd, Needham, & Gann, 1999). Die Webseiten wurden generiert, indem krebsbezogene Suchbegriffe (z. B. "Krebs", "Krebstherapie", "Brustkrebs" oder "Darmkrebs") in gängigen Suchmaschinen wie Google oder Bing eingegeben wurden, wobei der Schwerpunkt auf den ersten Suchergebnissen lag (Borgmann et al., 2016; Bruce, Tucholka, Steffens, & Neuman, 2015; Hargrave, Hargrave, & Bouffet, 2006; Liebl et al., 2015; Nghiem, Mahmoud, & Som, 2016; Wasserman, Baxter, Rosen, Burnstein, & Halverson, 2014). Die Informationen auf den bewerteten Webseiten waren häufig unvollständig und enthielten nicht alle Details, die Krebspatient(inn)en benötigen, um eine fundierte Entscheidung treffen zu können (Borgmann et al., 2016; Bruce et al., 2015; Hargrave et al., 2006; Liebl et al., 2015; Nghiem et al., 2016; Wasserman et al., 2014). Zwei Studienergebnisse zeigten einen Unterschied zwischen der Informationsqualität verschiedener Webseiten-Typen. Die Qualität von Webseiten von gemeinnützigen Organisationen oder der Regierung war höher als die Qualität von Webseiten von Arzt(innen)praxen oder kommerziellen Webseiten mit Gesundheitsinformationen (Liebl et al., 2015; Nghiem et al., 2016). Es bedarf weiterer Forschung zur Qualität der Informationen, die auf gängigen sozialen Netzwerken wie Facebook oder Twitter oder in Diskussionsforen und Blogs gepostet werden, wo informelle Ratschläge und Unterstützung von Freunden und Fremden ohne Kontrolle gegeben werden. Erste Studien zeigen erfreulicherweise, dass die Verbreitung von evidenzbasierten Informationen und sozialer Unterstützung über Twitter-Nachrichten mit einem Anstieg des selbst wahrgenommenen krebsbezogenen Wissens assoziiert ist (Attai et al., 2015) und dass häufiger retweetete Tweets mit größerer Wahrscheinlichkeit medizinisch korrekte Informationen enthalten als zufällig ausgewählte Tweets (Park et al., 2016).

1.1.3 Vertrauen in krebsbezogenen Online-Informationen

Die unterschiedliche Qualität der online verfügbaren krebsbezogenen Informationen stellt Krebspatient(inn)en vor große Herausforderungen bei der Bewertung und Auswahl zuverlässiger Online-Informationsquellen und insbesondere bei der Bewertung der Glaubwürdigkeit und Vertrauenswürdigkeit dieser Quellen. Vertrauen ist ein wichtiger Faktor im Hinblick auf die Absicht, auf einer Website gefundene Informationen zu nutzen (Dutton & Shepherd, 2006; Lemire, Paré, Sicotte, & Harvey, 2008). Konsumenten, die Vertrauen in Online-Gesundheitsinformationen haben, werden motiviert, Gesundheitsinformationen online zu suchen (Fisher, Burstein, Lynch, & Lazarenko, 2008). Die Entscheidung, ob man einer krebsbezogenen Online-Information vertraut, kann sehr komplex sein, da die Fähigkeiten zur Online- Informationssuche, frühere Erfahrungen mit der Informationswebseite und der Informationssuche im Internet, sowie die Merkmale der Quelle die Entscheidung des Krebspatient(inn)en beeinflussen können. In der Literatur werden verschiedene Ebenen des Vertrauens (individuell, interpersonell, relational und gesellschaftlich) untersucht. Die interpersonelle Ebene scheint die geeignete Ebene für die Bestimmung des Vertrauens in Online-Informationen zu sein, da die Informationen von einem Autor (Treuhänder) bereitgestellt und über einen bestimmten Kanal (dem Internet) an einen Empfänger (Treugeber) übermittelt werden (Kelton, Fleischmann & Wallace, 2008).

Die Begriffe Vertrauen und Glaubwürdigkeit werden häufig synonym verwendet. Glaubwürdigkeit kann jedoch als wahrgenommene Informationsqualität oder als die Bewertung der Informationsqualität durch einen Nutzer(in) beschrieben werden (Fogg & Tseng, 1999). Nach der Bewertung der Glaubwürdigkeit einer Information kann ein Leser entscheiden, ob er ihr vertraut oder nicht. Der Prozess der Glaubwürdigkeitsbewertung in Online-Umgebungen kann durch ein duales Verarbeitungsmodell (Metzger, 2007) oder das 3S-Modell [wobei die drei "S" für Semantik, Oberfläche („Surface“) und Quellenmerkmale („Source Features“) von Informationen stehen] erklärt werden (Lucassen & Schraagen, 2011). Das duale Verarbeitungsmodell besagt, dass die Entscheidung, ob eine heuristische (periphere) oder systematische (zentrale) Bewertung durchgeführt wird, von der Motivation und den Fähigkeiten der Nutzer(innen) abhängt. Mit anderen Worten: Wenn Menschen durch persönliche oder situative Faktoren motiviert sind, wie z. B. ein hohes Bedürfnis nach genauen Informationen oder ein persönliches Interesse am Verständnis eines Themas, werden sie einer Nachricht wahrscheinlich mehr Aufmerksamkeit schenken, über die vorgetragenen Argumente nachdenken und mehr kognitive Ressourcen aufwenden, um die Informationen und ihre Quelle zu verarbeiten und zu bewerten. Im Gegensatz dazu sagt das Modell voraus, dass bei geringer Motivation und/oder geringen Fähigkeiten Informationen auf der Grundlage oberflächlicherer und weniger durchdachter Kriterien verarbeitet oder bewertet werden (Metzger, 2007). Ich bevorzuge das 3S-Modell, weil ich der Meinung bin, dass Krebspatient(inn)en aufgrund ihrer existenziellen Sorgen und ihres Bedürfnisses nach Hoffnung eine verletzliche Bevölkerungsgruppe sind (Davey, Butow, & Armstrong, 2003) und daher bei ihrer Online-Suche hoch motiviert sind. Das 3S-Modell geht davon aus, dass die direkteste Strategie zur Bewertung der Glaubwürdigkeit darin besteht, nach semantischen Hinweisen (sachliche Richtigkeit, Neutralität oder Vollständigkeit der Informationen) in den Informationen zu suchen (Lucassen & Schraagen, 2011). Krebspatient(inn)en suchen jedoch häufig nach Informationen, die für sie neu sind, und verfügen daher nicht immer über das nötige Fachwissen, um die Semantik der Informationen zu bewerten, und greifen daher auf oberflächliche Hinweise zurück (Schreibstil, Textlänge oder Anzahl der Referenzen) (Lucassen & Schraagen, 2011) Systematische und heuristische Verarbeitung können somit beide während eines einzigen Suchprozesses eingesetzt werden. Darüber hinaus wird das Vertrauen in Online-Informationen durch das Vertrauen in die Quelle (Website) beeinflusst, das wiederum durch das Vertrauen in das Medium (Internet) dieser Quelle und die allgemeine Neigung zum Vertrauen beeinflusst wird (Lucassen, Muilwijk, Noordzij, & Schraagen, 2013). Das Vertrauen in das Internet wird weitgehend von früheren Erfahrungen mit diesem Medium beeinflusst (Dutton & Shepherd, 2006) .

Darüber hinaus berichten zwei systematische Übersichtsstudien, dass das Vertrauen der Nutzer(innen) in Webseiten mit Gesundheitsinformationen mit (1) individuellen Nutzereigenschaften, mit (2) Webseiten-bezogene Faktoren, und mit (3) Faktoren, die mit der Interaktion zwischen Nutzer(innen) und Website zusammenhängen, assoziiert werden (Kim, 2016; Sbaffi & Rowley, 2017). Nutzer(innen), die jünger sind, ein höheres Bildungsniveau haben, weiblich sind, ein höheres Maß an Zustimmung zeigen, über ein höheres Einkommen verfügen, sich nach eigenen Angaben in einem guten Gesundheitszustand befinden und über ein höheres Maß an Gesundheitskompetenz verfügen, scheinen Gesundheitsinformations-Webseiten mehr zu vertrauen. Webseiten, die vollständig, verständlich, unvoreingenommen, modern, nützlich und leicht zu navigieren sind, ein klares und professionelles Layout haben, leicht zugänglich sind, von medizinischen Universitäten oder der Bundesregierung betrieben werden und qualitativ hochwertige Informationen enthalten, werden eher als vertrauenswürdig eingestuft. Erfahrung im Umgang mit dem Internet und Vertrautheit mit der Webseite beeinflussen wahrscheinlich das Vertrauen der Nutzer(innen) in die Gesundheitsinformationen. Erfahrene Nutzer(innen) haben mehr Vertrauen in das Internet und sind weniger besorgt über die Risiken, die mit seiner Nutzung verbunden sind, was die Wahrscheinlichkeit erhöht, dass sie gesundheitsbezogenen Webseiten vertrauen (Kim, 2016; Sbaffi & Rowley, 2017).

1.1.4 eHealth Kompetenz

Aufgrund der variierenden Qualität der gesundheitsbezogenen Online-Informationen sind Patient(inn)en somit auf ihre eigenen Fähigkeiten zum Suchen und kritischen Beurteilen von Online-Krebsinformationen angewiesen. Diese Fähigkeiten sind Bestandteil des Konzepts der eHealth-Kompetenz (eHK). Der Begriff eHK wurde erstmals 2006 von Norman und Skinner definiert als "die Fähigkeit, Gesundheitsinformationen aus elektronischen Quellen zu suchen, zu finden, zu verstehen und zu bewerten und das gewonnene Wissen zur Lösung eines Gesundheitsproblems anzuwenden " (Norman & Skinner, 2006). Ein Problem mit diesem ursprünglichen Konzept der eHK ist, dass es für die erste Generation von eHealth-Diensten entwickelt wurde und daher die Nutzung sozialer (z.B. Twitter und Facebook) und mobiler Medien (z. B. Apps) nicht einschließt (J. Lee, Lee, & Chae, 2021). Dies hat zur Entwicklung von Instrumenten der zweiten Generation geführt (z. B. die Electronic Health Literacy Skala, das Digital Health Literacy Instrument, und das eHealth Literacy Assessment Toolkit) die ein breiteres Spektrum von Konzepten der eHK messen, um sie für Menschen, die in der Social-Media-Ära von eHealth leben, angemessener zu machen (J. Lee et al., 2021). Die differenzierteste Definition der eHK in der derzeitigen Literatur lautet (Samerski & Muller, 2019): „Die eHealth-Kompetenz umfasst ein dynamisches und kontextspezifisches Bündel individueller und sozialer Faktoren sowie technologischer Einschränkungen (z. B. die Anpassung eines Systems an den Nutzer(innen) bei der Nutzung digitaler Technologien für die Suche, das Verständnis, die Bewertung, die Kommunikation, die Anwendung und die Erstellung von Gesundheitsinformationen in allen Kontexten der Gesundheitsversorgung mit dem Ziel, die Lebensqualität über die gesamte Lebensspanne zu erhalten oder zu verbessern.“ (Griebel et al., 2018). Eine hohe eHK wird mit gesundheitsförderndem Verhalten in Verbindung gebracht. Die Stärke der Evidenz wird jedoch als gering eingestuft (Neter & Brainin, 2019).

1.1.5 Internetsuchfähigkeiten

Im Entwicklungsprozess der zweiten Generation von Instrumenten wurden Performance-Test Studien durchgeführt, bei denen Teilnehmende bei der Ausführung von gesundheitsbezogenen Suchaufgaben im Internet beobachtet wurden (van der Vaart et al., 2013; van Deursen & van Dijk, 2011). Die Studien ergaben dass sieben Arten von Fähigkeiten für eine erfolgreiche Suche nach gesundheitsbezogenen Informationen auf Webseiten unerlässlich sind (van der Vaart et al., 2013). Diese sieben wesentlichen Fähigkeiten lassen sich in drei Kategorien unterteilen. Erstens benötigen die Patient(inn)en Bedienungs- und Navigationsfähigkeiten, um einen Computer, einen Webbrowser und eine digitale Applikation zu benutzen, d.h. eine Tastatur zu benutzen, eine Maus oder einen Touchscreen zu verwenden, zwischen Webseiten vorwärts und rückwärts zu navigieren und sich auf einer

Website zu orientieren (van der Vaart et al., 2013; van Deursen & van Dijk, 2011). Zweitens benötigen die Patient(inn)en grundlegende Informations- und Bewertungsfähigkeiten, um gesundheitsbezogene Online-Informationen zu suchen, zu finden und zu bewerten, d.h. angemessene Suchbegriffe zu formulieren, ein relevantes Suchergebnis auszuwählen, entscheiden, ob die gefundene Informationen, auf sie zutreffen, die Informationsquelle überprüfen und die gefundenen Informationen nutzen (van der Vaart et al., 2013; van der Vaart et al., 2011). Drittens, für die Nutzung von interaktiven webbasierten Applikationen wie Diskussionsforen, Blogs und soziale Medien benötigen die Patient(inn)en zusätzliche Fähigkeiten zum Hinzufügen von selbst erstellten Inhalten und die Fähigkeit zum Schutz der (van Deursen & van Dijk, 2011) eigenen Privatsphäre und die Privatsphäre anderer. Ie Fähigkeiten zum Hinzufügen von selbst erstellten Inhalten und die Fähigkeit zum Schutz der (van Deursen & van Dijk, 2011) eigenen Privatsphäre und die Privatsphäre anderer. Die Patient(inn)en sollten in der Lage sein, ihre Frage oder gesundheitsbezogenen Anliegen klar zu formulieren, damit andere Patient(inn)en verstehen was sie meinen und wissen, wer lesen kann, was man im Internet veröffentlicht hat (van der Vaart & Drossaert, 2017; van der Vaart et al., 2013). Die Ergebnisse beider Studien deuteten darauf hin, dass etwa ein Drittel der Teilnehmenden erhebliche Probleme bei der Anwendung von Bedienungs- und Navigationsfähigkeiten hatte (van der Vaart et al., 2013). Die in den zwei Studien beobachteten Niveaus der Informations- und Bewertungskompetenz schienen deutlich niedriger zu sein (van der Vaart et al., 2013; van Deursen & van Dijk, 2011). Viele Teilnehmende berichteten von Problemen bei der Auswahl relevanter Suchbegriffe (14/15, 93 %) und der Auswahl eines zuverlässigen Suchergebnisses (13/15, 87 %). Ebenso überprüften 93% (15/15) der Teilnehmenden nicht die Informationsquelle der Internetseiten (van der Vaart et al., 2013). Die Performance Tests zeigten darüber hinaus Assoziationen zwischen soziodemographischen Charakteristiken der Teilnehmenden und ihren Internetsuchfähigkeiten. Ein jüngeres Alter, ein höheres Bildungsniveau, mehr Interneterfahrung und eine höhere selbst wahrgenommene Internetkompetenz waren mit einer erfolgreicheren Aufgabenbewältigung verbunden (van der Vaart et al., 2013; van Deursen, van Dijk, & Peters, 2011). Darüber hinaus stimmen die Resultate der zwei Studien auch mit den Ergebnissen der ersten Erhebung der eHK einer repräsentativen Stichprobe für die deutsche Bevölkerung (D Schaeffer et al., 2021) und einer systematischen Übersichtsarbeit zu Gesundheitskompetenzen bei deutschen Patient(inn)en mit chronischen Erkrankungen überein (Griese, 2021). Im zweiten „Health Literacy Survey Germany“ (HLS-GER 2) wiesen drei Viertel (76 %) der Befragten eine geringe eHK auf und berichteten von großen Schwierigkeiten, im Umgang mit digitalen Informationen. Besonders die Beurteilung der Vertrauenswürdigkeit (83 %) und die Einschätzung, ob hinter den Informationen kommerzielle Interessen stehen (82%), werden als schwierig erachtet (D Schaeffer et al., 2021). Die Ergebnisse des ersten „Health Literacy Survey Germany“ (HLS-GER 1) Studie (54% der für die deutsche Bevölkerung repräsentativen Stichprobe verfügte über eine einschränkte Gesundheitskompetenz waren einer der entscheidenden Auslöser für den Start des Nationalen Aktionsplans für Gesundheitskompetenz (NAG) im Jahr 2018. (D Schaeffer et al., 2021; D. Schaeffer, Hurrelmann, Bauer, & Kolpatzik, 2018).

1.2 Onkologische Rehabilitation

Krebsüberlebende können unter den langfristigen körperlichen und psychischen Folgen von Krebs und seiner Behandlung leiden (Duijts et al., 2014; Harrington, Hansen, Moskowitz, Todd, & Feuerstein, 2010; Hewitt, Rowland, & Yancik, 2003). Fatigue, Schmerzen und Distress gehören zu den am häufigsten berichteten Symptomen während und nach der primären Krebsbehandlung (Al Maqbali, Al Sinani, Al Naamani, Al Badi, & Tanash, 2020; Faller et al., 2016; Laird et al., 2011; Luctkar-Flude, Groll, Tranmer, & Woodend, 2007; van den Beuken-van Everdingen, Hochstenbach, Joosten, Tjan-Heijnen, & Janssen, 2016) . Angesichts der zunehmenden Zahl von Krebsüberlebenden und der steigenden Überlebensraten aufgrund von Fortschritten bei der Früherkennung, der Behandlung und dem Krebsmanagement (De Angelis et al., 2014; Miller et al., 2019) spielt die Rehabilitation eine immer wichtigere Rolle.

Weltweit werden unterschiedliche Rehabilitationsansätze für Krebspatient(inn)en eingesetzt. Basierend auf dem bio-psycho-sozialen Modell der Weltgesundheitsorganisation (WHO) basieren diese Programme auf einem ähnlichen, multidisziplinären Verständnis von Krebsrehabilitation (Hellbom et al., 2011; Silver et al., 2018; Stout et al., 2016). In Deutschland hat jeder Krebspatient(in) nach der Primärbehandlung einen gesetzlichen Anspruch auf die Teilnahme an einem dreiwöchigen kombinierten multidisziplinären Behandlungsprogramm, das aus Physiotherapie, Patientenschulung, Entspannungstraining, Funktionstraining, psychoonkologischer Behandlung, Ernährungsberatung und Berufsberatung besteht, je nachdem, wie die Funktionsfähigkeit und die Bedürfnisse der Patient(inn)en zu Beginn der

Rehabilitation eingeschätzt werden (Hellbom et al., 2011; A. Mehnert et al., 2017). Eine Besonderheit ist, dass in Deutschland die Krebsrehabilitation hauptsächlich in stationären Kliniken durchgeführt wird (Hellbom et al., 2011). Unkontrollierte Vorher-Nachher-Studien haben gezeigt, dass Krebsrehabilitanden ihren somatischen Status, ihren psychosozialen Status und ihre Lebensqualität verbessern und ihre Ängste, Depressionen und Belastungen von Beginn bis zum Ende der stationären Rehabilitation reduzieren können (Heim, Kunert, & Ozkan, 2001; Krüger et al., 2009; Teichmann, 2002).

1.2.1 Soziale Unterstützung unter Rehabilitanden

Zwei wesentliche Elemente der stationären und teilstationären Rehabilitation sind die soziale Unterstützung durch andere Patient(inn)en in der onkologischen Rehabilitation und körperliche Aktivität (Hellbom et al., 2011). Soziale Unterstützung ist ein wichtiger Faktor für das allgemeine Wohlbefinden (Cohen & Wills, 1985; Schaefer, Coyne, & Lazarus, 1981) und wurde sowohl mit der Verbesserung von krebsbedingtem Stress (Haugland, Wahl, Hofoss, & DeVon, 2016) als auch mit posttraumatischem Wachstum bei Krebspatient(inn)en (McDonough, Sabiston, & Wrosch, 2014) in Verbindung gebracht. In der stationären Krebsrehabilitation erhalten Krebspatient(inn)en soziale Unterstützung von anderen Rehabilitanden mit einer Krebsdiagnose (Peer-Unterstützung) während der von Therapeuten geleiteten Gruppenbehandlungssitzungen und unmoderierte Peer-Unterstützung bei Freizeitaktivitäten. Die drei wichtigsten Merkmale der Peer-Unterstützung sind: (1) emotionale Unterstützung durch das Besprechen persönlicher Schwierigkeiten, (2) informationelle Unterstützung durch die Vermittlung von Wissen, und (3) Beurteilungsunterstützung, wie z. B. die Ermutigung, die Problemlösung fortzusetzen, und die Bestätigung, dass die Bemühungen zu positiven Ergebnissen führen werden (Dennis, 2003). In bisherigen Studien wurden geschlechts- und altersabhängige Unterschiede bei der Suche nach und Bereitstellung von sozialer Unterstützung festgestellt. Frauen scheinen sowohl Männern als auch Frauen mehr emotionale Unterstützung zu bieten, und sie scheinen im Gegenzug mehr Hilfe zu erhalten (Jiang, Drolet, & Kim, 2018). Ältere Menschen (60+) bitten seltener ausdrücklich um emotionale Unterstützung als jüngere Menschen. Ältere (im Vergleich zu jungen) Erwachsen machten sich mehr Sorgen über mögliche soziale Kosten für Andere, was sie dazu veranlasste, weniger explizite soziale Unterstützung zu suchen (Jiang et al., 2018; Klauer & Winkeler, 2002). Systematische Übersichten, die den Nutzen von Einzel- und

Gruppen-Peer-Support-Interventionen für Krebspatient(inn)en untersuchten, die analog und online durchgeführt wurden, zeigten gemischte Ergebnisse. Peer-Support-Interventionen verbesserten das emotionale Wohlbefinden von Brustkrebspatientinnen, ihre Lebensqualität und ihre Therapietreue (Hu et al., 2019) sowie die psychosoziale Funktionsfähigkeit von Krebspatient(inn)en (Hoey, Ieropoli, White, & Jefford, 2008). Unmoderierte und unstrukturierte Peer-Support-Gruppeninterventionen, die online ohne Peer-Training durchgeführt wurden, hatten jedoch keine Wirkung oder sogar negative Auswirkungen auf einige psychosoziale Ergebnisse (Hu et al., 2019; Salzer et al., 2010). Bei fehlender Moderation oder Gruppenstruktur nahmen Wut- und Angstäußerungen sowie Diskussionen über Tod und Sterben zu (Salzer et al., 2010; Vilhauer, McClintock, & Matthews, 2010).

2 Ziele und Fragestellung

Krebspatient(inn)en können nur dann von Online-Krebsinformationen profitieren, wenn Sie über ausreichende Bedienungs-, Navigations-, Informations- und Bewertungsfähigkeiten verfügen, um qualitativ hochwertige krebsbezogenen Online-Informationen zu finden. Darüber hinaus müssen sie den krebsbezogenen Informationen bzw. dem Internet als Informationsmedium vertrauen können. Die ersten beiden meiner Publikationen beschäftigten sich daher mit den folgenden Untersuchungsfragen.

Das primäre Ziel meiner *systematischen Übersichtsarbeit* war es, herauszufinden, inwieweit Krebspatient(inn)en krebsbezogenen Online-Informationen, Internet-Webseiten als Quelle für krebsbezogene Informationen oder dem Internet als Medium für krebsbezogene Informationen vertrauen. Das primäre Ziel meiner qualitativen Performance-Test-Studie war es einen Einblick in die operativen, Navigations-, Informations- und Bewertungsfähigkeiten und -probleme von Krebspatient(inn)en zu gewinnen, die krebsbezogene Suchaufgaben im Internet durchführen.

In der ursprünglichen Planung der Dissertation war vorgesehen, im Anschluss an die Leistungsteststudie eine Intervention für Krebspatient(inn)en zur Stärkung ihrer Fähigkeiten zur Suche von krebsbezogenen Online-Informationen durchzuführen. Der Antrag für diese Interventionsstudie wurde im September 2021 und ein zweites Mal im Mai 2022 bei der DFG eingereicht. Aufgrund der geplanten Dauer der Interventionsstudie von 2 Jahren wurde in der dritten Sitzung des Promotionsausschusses beschlossen, die Interventionsstudie durch eine andere dritte Studie zu ersetzen.

Der Ausgangspunkt dieser dritten Studie waren die Beobachtungen des medizinischen Personals einer kooperierenden onkologischen Rehabilitationsklinik, dass ein hohes Ausmaß an Internetnutzung zwischen und nach den Rehabilitationssitzungen die sozialen Interaktionen zwischen den Patient(inn)en während ihres Klinikaufenthalts reduziert und das Rehabilitationsprogramm der Patient(inn)en beeinträchtigt. Sie stellten daher die Hypothese auf, dass die Verringerung der sozialen Interaktionen (als wesentliches Element der stationären Rehabiliation) zwischen Rehabilitanden sich negativ auf die Rehabilitationsergebnisse der Patient(inn)en auswirken würde. In der Studie wurden daher die folgenden Forschungsfragen untersucht: (1) Steht das *Ausmaß der Internetnutzung* von Krebspatient(inn)en während ihres Klinikaufenthalts in einem negativen Zusammenhang (Assoziation) mit der *wahrgenommenen sozialen Unterstützung unter Krebspatient(inn)en* während ihres Klinikaufenthalts? (2) Steht das *Ausmaß der Internetnutzung* von Krebspatient(inn)en während ihres Klinikaufenthalts in einem negativen Zusammenhang mit den Veränderungen der Werte für *Distress, Fatigue und Schmerzen* vom Beginn bis zum Ende des stationären Klinikaufenthalts, wobei *Distress* das primäre Ergebnis ist? Darüber hinaus wollte ich das Ausmaß und den Zweck der Internetnutzung von Krebspatient(inn)en während ihres Klinikaufenthalts und zu Hause beschreiben.

3 Methodik

3.1 Systematische Übersichtsarbeit

3.1.1 Studiendesign

Es wurde eine systematische Literaturübersicht durchgeführt, um das Vertrauen von Krebspatient(inn)en in krebsbezogene Online-Informationen, in Internet-Webseiten als Quelle für krebsbezogene Informationen oder in das Internet als Medium für Krebsinformationen zu untersuchen. Das Protokoll für die systematische Übersichtsarbeit wurde im internationalen prospektiven Register für Übersichtsarbeiten (PROSPERO) unter dem Registrierungscode CRD42017070190 erfasst.

3.1.2 Informationsquellen und Suchstrategie

Wir führten eine elektronische Literaturrecherche in den Datenbanken Medline, CINAHL, Web of Science, PsycINFO und PSYINDEX mit vorgegebenen Suchbegriffen und ohne Einschränkung des Veröffentlichungszeitraums durch. Alle Recherchen wurden am 4. Januar 2017 durchgeführt. Zusätzlich wurden die Referenzlisten der eingeschlossenen Studien manuell nach potenziell relevanten Studien durchsucht.

Um systematisch Suchbegriffe zu identifizieren, die den Forschungsfragen entsprechen könnten, wurden die PICO-Kriterien angepasst. PICO-Kriterien können den Prozess der Suche nach einer Antwort auf eine klinische Frage erleichtern, indem sie geeignete Schlüsselwörter identifizieren, die für die Durchführung einer Literatursuche verwendet werden können (Richardson, Wilson, Nishikawa, & Hayward, 1995). Der Schwerpunkt lag dabei auf den folgenden Kriterien: (P) „Population“ (Krebspatient(inn)en); und (O) Ergebnis (Vertrauen/Misstrauen/Bewertung der Glaubwürdigkeit). Wir schlossen alle Studien ein, unabhängig davon, ob es sich um eine Interventionsstudie handelte oder ob eine Vergleichsgruppe vorhanden war. Zusätzliche Suchbegriffe wurden nach einer Analyse der in den Schlüsselartikeln verwendeten „Medical Subject Headings“ (MeSH) und Textwörter ausgewählt, die bei früheren nicht systematischen explorativen Literaturrecherchen ermittelt wurden. Die einbezogenen Suchbegriffe wurden von den Autoren diskutiert und dann zu einem Suchstring zusammengestellt. Die Suchstrings wurden in jeder der genannten Datenbanken verwendet und berücksichtigten Synonyme, Pluralformen, Bindestriche und Mehrfachwortkombinationen. Die Suchstrategie wurde für jede Datenbank entsprechend modifiziert, um in Frage kommende Studien zu ermitteln.

3.1.3 Datenextraktion

Die Datenextraktion wurde von mir durchgeführt und von Mona Peikert gegengeprüft. Die folgenden Daten wurden aus den eingeschlossenen Studien extrahiert: (1) Studiencharakteristika, einschließlich Name des Autors, Jahr der Veröffentlichung, Titel der Veröffentlichung, des Ort der Datenerhebung, des Studiendesigns und der Stichprobengröße; (2) Charakteristika der Studienteilnehmenden, wie Alter, Geschlecht, Krebsart, Bildungsstatus, Gesundheitszustand; (3) Ergebnismerkmale, wie Fragebogen oder Items, die zur Messung des Vertrauens verwendet wurden; und (4) das gemessene Ergebnis des Vertrauens, die wahrgenommene Glaubwürdigkeit oder das Misstrauen (d. h. als Mittelwert oder Verteilung).

3.1.4 Bewertung der methodischen Qualität

Die Bewertung der methodischen Qualität der eingeschlossenen Arbeiten wurde von zwei Forschern der Studiengruppe unabhängig voneinander durchgeführt und basierte auf der RTI-Itembank (Viswanathan et al., 2013). Es wurden keine Studien aufgrund des Verzerrungsrisikos von der Überprüfung oder von nachfolgenden Analysen ausgeschlossen. In Übereinstimmung mit den Anweisungen der Entwickler wurde das Instrument an die Designs der eingeschlossenen Beobachtungsstudien angepasst. Sieben wurden verwendet, um Selektionsverzerrungen, Entdeckungsverzerrungen, Verwechslungen, selektive Ergebnisberichterstattung und Gesamtverzerrungen in den eingeschlossenen Studien zu bewerten.

3.1.5 Datenanalyse und Beschreibung

Zur Untersuchung der eingeschlossenen Studien wurde eine narrative Synthese durchgeführt (Dixon-Woods, Agarwal, Jones, Young, & Sutton, 2005). Außerdem wurden die Merkmale und Ergebnisse der eingeschlossenen Studien deskriptiv zusammengefasst.

3.2 Performance-Test-Studie

3.2.1 Studiendesign

Wir haben ein Performance-Test durchgeführt, um einen tieferen Einblick in die operativen, Navigations-, Informations- und Bewertungsfähigkeiten und -probleme von Krebspatient(inn)en zu erhalten, die das Internet für die Suche nach krebsbezogenen Informationen im Web nutzen. Es wurden drei qualitative Methoden der Datenerhebung eingesetzt: (1) die Think-Aloud-Methode (Ericsson & Simon, 1980) in Kombination mit (2) den Echtzeit-Notizen des Studienleiters und (3) Video- und Audiodaten der Bildschirmaktivitäten der Teilnehmenden.

Das Studienprotokoll für diese qualitative Studie ist im Open Science Framework (https://osf.io/mqu8z) frei verfügbar und wurde vor der Rekrutierung des ersten Teilnehmenden veröffentlicht.

3.2.2 Verfahren und Materialien

Jeder Termin begann mit einem kurzen Fragebogen zur Erfassung der folgenden Daten: (1) die sozioökonomischen Merkmale der Teilnehmenden, (2) ihre medizinischen Merkmale; und (3) ihre allgemeinen und krebsbezogenen Internetnutzungsmerkmale. Die Teilnehmenden mussten ihre Fähigkeiten bei der Internetsuche auf vier 5-Punkte-Skalen (von sehr schlecht bis sehr gut) bewerten. Diese maßen die von den Teilnehmenden selbst wahrgenommenen Bedienungsfähigkeiten, Navigationsfähigkeiten, Fähigkeiten zur Bewertung der Zuverlässigkeit von Informationen und Fähigkeiten zur Bestimmung der Relevanz maßen (van der Vaart & Drossaert, 2017).

Die Performance-Tests wurden gestartet, wenn alle Items abgeschlossen waren. Die Patient(inn)en führten 8 krebsbezogene Internet-Suchaufgaben aus, die auf den häufigsten Themen der krebsbezogenen Informationssuche im Internet basierten (Castleton et al., 2011; Mattsson et al., 2017). Die Teilnehmenden wurden aufgefordert und trainiert, laut zu denken, während sie die Aufgaben ausführten. Die Verbalisierung der Gedanken der Teilnehmenden ermöglichte es dem Forscher, einen Einblick in die kognitiven Prozesse der Teilnehmenden bei der Suche nach webbasierten Informationen zu gewinnen (van den Haak, De Jong, & Jan Schellens, 2003). Darüber hinaus beobachtete der Forscher die Teilnehmenden und machte sich in Echtzeit Notizen, um Probleme bei der Bedienung der Hardware zu erkennen.

3.2.3 Datenanalyse

Die soziodemografischen Merkmale der Teilnehmenden, die medizinischen Merkmale sowie die allgemeine und krebsbezogene Internetnutzung wurden deskriptiv zusammengefasst.

Die Video- und Audiodaten sowie meine Echtzeitaufzeichnungen wurden analysiert, um (1) die Leistungsprobleme der Teilnehmenden zu ermitteln, (2) die Leistung der Teilnehmenden zu bewerten und (3) Leistungs- und strategische Merkmale der Aufgabenausführung zu ermitteln.

Um die Leistungsprobleme der Teilnehmenden zu identifizieren, folgte ich einem induktiven Kodierungsprozess (Braun & Clarke, 2006). Die Verhaltensweisen oder Aussagen der Teilnehmenden wurden zunächst kodiert und anschließend in Kategorien und Unterkategorien eingeteilt, die dann benannt wurden.

Die Bewertung der Leistung der Teilnehmenden pro Aufgabe und der Schwierigkeit der Aufgaben basierte auf zwei Variablen: (1) Konnten die Teilnehmenden ihre Aufgabe vollständig selbständig, mit Hilfe oder gar nicht erledigen, und (2) die für die Ausführung der Aufgabe benötigte Zeit (je mehr Zeit für die Ausführung einer Aufgabe benötigt wird, desto höher ist die Schwierigkeit der Aufgabe).

3.3 Querschnitts- und Längsschnittstudie

3.3.1 Studiendesign

Im Querschnittsteil der Studie wurden Daten mithilfe eines Papierfragebogens erhoben, um Einblicke in das Ausmaß und den Zweck der Internetnutzung der Rehabilitanden, ihre Präferenzen in Bezug auf die künftige Nutzung von eHealth- oder webbasierten Programmen, ihre wahrgenommene soziale Unterstützung durch andere Patient(inn)en und ihre körperliche Aktivität während des Klinikaufenthalts zu gewinnen. Für den Längsschnittteil der Studie wurden am ersten und letzten Tag des Klinikaufenthalts medizinische Daten und drei patientenbezogene Ergebnismessungen (Patient Reported Outcome Measures - PROMS) erhoben. Das Studienprotokoll für diese Studie ist im Open Science Framework frei verfügbar (https://osf.io/y2hgr) und wurde vor der Rekrutierung des ersten Teilnehmenden veröffentlicht.

3.3.2 Setting, Rekrutierung und Teilnehmende

Die Teilnehmenden wurden in der dritten Woche ihres dreiwöchigen stationären Krebsrehabilitationsaufenthalts in einer VAMED Klinik Lehmrade rekrutiert. Potenzielle Teilnehmenden wurden während der Patientensprechstunde angesprochen. Eingeschlossen wurden Patient(inn)en, bei denen eine Krebserkrankung diagnostiziert wurde, die 18 Jahre alt waren und über ausreichende mündliche und schriftliche Kenntnisse der deutschen Sprache verfügten. Die medizinischen Daten werden routinemäßig am ersten und letzten Tag des Klinikaufenthalts erhoben. Anschließend händigte der ärztliche Leiter den Teilnehmenden den Fragebogen aus, den die Teilnehmenden ausfüllten und am nächsten Tag ihrem(r) behandelnden Arzt(in) übergaben.

3.3.3 Messungen und Datenquellen

3.3.3.1 Querschnittlicher Fragebogen

Soziodemographische, medizinische Merkmale

Der Fragebogen, der in der letzten Woche des Klinikaufenthalts ausgefüllt wurde, enthielt Multiple-Choice-Items zur Beschreibung soziodemografischer (Alter, Geschlecht, Schulbildung, berufliche Situation, aktuelle Lebenssituation) und medizinischer Merkmale (Krebsart) der Teilnehmenden.

Ausmaß und Zweck der Internetnutzung der Patient(inn)en

Wir verwendeten eine angepasste Version des von verwendeten Fragebogens, um die Internetnutzung der Patient(inn)en während ihres Klinikaufenthalts und zu Hause zu erfassen. Zunächst gaben die Teilnehmende an, ob sie das Internet nutzen.

Die Häufigkeit der Internetnutzung zu Hause und während des Klinikaufenthalts wurde auf einer 4-stufigen Antwortskala von "nie" bis "täglich" angegeben. Zwei Fragen zur täglichen Zeit, die während des Klinikaufenthalts und zu Hause online verbracht wurde, wurden auf einer 5-stufigen Antwortskala von "keine" bis "mehr als 120 Minuten" beantwortet. Um die häufigsten Online-Aktivitäten während des Klinikaufenthalts und zu Hause anzugeben, konnten die Teilnehmenden eine oder mehrere von zehn vordefinierten Optionen auswählen oder selbst eine Aktivität eingeben.

Ansichten der Patient(inn)en zur Internetnutzung während des Klinikaufenthalts.

Die Teilnehmende bewerteten die folgenden Aussagen auf einer 4-stufigen Likert-Skala von "stimme überhaupt nicht zu" bis "stimme voll und ganz zu": "Ich fühle mich durch die Nutzung des Internets während des Rehabilitationsaufenthalts von der Rehabilitation abgelenkt", und "Ich war bei den Freizeitaktivitäten der Klinik abwesend, weil ich die Zeit im Internet verbracht habe".

Wahrgenommene soziale Unterstützung zwischen Patient(inn)en während des Klinikaufenthalts

Zur Messung der wahrgenommenen sozialen Unterstützung zwischen Patient(inn)en während des Klinikaufenthaltes wurde der Fragebogen zur sozialen Unterstützung zwischen Patient(inn)en (F-SozU-P) verwendet (Kastner, 2013). Der F-SozU-P ist eine Adaptation des deutschen Selbstauskunftsbogens zur Erfassung sozialer Unterstützung (F-SozU) (Fydrich, Geyer, Hessel, Sommer, & Brähler, 1999), der die Langversion der Kurzform zur Erfassung sozialer Unterstützung (F-SozU K-6) (Kliem et al., 2015) darstellt. Sowohl die Reihenfolge als auch der Satzbau der F-SozU-Items wurden im F-Sozu-P beibehalten. Allerdings wurden Wörter wie "Menschen, Verwandte, Familie" im F-Sozu durch "Mitpatient(inn)en" oder "Patient(inn)en" in der F-Sozu-P ersetzt. Alle 54 Items wurden auf einer fünfstufigen Likert-Skala bewertet, die von 1 = 'stimme überhaupt nicht zu' bis 5 = 'stimme voll und ganz zu' reichte. In der Validierungsstudie hatte die Globalskala (WasU-P) einen hohen Wert für die interne Konsistenz (α = .93) (Kastner, 2013).

3.3.3.2 Longitudinaler Fragebogen

Der Longitudinale Fragebogen umfasste drei validierte PROMS. Erstens, die deutsche Version des Distress Thermometers (DT) (Anja Mehnert, Müller, Lehmann, & Koch, 2006). Es besteht aus einer Ein-Item-Skala von 0 = keine Belastung bis 10 = extreme Belastung, die angibt, wie viel Distress der Teilnehmende in der letzten Woche, einschließlich heute, empfunden hat (Anja Mehnert et al., 2006). Zweitens, die deutsche Version der numerischen Ratingskala (NRS) für Schmerzen (Hawker, Mian, Kendzerska, & French, 2011). Bei der NRS für Schmerzen handelt es sich um eine 11-stufige numerische Skala von 0 = kein Schmerz bis 10 = schlimmster vorstellbarer Schmerz (Hawker et al., 2011). Drittens füllten die Teilnehmenden die deutsche Version des Brief Fatigue Inventory (BFI) aus (Radbruch et al., 2003). Das BFI wird für die spezifische Bewertung der Fatigue bei Patient(inn)en mit onkologischen Erkrankungen verwendet. Der Fragebogen enthält zehn Items. Drei Items fordern die Patient(inn)en auf, den Schweregrad ihrer Fatigue im Durchschnitt, am schlimmsten und im Moment zu bewerten, wobei 0 = keine Fatigue und 10 = Fatigue so schlimm, wie man sie sich vorstellen kann. Außerdem wird mit sechs Items gemessen, inwieweit die Fatigue die allgemeine Aktivität, die Stimmung, das Gehen, die Arbeit, die Beziehungen zu anderen Menschen und die Lebensfreude der Patient(inn)en beeinträchtigt. Diese Items werden auf einer Skala von 0 = keine Beeinträchtigung bis 10 = vollständige Beeinträchtigung bewertet (Radbruch et al., 2003). Ein Wert zwischen 3 und 4 Punkten bedeutet, dass die Fatigue bei Tumorpatient(inn)en einen mittleren Schweregrad aufweist.

3.3.4 Pilotierung

Wir haben den kompletten Satz von Items im März 2018 an sechs Reha-Patient(innen), der VAMED Klinik Lehmrade pilotiert. Die Einschlusskriterien für die Teilnahme am Pilottest waren identisch mit denen der Hauptstudie. Die Teilnehmenden wurden angewiesen, laut zu denken, während sie die Fragebögen ausfüllten, um festzustellen, wie die Teilnehmenden die Items interpretierten, ob die Anweisungen leicht zu verstehen waren, ob Probleme auftraten und ob die Teilnehmendenr die Items so verstanden, wie sie gemeint waren (Collins, 2003). Die Pilotstudie zeigte zufriedenstellende Ergebnisse und ergab, dass die Teilnehmenden die Aufgaben im Allgemeinen gut verstanden. Das Ausfüllen des Fragebogens dauerte zwischen 25 und 50 Minuten.

3.3.5 Datenanalyse

Die soziodemografischen Merkmale der Teilnehmenden, die medizinischen Merkmale, das Ausmaß und der Zweck der Internetnutzung der Rehabilitanden wurden deskriptiv zusammengefasst.

Für die weitere Analyse schlossen wir Fälle aus, bei denen mehr als 30 % der F-SozU-P-Items fehlten (Wirtz, 2004). Wir verwendeten eine multiple lineare Regressionsanalyse, um den Zusammenhang zwischen dem Ausmaß der Internetnutzung der Teilnehmenden (unabhängige Variable) und der wahrgenommenen sozialen Unterstützung der Patient(inn)en während des Klinikaufenthalts (abhängige Variable) zu bestimmen. Zur Kontrolle potenzieller Störvariablen wurden körperliche Aktivität während des Klinikaufenthalts, Alter, Bildung und Geschlecht als zusätzliche unabhängige Variablen einbezogen. Kategorische Variablen wurden als Dummys kodiert. Die Variable Ausmaß der Internetnutzung war das Produkt aus den beiden Faktoren Zeit, die während des Klinikaufenthalts online verbracht wurde, und Häufigkeit der Internetnutzung während des Klinikaufenthalts. Fehlende Werte des F-SozuU-P und der unabhängigen Variablen Ausmaß der Internetnutzung während der Rehabilitation, GSLTPAQ, Alter und Bildung wurden mit Hilfe des EM-Algorithmus (Dempster, Laird, & Rubin, 1977) korrigiert.

Wir verwendeten drei lineare gemischte Modelle mit wiederholten Messungen, um den Zusammenhang zwischen dem Ausmaß der Internetnutzung der Teilnehmenden während der stationären Rehabilitation (unabhängige Variable) und der Veränderung des Distress als primärem Ergebnis sowie den sekundären Ergebnissen Fatigue und Schmerzen (abhängige Variablen) vom Beginn bis zum Ende der stationären Rehabilitation zu bestimmen. Zur Beantwortung der Forschungsfrage haben wir die Interaktionen zwischen dem Ausmaß der Internetnutzung der Teilnehmenden während des Klinikaufenthalts und der Zeit (zweiter Messzeitpunkt als Referenzkategorie) in das Modell aufgenommen. Wir haben die Interaktion zwischen der sozialen Unterstützung der Patient(inn)en und der Zeit sowie die Interaktion zwischen dem Ausmaß der Internetnutzung während des Klinikaufenthalts, dem Ausmaß der Internetnutzung der Patient(inn)en und der Zeit in das Modell aufgenommen. Wir nahmen die beiden Interaktionen auf, um zu testen, ob die soziale Unterstützung den Zusammenhang zwischen dem Ausmaß der Internetnutzung der Teilnehmenden und den drei PROMS moderiert. Zusätzlich testeten wir die Haupteffekte soziale Unterstützung unter den

Patient(inn)en, Zeit und den Interaktionseffekt von Ausmaß der Internetnutzung der Teilnehmenden und sozialer Unterstützung unter den Teilnehmenden. Die allgemeine Anpassung der Modelle wurde anhand der -2log-Likelihood (-2LL) bewertet. Zur Schätzung der Parameter in allen drei Modellen verwendeten wir die Methode der eingeschränkten maximalen Wahrscheinlichkeit (REML) (Liu, Luo, Zhang, & Liu, 2016). Für unsere Modelle wählten wir die heterogene autoregressive (ARH(1)) Kovarianzstruktur erster Ordnung. Wir erwarteten, dass die Varianz von Distress, Schmerz und Fatigue am ersten Tag größer sein würde als am letzten Tag des Klinikaufenthalts (Pusponegoro, Rachmawati, Notodiputro, & Sartono, 2017).

Für die geplanten multiplen Regressionsanalysen führten wir eine a priori Powerberechnung mit G*Power durch. Auf der Grundlage dieser Analyse kamen wir zu dem Schluss, dass Studiendaten von 352 Patient(inn)en verfügbar sein sollten. Diese Patient(inn)enzahl ist ausreichend, um in einer multiplen linearen Regressionsanalyse mit sieben Prädiktorvariablen einen Zusammenhang mit kleiner bis mittlerer Effektgröße von R=.20 (entsprechend einem f-Quadrat=.0417) mit 80% Power und einem Signifikanzniveau von Alpha =.05 nachzuweisen.

4 Ergebnisse

4.1 Systematische Übersichtsarbeit

4.1.1 Auswahl der Studien

Die Suche in den Datenbanken ergab 7.314 Treffer. Alle Studien sind bei Figshare (https://doi.org/10.6084/m9.figshare.7701014.v1) verfügbar. Von diesen erfüllten 54 Studien die Zulassungskriterien der ersten Auswahlphase. Von den verbleibenden 54 Artikeln erfüllten sieben (Crutzen et al., 2014; Lussiez et al., 2017; Mayer et al., 2007; Pereira, Koski, Hanson, Bruera, & Mackey, 2000; Roach et al., 2009; Shea-Budgell, Kostaras, Myhill, & Hagen, 2014) die Zulassungskriterien der zweiten Phase und wurden daher in die Überprüfung einbezogen.

4.1.2 Merkmale der Studien

Alle Studien wurden zwischen 2000 und 2014 in englischer Sprache in Fachzeitschriften mit Peer-Review veröffentlicht. Sechs der sieben Studien wurden in Nordamerika durchgeführt, eine (Crutzen et al., 2014) in Europa (Niederlande). Alle sieben Studien waren Querschnittsstudien. Mit einer Ausnahme verwendeten alle Studien ein Item um das Vertrauen der Teilnehmenden in Informationen aus dem Internet (Losken, Burke, Elliott, &

Carlson, 2005; Lussiez et al., 2017; Pereira et al., 2000) oder das Internet als Medium für Gesundheitsinformationen (Mayer et al., 2007; Roach et al., 2009; Shea-Budgell et al., 2014) zu messen. Die Stichprobengröße der Krebspatient(inn)en den einbezogenen Studien reichte von 63 bis 719 (Median 157).

4.1.3 Synthese der Ergebnisse

Insgesamt 1.054 Patient(inn)en gaben an, dass sie den Online-Krebsinformationen etwas oder sehr vertrauen, während 154 Patient(inn)en angaben, dass sie mäßig vertrauen oder unentschlossen sind, ob sie Online-Gesundheitsinformationen vertrauen sollten, und 833 Patient(inn)en gaben an, dass sie kein oder wenig Vertrauen in krebsbezogene Informationen haben, die sie im Internet oder im Internet als Medium für krebsbezogene Informationen finden. Im Hinblick auf die einzelnen Ergebnisse der einzelnen Studien sind zwei Punkte auffällig. In allen Studien bis auf Eine (Roach et al., 2009) gab die Mehrheit der Teilnehmenden an, ein gewisses oder großes Vertrauen in Online-Krebsinformationen zu haben. Darüber hinaus gaben 55 % der ambulant behandelten Brustkrebspatientinnen an, dass sie unentschlossen seien, ob sie Online-Informationen vertrauen sollten (Pereira et al., 2000).

4.1.4 Bewertung der Qualität der eingeschlossenen Studien

Vier Studien gaben keine Einschlusskriterien der Studienteilnehme an (Crutzen et al., 2014; Lussiez et al., 2017; Mayer et al., 2007). Keine der Studien verwendete unterschiedliche Rekrutierungsmaßnahmen für verschiedene Personen (Frage 2). Drei Studien (Crutzen et al., 2014; Mayer et al., 2007; Roach et al., 2009) verwendeten gültige und zuverlässige Instrumente, während die übrigen vier Studien selbst entwickelte Fragebögen verwendeten, die nicht psychometrisch validiert waren. Confounding wurde in allen Studien berücksichtigt, indem die Studienbeschränkungen glaubhaft in Betracht gezogen wurden (Frage 11). In fünf der Studien wurden wichtige Confounding-Variablen berücksichtigt (Frage 13). Eine Studie berichtete über die deskriptiven Ergebnisse möglicher Störfaktoren wie Alter oder Bildung, untersuchte aber nicht, ob einer der Störfaktoren einen Einfluss auf das gemessene Ergebnis hatte (Losken et al., 2005). In einer weiteren Studie wurde nicht angegeben, ob die Art der von den Patient(inn)en gesuchten Informationen nach sozioökonomischen Faktoren variiert (Shea-Budgell et al., 2014).

4.2 Performance-Test-Studie

4.2.1 Soziodemografische und medizinische Merkmale der Teilnehmenden

Es nahmen mehr Frauen (12/22, 55 %) als Männer an der Studie teil. Das Alter der Teilnehmenden lag zwischen 25 und 81 Jahren (Mittelwert 57 Jahre). Fast drei Viertel der Teilnehmenden lebte mit einem Partner zusammen (16/22, 73 %). Die meisten Teilnehmenden (13/22, 59 %) hatten eine Schulbildung von 10 Jahren oder weniger, während 27 % (6/22) über einen Hochschulabschluss verfügten. Brust- (6/22, 27 %), Dickdarm- (4/22, 18 %) und Prostatakrebs (3/22, 13 %) waren die am häufigsten genannten Krebsdiagnosen. Der durchschnittliche Wert für den selbst wahrgenommenen Gesundheitszustand lag bei 4.5.

4.2.2 Internetnutzung durch Patient(inn)en und Selbsteinschätzung der Internetsuchfähigkeiten

Die durchschnittliche Interneterfahrung der Teilnehmenden betrug 15 Jahre. Die meisten der Teilnehmenden (13/22, 59 %) nutzten das Internet weniger als 1 Stunde pro Tag. Die häufigsten krebsbezogenen Aktivitäten im Internet waren die Suche nach krebsbezogenen Informationen (14/22, 64 %) und die Kommunikation mit Angehörigen (14/22, 64 %). Die Teilnehmenden bewerteten ihre operativen, Navigations-, Informations- und Bewertungsfähigkeiten als mittel bis gut.

4.2.3 Suchstrategie und Effektivität der Recherchen

Die Performance-Tests von 21 Teilnehmenden wurden in die Analyse einbezogen. Keiner der Teilnehmenden nutzte medizinische Webseiten als Ausgangspunkt. Alle Suchaufgaben wurden mit der Suchmaschine Google gestartet. Im Durchschnitt schlossen die Teilnehmenden 59,9 % (85/142) aller Aufgaben erfolgreich ab.

4.2.4 Probleme bei der Suche nach krebsbezogenen Online-Informationen

4.2.5 Bedienung von Computer und Webbrowser

Insgesamt 62 % (13/21) der Teilnehmenden hatten mindestens ein Problem mit der Computer-Hardware (Tastatur und Maus) oder Probleme mit den grundlegenden Webbrowser-Funktionen. Zu den häufigen Problemen gehörte das Auffinden des Webbrowser-Symbols auf dem Desktop und das Schließen und erneute Öffnen des Webbrowsers, um die Suchbegriffe anzupassen, anstatt die Zurück-Taste des Webbrowsers zu verwenden. Die meisten Bedienungsprobleme (94/122, 77 %) traten bei denselben 6 Teilnehmenden auf. Nach Beendigung mehrerer Aufgaben beobachtete der Forscher, dass die

Teilnehmenden wegen der wiederkehrenden Bedienungsprobleme zunehmend frustriert wurden.

4.2.6 Navigieren und Orientieren

Insgesamt 33 % (7/21) der Teilnehmenden hatten mindestens ein Problem mit der Navigation und Orientierung in Webbrowsern und auf Webseiten. Probleme traten häufig auf, wenn die Webseiten komplexe Strukturen aufwiesen, wie z. B. verschiedene grafische Steuerelemente (z. B. Dropdown-Listen oder Ankerlinks). Bemerkenswert ist, dass die meisten Orientierungs- und Navigationsprobleme (94/122, 77 %) von der gleichen Gruppe von 6 Teilnehmenden auftraten, die auch die meisten operativen Probleme hatten.

4.2.6.1 Verwendung von Suchstrategien

Insgesamt 95 % (20/21) der Teilnehmenden hatten mindestens ein Problem bei der Anwendung von Suchstrategien. Die meisten Probleme traten in der ersten Phase auf, als die Teilnehmenden die Suchbegriffe formulierten. Insgesamt verwendeten 90 % (19/21) der Teilnehmenden nicht aufgabenbezogene Suchbegriffe oder unspezifische Suchbegriffe.

4.2.7 Bewertung von Relevanz und Zuverlässigkeit

Alle Teilnehmenden hatten mindestens ein Problem bei der Bewertung ihrer Relevanz und Zuverlässigkeit. Keiner der Teilnehmenden kontrollierte die Quelle oder Aktualität der Informationen, mit Ausnahme vom Teilnehmenden 19. Außerdem hat keiner der Teilnehmenden die Informationen auf einer Website mit denen auf einer anderen Website für jede Aufgabe überprüft. Die meisten Teilnehmenden öffneten nur dann eine zweite Website, wenn sie mit den Informationen auf der ersten Website nicht zufrieden waren.

4.3 Querschnitts- und Längsschnittstudie

4.3.1 Soziodemografische und medizinische Merkmale der Teilnehmenden

323 Rehabilitationspatient(inn)en nahmen teil. 900 Rehabilitationspatient(inn)en wurden zur Teilnahme aufgefordert, was eine Rücklaufquote von 36 % ergibt. Das Alter der Teilnehmenden reichte von 29 bis 88 Jahren. Es gab mehr weibliche (172/323, 53,3 %) als männliche Teilnehmende. Etwa ein Drittel (111/323, 34,4 %) der Teilnehmenden hatte eine Schulbildung von mehr als 10 Jahren. Fast die Hälfte (146/323, 48,3 %) der Teilnehmenden war im Ruhestand. 70 % (226/323) der Teilnehmenden waren verheiratet oder lebten in einer festen Beziehung. Dickdarmkrebs (69/323, 17,5 %), Brustkrebs (66/323, 16,7 %) und Prostatakrebs (49/323, 12,4 %) waren die häufigsten Krebsarten unter den Teilnehmenden.

4.3.2 Ausmaß und Zweck der Internetnutzung durch Patient(inn)en

Von den 323 Teilnehmenden gaben 279 Teilnehmende (86,4 %) an, dass sie das Internet nutzen. Diese Teilnehmende werden im folgenden Abschnitt als "Internetnutzer(innen)" bezeichnet. Während ihres Klinikaufenthalts nutzten 71 % (198/279) der Internetnutzer(innen) das Internet täglich. Zu Hause nutzten 85% (237/279) der Internetnutzer(innen) das Internet täglich. 30 der 279 (10,8%) Internetnutzer(innen) haben das Internet während des Klinikaufenthalts nie genutzt. Während des Klinikaufenthalts nutzten 27 der 279 Internetnutzer(innen) (9,8 %) das Internet mehr als eine Stunde pro Tag, verglichen mit 84 der 277 Teilnehmenden (30,3 %) zu Hause. Während des Klinikaufenthalts und zu Hause gehörten die Nutzung sozialer Medien (192/279, 68,9 %; 208/279, 74,6 %) und das Schreiben von E-Mails (143/279, 51,3 %; 228/279, 81,7 %) zu den drei am häufigsten genannten Online-Aktivitäten. 9,3 % (26/279) der Internetnutzer(innen) fühlten sich durch die Nutzung des Internets während ihres Klinikaufenthalts von der Rehabilitation abgelenkt (46/279, 16,5 %) und 1,8 % (5/279) gaben an, Freizeitaktivitäten der Klinik verpasst zu haben, weil sie Zeit im Internet verbrachten

4.3.3 Zusammenhang zwischen dem Ausmaß der Internetnutzung und der sozialen Unterstützung der Rehabilitanden während der Rehabilitation

Das Ausmaß der Internetnutzung der Teilnehmenden während ihres Klinikaufenthalts (t_{315}=0.78, P=.43) war nicht negativ signifikant mit der wahrgenommenen sozialen Unterstützung der Patient(inn)en assoziiert. 17% (R^2=.17) der Varianz der wahrgenommenen sozialen Unterstützung unter Rehabilitationspatient(inn)en während der Rehabilitation wurde durch das Modell erklärt.

4.3.4 Zusammenhang zwischen dem Ausmaß der Internetnutzung und den Veränderungen des Distresslevel zwischen dem ersten und dem letzten Tag des Klinikaufenthalts (primäres Outcome)

Die Interaktionen zwischen dem Ausmaß der Internetnutzung der Teilnehmenden während des Klinikaufenthalts und der Zeit ($F_{1,\ 306.08}$=0.29, P=.59) und die Interaktion zwischen der wahrgenommenen sozialen Unterstützung unter den Patient(inn)en und der Zeit ($F_{1,\ 306.15=}$0.99, P=.32) waren nicht negativ mit den Veränderungen des Distresslevels der Teilnehmenden assoziiert. Die Interaktion zwischen dem Ausmaß der Internetnutzung der Teilnehmenden während ihres Klinikaufenthalts und der wahrgenommenen sozialen

Unterstützung durch Patient(inn)en und Zeit (F1, 306.02=0.17, P=.68) war nicht signifikant mit den Veränderungen des Distresslevels der Teilnehmenden assoziiert.

4.3.5 Zusammenhang zwischen dem Ausmaß der Internetnutzung und Veränderungen der Fatigue und der Schmerzen zwischen dem ersten und dem letzten Tag des Klinikaufenthalts (sekundäre Ergebnisse)

Die Interaktionen zwischen dem Ausmaß der Internetnutzung der Teilnehmenden während des Klinikaufenthalts und der Zeit ($F_{1,\ 308.89}$=0.02, P=.90) und die Interaktion zwischen der wahrgenommenen sozialen Unterstützung unter den Patient(inn)en und der Zeit ($F_{1,\ 308.99}$=0.08, P=.78) waren nicht signifikant negativ mit den Veränderungen des Fatiguelevels der Teilnehmenden assoziiert. Die Interaktion zwischen dem Ausmaß der Internetnutzung der Teilnehmenden während ihres Klinikaufenthalts und der wahrgenommenen sozialen Unterstützung durch Patient(inn)en und der Zeit ($F_{1,\ 308.79}$=0.00, P=.99) war nicht signifikant mit den Veränderungen des Fatiguelevels der Teilnehmenden verbunden.

Die Interaktionen zwischen dem Ausmaß der Internetnutzung der Teilnehmenden während ihres Klinikaufenthalts und der Zeit ($F_{1,\ 306.31}$=1.84, P=.18) und die Interaktion zwischen der wahrgenommenen sozialen Unterstützung unter den Patient(inn)en und der Zeit (F1, 306.31=1.52, P=.22) waren nicht signifikant negativ mit den Veränderungen des Schmerzlevels der Teilnehmenden assoziiert. Die Interaktion zwischen dem Ausmaß der Internetnutzung der Teilnehmenden während ihres Klinikaufenthalts und der wahrgenommenen sozialen Unterstützung durch Patient(inn)en und der Zeit ($F_{1,\ 306.09}$=1.79, P=.18) war nicht signifikant mit den Veränderungen des Schmerzlevels der Teilnehmenden verbunden.

5 Diskussion

5.1 Zusammenfassung der wichtigsten Ergebnisse

Das primäre Ergebnis der systematischen Übersichtsarbeit war es, dass die Hälfte der Krebspatient(inn)en in den einbezogenen sieben Studien angaben, dass sie krebsbezogene Online-Informationen, Internet-Webseiten als Quelle für krebsbezogene Informationen oder dem Internet als Medium für krebsbezogene Informationen vertrauen. Die Bewertung der eingeschlossenen Studien mit der RTI-Itembank (Viswanathan et al., 2013) zeigt, dass die Schätzungen der selektiven Ergebnisberichterstattung, des Confoundings und der

Gesamtbewertung einen positiven Eindruck von der methodischen Qualität der eingeschlossenen Studien vermitteln.

Die Ergebnisse der Performance-Test-Studie deuten darauf hin, dass eine beträchtliche Gruppe von Krebspatient(inn)en nicht über die notwendigen Bedienungs-, Navigations-, Informations- und Bewertungskompetenzen verfügte, um von krebsbezogenen Internetsuchen zu profitieren. 6 Teilnehmende hatten erhebliche Probleme mit der Bedienung der Hardware, der Bedienung des Computers und des Webbrowsers sowie mit der Navigation und Orientierung in Webbrowsern und auf Webseiten. Diese Teilnehmenden verursachten drei Viertel (94/122, 77 %) der Bedienungs- und Navigationsprobleme und konnten nur 29% ihrer Aufgaben erfolgreich abschließen (gegenüber 65% bei den anderen 15 Teilnehmenden). Obwohl die Bedienungs- und navigatorischen Fähigkeiten der meisten Teilnehmenden für die Internetrecherche ausreichend zu sein schienen, waren die Informations- und vor allem die Bewertungsfähigkeiten deutlich geringer. Viele Teilnehmende hatten Schwierigkeiten, eine aufgabenbezogene Suchanfrage zu formulieren (19/21, 90%), ein aufgabenbezogenes Suchergebnis (11/21, 52%) eines Anbieters ohne kommerzielles Interesse auszuwählen (8/21, 38%) und die Webseite zu durchsuchen, um die Antwort auf die Aufgabe zu finden (6/21, 29%). Besorgniserregende ist, dass nur 19 % (4/21) der Teilnehmenden die Informationen auf einer Website mit denen auf einer anderen Website verglichen, und nur 5 % (1/21) der Teilnehmenden informierten sich über den Anbieter der Website. Die übrigen Teilnehmenden schienen sich nicht für die Quelle oder die Aktualität der Informationen zu interessieren.

Die Hypothesen der Quer- und Längsschnittstudie werden durch die Studienergebnisse nicht gestützt. Das Ausmaß der Internetnutzung der Teilnehmenden während ihres Aufenthalts in der onkologischen Rehabilitationsklinik war nicht negativ mit der wahrgenommenen sozialen Unterstützung unter Krebspatient(inn)en während ihres Klinikaufenthalts verbunden. Darüber hinaus war das Ausmaß der Internetnutzung der Teilnehmenden während ihres Klinikaufenthalts auch nicht negativ mit der Veränderung der drei PROMS Distress (primärer Endpunkt), Schmerzen und Fatigue vom ersten bis zum letzten Tag des Klinikaufenthalts verbunden.

Darüber hinaus zeigen die Ergebnisse, dass mehr als vier Fünftel der Teilnehmenden Internetnutzer(innen) waren. Während des Klinikaufenthalts nutzten 71 % der Internetnutzer(innen) das Internet täglich. Etwa 10 % der Internetnutzer(innen) nutzten das

Internet während ihres Klinikaufenthalts nie. Während ihres Klinikaufenthaltes schienen die Teilnehmenden das Internet vor allem für die Kommunikation mit Verwandten, Bekannten und Fremden zu nutzen und weniger für gesundheitsbezogene Aktivitäten.

5.2 Diskussion der Ergebnisse

Die Ergebnisse der sieben Studien, die in die systematische Übersichtsarbeit einbezogen wurden, unterschieden sich je nach Formulierung der Vertrauensfrage. In drei Studien wurden die Teilnehmenden gebeten, ihr Vertrauen in das Internet als Medium für krebsbezogene Informationen einzuschätzen (Mayer et al., 2007; Roach et al., 2009; Shea-Budgell et al., 2014). In diesen drei Studien war die Vertrauenswerte niedriger als in den vier anderen Studien, in denen die Teilnehmenden gefragt wurden, wie sehr sie den krebs- oder gesundheitsspezifischen Informationen, die sie online fanden, vertrauten (Crutzen et al., 2014; Losken et al., 2005; Lussiez et al., 2017; Pereira et al., 2000). Eine mögliche Erklärung ist, dass wenn Patient(inn)en gebeten werden, anzugeben, wie sehr sie den Informationen, die sie online finden, vertrauen, könnten sie die Frage eher als eine Bewertung ihrer Fähigkeiten Informationen im Internet zu finden (van der Vaart & Drossaert, 2017; van der Vaart et al., 2013) interpretieren. Die potenzielle Verzerrung, die entsteht, wenn Patient(inn)en ihre eigene Informationskompetenz oder eHealth-Kompetenz einschätzen, besteht darin, dass sie ihre eigenen Fähigkeiten wahrscheinlich überschätzen (Merritt & Smith, 2005; van der Vaart et al., 2011).

Die methodische Qualität der eingeschlossenen Studien vermittelte insgesamt einen positiven Eindruck. Allerdings wurde in vier Studien nicht angegeben, ob die Einschlusskriterien für die verschiedenen Teilnehmenden variierten. Aufgrund der fehlenden Angaben zu den Einschlusskriterien kann ein Selektionsbias nicht ausgeschlossen werden, der die Verallgemeinerbarkeit der Studienergebnisse einschränken kann (Hernán, Hernández-Díaz, & Robins, 2004). Die Nichtangabe der Einschlusskriterien lässt jedoch nur Rückschlüsse auf die Berichtsqualität der eingeschlossenen Studien zu, nicht aber auf die Qualität der Studien (Margulis et al., 2014). Darüber hinaus verwendeten nur drei der Studien gültige und zuverlässige Instrumente, was ein Indikator für eine Verzerrung bei der Erfassung ist (Viswanathan et al., 2013). Weitere Forschung muss mit einem validierten Instrument durchgeführt werden, um das Vertrauen der Patient(inn)en in krebsbezogene Informations-Webseiten zu messen.

Die Ergebnisse der Performance-Studie stimmen mit denen früherer Studien überein, in denen Performance- Tests zur Analyse der Internetsuchfähigkeiten von gesunden Teilnehmenden (van Deursen & van Dijk, 2011) und Patient(inn)en mit rheumatoider Arthritis (van der Vaart et al., 2013) eingesetzt wurden. Bedienungs- und Navigationsprobleme traten ebenfalls bei etwa einem Drittel der Stichproben auf (van der Vaart et al., 2013; van Deursen & van Dijk, 2011). Darüber hinaus hatten fast alle Teilnehmenden unserer und der zwei ähnlichen Studien Probleme mit der Informations- und Bewertungsfähigkeit (van der Vaart et al., 2013; van Deursen & van Dijk, 2011). Aufgrund der Ähnlichkeit der Ergebnisse gehen wir davon aus, dass die festgestellten Probleme bei der Internetsuche auch bei Patient(inn)en mit anderen Gesundheitsstörungen und in der gesunden Bevölkerung zu finden sind. Zusätzlich zu den nationalen Aktionsplänen, die für die Zukunft eine Steigerung der Gesundheitskompetenz der gesamten Bevölkerung vorsehen, sind weitere webbasierte Interventionen erforderlich (D. Schaeffer et al., 2019), um die Internet-Suchfähigkeiten von Patient(inn)en mit derzeit geringen Fähigkeiten zu verbessern (Mitsuhashi, 2018; Robinson & Graham, 2010).

Die Hypothese vor Beginn der Querschnitts- und Längsschnittstudie war, dass ein hohes Maß an Internetnutzung während der Rehabilitation die soziale Interaktion zwischen den Patient(inn)en und damit die wahrgenommene soziale Unterstützung unter Krebspatient(inn)en während ihres Klinikaufenthalts verringern könnte. Diese Annahme beruhte auf den Beobachtungen des Gesundheitspersonals und nicht auf früheren Studienergebnissen. Die Feststellung, dass es keinen Zusammenhang zwischen dem Ausmaß der Internetnutzung der Teilnehmenden und der wahrgenommenen sozialen Unterstützung gibt, stimmt mit den Ergebnissen von Studien überein, die die Internetnutzung bei gesunden Personen (Klauer & Winkeler, 2002) und bei Patient(inn)en mit Rückenmarksverletzungen untersucht haben (Haugland et al., 2016). Darüber hinaus gaben nur 2 % der Internetnutzer(innen) in der Studie an, dass sie Freizeitaktivitäten in der Klinik verpassen, weil sie Zeit im Internet verbringen. Die Feststellung, dass es keinen Zusammenhang zwischen dem Ausmaß der Internetnutzung der Teilnehmenden und der Veränderung des Distresslevels, des Schmerzlevels und des Fatiguelevels der Teilnehmenden vom ersten bis zum letzten Tag ihres Klinikaufenthalts gibt, steht im Einklang mit den Wahrnehmungen der Teilnehmenden hinsichtlich der Beziehung zwischen Internetnutzung und Rehabilitationsaktivitäten. Nur 9 %

bzw. 2 % der Internetnutzer(innen) berichteten, dass sie sich vom Rehabilitationsprogramm abgelenkt fühlten oder dass sie Freizeitaktivitäten in der Klinik verpassten, weil sie Zeit im Internet verbrachten. Darüber hinaus moderierte die soziale Unterstützung nicht den Zusammenhang zwischen dem Ausmaß der Internetnutzung der Teilnehmenden und den Veränderungen in den drei PROMS.

5.3 Implikationen

Die Erkenntnis, dass nur die Hälfte aller Patient(inn)en krebsbezogenen Online-Informationen vertrauen, kann durch die unterschiedliche Qualität der krebsbezogenen Informationen (Borgmann et al., 2016; Bruce et al., 2015; Hargrave et al., 2006; Liebl et al., 2015; Nghiem et al., 2016; Wasserman et al., 2014) oder die schwachen Informations- und Bewertungsfähigkeiten der Krebspatient(inn)en (Lange-Drenth, Schulz, Endsin, & Bleich, 2021) erklärt werden. Wir können somit keine klinischen Implikationen aus den Studienergebnissen der systematischen Übersichtsarbeit abgeleitet werden. Allerdings zeigte sich, dass bisher kein validiertes Instrument zur Messung des Vertrauens in Online-Informationen, Internet-Webseiten als Quelle für krebsbezogene Informationen oder dem Internet als Medium für krebsbezogene Informationen besteht. Zukünftige Studien sollten ein solches Instrument entwickeln.

Um die unzureichenden Bedienungs-, Navigations-, Informations- und Bewertungskompetenzen von Krebspatient(inn)en zu erhöhen, sind webbasierte Interventionen erforderlich (D Schaeffer et al., 2021). Eine solche Interventionsstudie wäre ein wichtiger Schritt zur Umsetzung der Empfehlungen 13 („Fähigkeit zum Selbstmanagement von Menschen mit chronischer Erkrankung und ihren Familien stärken“) des NAG (D Schaeffer et al., 2021; D. Schaeffer et al., 2018). Laut der Sprecherin und Erstautorin des NAG steht die Interventionsentwicklung zur Stärkung von Gesundheitskompetenzen und eHK in Deutschland noch am Anfang und ist „auf die Forschung angewiesen“ (D Schaeffer et al., 2021). Eine webbasierte Interventionsstudie würde im Gegensatz zu den national angelegten langfristigen Zielen der NAG darauf abzielen, die eHK und speziell die Internet-Suchfähigkeiten von Krebspatient(inn)en, die einen hohen unerfüllten Informationsbedarf haben, zeitnah zu verbessern. Die Verbesserung der Informations- und Bewertungsfähigkeiten sollte der Schwerpunkt dieser Intervention sein, da Teilnehmende vor allem Probleme mit diesen Fähigkeiten hatten.

Die Beobachtungen des medizinischen Personals einer kooperierenden onkologischen Rehabilitationsklinik, dass ein hohes Ausmaß an Internetnutzung zwischen und nach den Rehabilitationssitzungen die sozialen Interaktionen zwischen den Patient(inn)en während ihres Klinikaufenthalts reduziert und das Rehabilitationsprogramm der Patient(inn)en beeinträchtigt, konnten nicht bestätigt werden. Wir empfehlen daher, dass Kliniken ihren Patient(inn)en eine kostenlose, leicht zugängliche und schnelle WLAN-Verbindung anbieten.

5.4 Limitationen der Studien

Diese systematische Übersichtsarbeit weist einige Limitation auf. Die wichtigste Limitation besteht darin, dass nicht bekannt ist, welche Webseiten die Grundlage für die Vertrauensbewertungen der Studienteilnehmenden bildeten. Wie in der Einleitung erwähnt, ist die Qualität der krebsbezogenen Informationen, auf die im Internet zugegriffen werden kann, sehr unterschiedlich (Borgmann et al., 2016; Bruce et al., 2015; Hargrave et al., 2006; Liebl et al., 2015; Nghiem et al., 2016; Wasserman et al., 2014). Wenn die Teilnehmenden zuvor negative Erfahrungen mit Krebs-Webseiten gemacht hatten, berichteten sie mit größerer Wahrscheinlichkeit über ein niedriges Vertrauensniveau (Kim, 2016).

Die größte Limitation der Performance Test-Studie ist, dass im Vergleich zu einer realen Situation die Beantwortung unserer krebsbezogenen Fragen keine direkten Auswirkungen auf die Behandlung oder das Wohlbefinden der Teilnehmenden hatte. Um sicherzustellen, dass die Aufgaben den Interessen und Bedürfnissen von Krebspatient(inn)en entsprachen, formulierten wir Suchaufgaben, die die häufigsten Themen krebsbezogener Informationen abdeckten, die im Internet gesucht wurden (Castleton et al., 2011; Mattsson et al., 2017), und testeten die Aufgaben in einem Pilotversuch. Durch ausbleibenden Folgen der Suche könnten die Teilnehmenden weniger motiviert gewesen sein, die Zuverlässigkeit der Website zu bewerten oder die auf einer zweiten Website gefundenen Informationen zu überprüfen.

Die größte Limitation der Querschnitts- und Längsschnittstudie liegt in der niedrigen Teilnehmendenrate, die ein Indikator dafür sein könnten, dass unsere Stichprobe einen Nonresponse-Bias aufweist (Groves et al., 2008). Die Werte der Studienteilnehmenden, die unter Fatigue litten, unterschieden sich jedoch nur geringfügig von den Werten aller Krebspatient(inn)en (n=1204), die 2019 in der untersuchten onkologischen Rehabilitationsklinik behandelt wurden, was darauf hindeutet, dass unsere Stichprobe repräsentativ für die Patient(inn)en der Rehabilitationsklinik war.

5.5 Schlussfolgerungen

Die Ergebnisse der systematischen Übersichtsarbeit deuten darauf hin, dass etwa die Hälfte der Krebspatient(inn)en offenbar Informationen aus dem Internet, Internet-Webseiten als Quelle für krebsbezogene Informationen oder dem Internet selbst als Medium für Krebsinformationen vertrauen. Die geringe Anzahl der eingeschlossenen Studien, die große Heterogenität der Teilnehmenden, Methoden und Ergebnisse sowie die unterschiedliche Qualität der eingeschlossenen Studien erfordern jedoch weitere systematische Forschung.

Eine beträchtliche Gruppe von Krebspatient(inn)en verfügt nicht über die notwendigen Fähigkeiten, um von krebsbezogenen Internetsuchen zu profitieren. Zu den Problemen gehörten die Bedienung der Hardware, die Navigation und Orientierung in Webbrowsern und auf Webseiten sowie insbesondere die Formulierung einer aufgabenbezogenen Suchanfrage und die kritische Bewertung und Überprüfung von webbasierten Inhalten. In Anbetracht der hohen Anzahl von Teilnehmenden mit höherer Bildung und relativ großer Interneterfahrung wird der Bedarf an zukünftigen Interventionen oder Programmen zur Verbesserung der Internetsuchfähigkeiten von Krebspatient(inn)en in dieser Studie möglicherweise unterschätzt. In zukünftigen Studien, die sich auf ältere, wenig gebildete Patient(inn)en mit wenig Interneterfahrung konzentrieren, könnten weitere wichtige Leistungsprobleme identifiziert werden.

Das Ausmaß der Internetnutzung durch Krebspatient(inn)en während ihres Klinikaufenthalts scheint nicht mit der wahrgenommenen sozialen Unterstützung unter den Patient(inn)en oder mit der Veränderung des Desitresslevels, des Fatiguelevels oder des Schmerzlevels der Patient(inn)en vom ersten bis zum letzten Tag des Klinikaufenthalts in Zusammenhang zu stehen. Wir empfehlen daher, dass Kliniken ihren Patient(inn)en eine kostenlose, leicht zugängliche und schnelle WLAN-Verbindung anbieten.

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7 Publikationen

7.1 Publikation 1

Lange, L., Peikert, M. L., Bleich, C., & Schulz, H. (2019). The extent to which cancer patients trust in cancer-related online information: a systematic review. PeerJ, 7, e7634. doi: 10.7717/peerj.7634 .

The extent to which cancer patients trust in cancer-related online information: a systematic review

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ABSTRACT

Background. The use of the internet to satisfy information needs is widespread among cancer patients. Patients' decisions regarding whether to act upon the information they find strongly depend on the trustworthiness of the information and the medium. Patients who are younger, more highly educated and female are more likely to trust online information. The objectives of this systematic review were to examine the extent to which cancer patients trust in cancer-related online information, internet websites as a source of cancer-related information or the internet as a medium of cancer information.

Methods. A systematic review was conducted using five databases (PROSPERO registration number: CRD42017070190). Studies of any kind were included if they measured cancer patients' trust in online health information. Study quality was assessed using the Research Triangle Institute (RTI) item bank. A narrative synthesis was undertaken to examine the included studies.

Results. Of the 7,314 citations obtained by the search, seven cross-sectional studies were included in the synthesis. A total of 1,054 patients reported having some or a great deal of trust in online cancer information; 154 patients reported moderately trusting such information; and 833 patients reported having no or little trust in online cancer information, internet websites as a source of cancer-related information or the internet as a medium of cancer-related information. Two of the seven studies reported between group comparisons for the above-stated patient characteristics. The methodological quality of the included studies was diverse.

Conclusion. The results of the included studies indicates that approximately half of cancer patients appear to trust cancer-specific online information, internet websites as a source of cancer-related information or the internet as an information medium. However, the small number of included studies, high heterogeneity of participants, methods and outcomes calls for further systematic research. It is important to understand that cancer patients do and will increasingly use trusted cancer information websites to search for information concerning their disease. Therefore, physicians and other health care providers should provide more support and advice to these patients.

Subjects Oncology, Public Health, Science and Medical Education, Human-Computer Interaction
Keywords Consumer health information, Telemedicine, Medical informatics, Trust, Systematic review

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INTRODUCTION

Information needs are among the most prevalent unmet supportive care needs of cancer patients throughout their cancer journey (*Harrison et al., 2009*). The majority of cancer patients want to have all available information concerning their illness and treatment (*Davies et al., 2008*; *Jenkins, Fallowfield & Saul, 2001*; *Newnham et al., 2006*). The internet allows cancer patients to fulfill their needs for information regarding their diagnosis, prognosis or likelihood of cure, disease stage, and treatment options or the side effects of the treatment in question (*Castleton et al., 2011*; *Maddock et al., 2011*; *Tariman et al., 2014*). Internet utilization is widespread in advanced economies: 89% of the US population and 80% of the European population reported using the internet at least occasionally (*Poushter, 2016*). Compared with other information sources, the internet has the unique advantage of convenience. Cancer patients can anonymously access the internet anytime from almost anywhere (*Maddock et al., 2011*; *Ziebland et al., 2004*).

The prevalence of cancer patients who used the internet to look for cancer-related information in a Dutch sample, two American samples and a Swedish sample ranged from 60% to 75% (*Castleton et al., 2011*; *Mattsson et al., 2017*; *Mayer et al., 2007*; *Van de Poll-Franse & Van Eenbergen, 2008*), and the prevalence appears to be increasing (*Finney Rutten et al., 2016*).

There are various motivational reasons for cancer patients to search for cancer information on the internet. Patients reported going online because they wanted to develop questions to discuss with their physician, verify information given by their physician, or seek alternative treatments (*Castleton et al., 2011*) and because they felt that the amount of information they received from their physician was insufficient (*Chen & Siu, 2001*).

Information obtained from the internet can impact clinical care in different ways. Cancer-related online information can change patients' choice of treatment, their choice of physician, and their decisions regarding enrollment in a clinical trial (*Castleton et al., 2011*). Most cancer patients do not believe that online information searching negatively affects the doctor-patient relationship (*Newnham et al., 2006*). However, some cancer patients are careful about discussing online information with their physicians. These patients worry that their online searches might have a negative influence on their relationship and might cause physicians to treat them as a problematic patient (*Broom, 2005*; *Chiu, 2011*). Additionally, some oncologists admit to having some difficulty discussing internet-based information with their patients. These oncologists are more likely to report that information obtained from the internet confuses patients (*Helft, Hlubocky & Daugherty, 2003*).

Cancer patients who search the internet for cancer-related information tend to be younger and more highly educated than those who do not (*Castleton et al., 2011*; *Mattsson et al., 2017*; *Shahrokni, Mahmoudzadeh & Lu, 2014*), and they are more likely to have a partner (*Mattsson et al., 2017*). Both age and education are also associated with higher unmet information needs among cancer patients (*Sondergaard et al., 2013*). One study found that female gender was a factor associated with seeking cancer-related information (*Mayer et al., 2007*), while another study did not (*Castleton et al., 2011*). A higher likelihood of internet use was further associated with better self-reported health among cancer survivors (*Chou et al., 2011*).

The quality of the cancer-related information that can be accessed on the internet is highly variable. Several studies used the DISCERN scale, a validated instrument developed to help consumers evaluate the quality of health-related information on treatment choices for a specific health problem (*Charnock et al., 1999*), to evaluate the quality of websites that provide cancer-related information. The websites were generated by typing cancer-related search terms (i.e., 'cancer', 'cancer therapy', 'breast cancer' or 'colon cancer') in popular search engines, such as Google or Bing and focusing mainly on the first search results (*Borgmann et al., 2016*; *Bruce et al., 2015*; *Hargrave, Hargrave & Bouffet, 2006*; *Liebl et al., 2015*; *Nghiem, Mahmoud & Som, 2016*; *Ni Riordain & McCreary, 2009*; *Wasserman et al., 2014*), as most users will not proceed any further (*Eysenbach & Köhler, 2002*). The evaluated websites' information was often incomplete and did not provide all of the details necessary to allow cancer patients to make well-informed decisions (*Al-Bahrani & Plusa, 2004*; *Borgmann et al., 2016*; *Bruce et al., 2015*; *Hargrave, Hargrave & Bouffet, 2006*; *Liebl et al., 2015*; *Nghiem, Mahmoud & Som, 2016*; *Ni Riordain & McCreary, 2009*; *Wasserman et al., 2014*). However, the results of two studies indicate a difference between the information quality of different website types. The quality of websites from nonprofit organizations or the government was higher than the quality of websites from the medical practices or commercial health information websites (*Liebl et al., 2015*; *Nghiem, Mahmoud & Som, 2016*).

Few studies have investigated which types of websites cancer patients visit to satisfy their information needs. Nonetheless, cancer patients consider health information websites to be a more valuable source of health information than forums or blogs (*Mattsson et al., 2017*). These patients report preferring to obtain reliable information regarding cancer from websites of their oncologist, hospital, or cancer society and are less likely to access websites with a profit interest. However, the same patients mostly accessed websites that were financed and created by pharmaceutic industries (*Van de Poll-Franse & Van Eenbergen, 2008*), which might promote their own interests and can be of lower quality than nonprofit websites (*Liebl et al., 2015*). Additionally, studies have revealed that health seekers do not consistently check the source and date of the health information they found online (*Eysenbach & Köhler, 2002*; *Fox, 2006*).

The varying quality of the cancer-related information available online presents cancer patients with significant challenges in evaluating and selecting reliable online information sources and, more specifically, in assessing the credibility and trustworthiness of these sources. Trust is an important factor associated with the intention to use information found on a website (*Dutton & Shepherd, 2006*; *Lemire et al., 2008*). People who trust in online health information become motivated to participate in various online health-related activities that meet their informational and emotional needs (*Fisher et al., 2008*).

The decision whether to trust a cancer-related online information can be a complex one as information-searching skills, prior experiences with the source and medium of the information, and characteristics of the source may influence the cancer patient's decision. There are different levels (individual, interpersonal, relational and societal) of trust that have been studied in the literature. The interpersonal level appears to be the appropriate level for determining trust in online information, as information is provided by an author (trustee) and communicated over a certain channel (the internet) to a receiver (trustor) (*Kelton, Fleischmann & Wallace, 2008*). A definition of trust that is often used at this level is that: "The willingness of a party to be vulnerable to the actions of another party based on the expectation that the other will perform a particular action important to the trustor, irrespective of the ability to monitor or control that other party" (*Mayer, Davis & Schoorman, 1995*).

The terms trust and credibility are often used interchangeably. However, credibility can be described as perceived information quality, or the evaluation of information quality by a user (*Fogg & Tseng, 1999*). After evaluating the credibility of information, a reader may decide whether to trust or not trust it. The credibility evaluation process in online environments can be explained by a dual processing model (*Metzger, 2007*) or the 3S-model (where the three "Ss" stand for semantics, surface, and source features of information) (*Lucassen & Schraagen, 2011*). The dual processing model states that the decision whether a heuristic (peripheral) or systematic (central) evaluation is performed is decided by the users' motivation and ability. The users' motivation results from the consequence of receiving inferior, unreliable or inaccurate information online (*Metzger, 2007*). We prefer the 3S-model, because we believe that due to existential concerns and their need for hope, cancer patients are a vulnerable population (*Davey, Butow & Armstrong, 2003*) and therefore would be highly motivated. The 3S-model asserts that the most direct strategy for evaluating credibility is to search for semantic cues (factual accuracy, neutrality or completeness of the information) in the information (*Lucassen & Schraagen, 2011*). However, cancer patients usually search for information that is new to them and thus do not always have the necessary expertise to evaluate the semantics of the information and consequently revert to surface cues (writing style, text length or number of references) (*Lucassen & Schraagen, 2011*). Systematic and heuristic processing are thus both used within a single search process. Additionally, trust in online information is influenced by trust in its source (website), which in turn is influenced by trust in the medium (internet) of this source and a general propensity to trust (*Lucassen et al., 2013*). Users with low trust in the source (website) cannot distinguish between high quality and inferior information (*Lucassen & Schraagen, 2012*). Trust in the internet is largely affected by prior experience with this medium (*Dutton & Shepherd, 2006*). In this study, we are interested in cancer patients' trust in the cancer-related information online, their trust in certain cancer information websites (source) as well as their trust in the internet as a medium of cancer information.

Consumers' trust in health information websites can be influenced by various factors. Two systematic reviews (*Kim, 2016*; *Sbaffi & Rowley, 2017*) assessed these factors, which can be organized into three categories as follows. (1) Individual consumer characteristics: consumers who are younger, are mostly highly educated, are female, have a higher level of agreeableness, have a higher income, reported being in good health condition and have a higher level of health literacy appear to be more trusting of health information websites. (2) Website-related factors: websites that are complete, understandable, unbiased, modern, useful, and easy to navigate; have a clear and professional layout; are easy to access; are run by medical universities or the federal government; and contain high-quality information are more likely to be trusted. (3) Consumer-to-website interaction-related factors: experience in using the internet and familiarity with the website are likely to influence consumer trust in the health information. Experienced users are more confident in the internet and less concerned over the risks entailed in its use, thereby increasing the likelihood of trusting health-related websites. Additionally, patients prefer health information written by people experiencing similar health issues (*Kim, 2016*; *Sbaffi & Rowley, 2017*).

In summary, it can be stated that cancer patients can only benefit from online cancer information if they can trust the information or the internet as a medium of this information. To date, no systematic review that analyzed cancer patients' trust in online health information has been published. The primary goal of this systematic review is to identify the extent to which cancer patients trust cancer-related online information, internet websites as a source of cancer-related information or the internet as a medium of cancer-related information. As a secondary goal, the review seeks to determine whether trust in cancer-related online information differs across patients of different ages, genders, health statuses, education levels or cancer types.

METHODS

A systematic literature review was conducted to explore cancer patients' trust in cancer-related online information, internet websites as a source of cancer-related information or in the internet as a medium of cancer information. The protocol for the systematic review was registered in the international prospective register of reviews (PROSPERO) with the registration code CRD42017070190 (File S1). Additionally, the reporting of this review followed the recommendations of the PRISMA statement (*Moher et al., 2009*), an evidence-based minimum set of items for reporting in systematic reviews and meta-analyses (Table S1).

Information sources and search strategy

We performed an electronic literature search of the electronic databases Medline, CINAHL, Web of Science, PsycINFO and PSYINDEX using prespecified search terms with no restriction on the publication period. All searches were performed on the 4th of January 2017 (last update, 4th of October 2018). Additionally, the reference lists of the included studies were manually searched for potentially relevant studies.

To systematically identify search terms that could address the research questions, the PICO criteria were adapted. PICO criteria can help facilitate the process of finding an answer to a clinical question, by identifying appropriate keywords that can be used to conduct a literature search (*Richardson et al., 1995*; *Van Loveren & Aartman, 2007*). The focus was on the following criteria: (P) population (cancer patients); and (O) outcome (trust/distrust/evaluation of credibility). We included all studies independent of being an intervention study or the presence or absence of a comparison group. Therefore, we did not specify the intervention (I) or comparison (C) in our research question. Additional search terms were selected after an analysis of the Medical Subject Headings (MeSH) and text words used in key articles, which were identified in prior nonsystematic exploratory literature searches. The included search terms were discussed by the authors and then arranged to create a search string. The search strings were used in each database and accounted for synonyms, plurals, hyphenations and multiple word combinations. All search results were exported into EndNote X7, and all duplicates were removed. The search strategy for MEDLINE is provided in Table S2. The search strategy was appropriately modified for each database to identify eligible studies.

Eligibility criteria

All studies obtained from the initial search had to fulfill the inclusion criteria of the two selection phases. During the first phase, the corresponding author screened the titles and abstracts of all studies. Consistent with the broad research questions, studies of any type were included if the study title or abstract stated that cancer patients or cancer survivors of any age and with any type of cancer participated in the study and if one of the reported outcomes appeared to be participants' trust, perceptions of credibility or distrust in online cancer-related information, internet websites as a source of cancer-related information or in the internet as a medium of cancer information.

During the second phase, two researchers independently assessed the full texts of the remaining potentially relevant articles. The eligibility criteria used in the full text screening addressed two aspects: study characteristics and report characteristics (*Liberati et al., 2009*). The inclusion criteria for study characteristics were as follows: (1) the full text was available; (2) any study type was included if it included some form of quantitative data; (3) at least some of the participants were cancer patients or cancer survivors; (4) the participants were 18 years or older; (5) the measured constructs were trust, perceived credibility or distrust; and (6) the study measured participants' trust in online cancer-related information, internet websites as a source of cancer-related information or the internet as a medium of cancer-related information. The reporting of the study had to meet one inclusion criterion: (1) the study was included in the review if it was reported in English or German. Disagreements between the researchers regarding the eligibility of studies were resolved via discussion. The reasons for exclusion and the number of studies excluded for each reason can be found in Table S3.

Data extraction and quality assessment

Data extraction was performed by the corresponding author (LL) and cross-checked by another member (MLP) of the research group. The following data were extracted from the included studies: (1) study characteristics, including the author name, year of publication, title of publication, place of data collection, study design, and sample size; (2) characteristics of the study participants, such as age, gender, cancer type, education status, health status; (3) outcome characteristics, such as questionnaire or items used to measure trust; and (4) the measured outcome of trust, perceived credibility or distrust (i.e., as the mean or distribution). Additionally, six corresponding authors of the studies in question were contacted for further information (e.g., questionnaires, data sets); four of them responded. Most provided additional information concerning their publications.

Three authors provided additional descriptive information, and the fourth author shared the complete data file of the study results.

The methodological quality assessment of the included papers was independently performed by two researchers in the study group and based on the RTI item bank (*Viswanathan et al., 2013*). The RTI item bank provided the researchers with a set of items to evaluate the conduct of observational studies included in systematic reviews and to detect possible risks of biases of the included studies (*Viswanathan & Berkman, 2012*; *Viswanathan et al., 2013*). Studies were not excluded from the review or any subsequent analyses on the basis of the risk of bias. In accordance with the developers' instructions, the instrument was adapted to fit the designs of the included observational studies. Seven questions (questions 1, 2, 3, 6, 9, 11, 13) were used to assess selection bias, detection bias, confounding, selective outcome reporting and overall bias in the included studies. The reasons for not integrating the additional questions of the RTI item bank into the quality assessment can be found in Table S4. Disagreements between the two reviewers regarding the assessed quality of the studies were resolved via discussion.

Data analysis and description

A narrative synthesis was undertaken to examine the included studies (*Dixon-Woods et al., 2005*). Furthermore, the characteristics and results of the included studies were summarized descriptively.

No planned meta-analysis was conducted to answer the secondary study goal (does trust in online cancer-related information, internet websites as a source of cancer-related information or in the internet as a source medium of cancer information differ across patients with different ages, genders, education levels, health status or cancer types) because only two of the included studies reported between-group comparisons for these patient characteristics. However, to illustrate the between-group comparisons of individual studies, we calculated the mean differences (MDs) by subtracting the mean score of one group of participants (i.e., female patients), which was expected to score higher, from the mean score of the second group of participants (i.e., male patients). For clarity, all the mean trust scores reported in the included studies were transformed into a 5-point scale (range, 1–5).

RESULTS

Study selection

The search of the databases (Medline, CINHAL, Web of Science, PsychINFO and PSYINDEX) resulted in 7,314 citations (Fig. 1). All citations are available at Figshare (https://doi.org/10.6084/m9.figshare.7701014.v1). After the removal of duplicate articles, 6132 titles and abstracts were scanned for eligibility. Of these, 54 studies fulfilled the eligibility criteria of the first selection phase. Four additional studies were added after the reference lists of the 54 potentially relevant studies were manually searched. The full text of two articles could not be retrieved despite contacting the authors. Of the remaining 51 articles, seven (*Crutzen et al., 2014*; *Losken et al., 2005*; *Lussiez et al., 2017*;

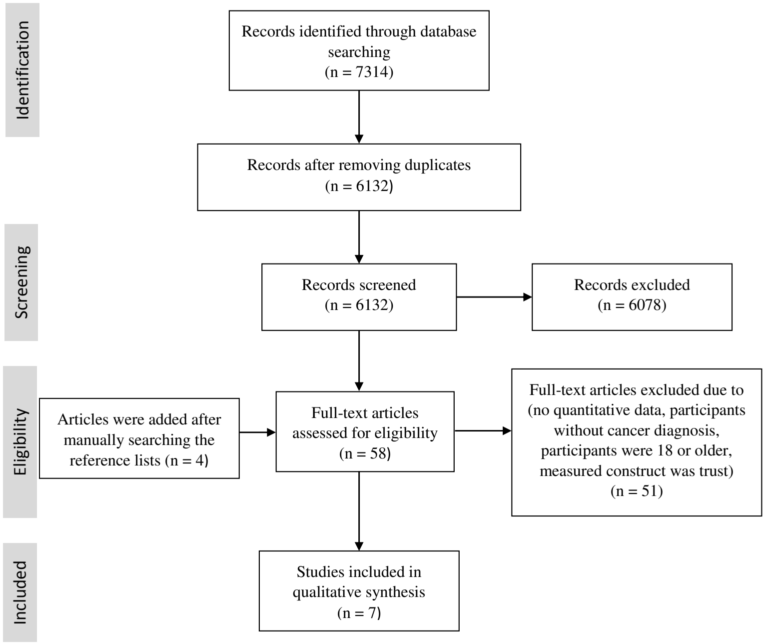

Figure 1 **Flowchart of the literature search.**

Full-size DOI: 10.7717/peerj.7634/fig-1

Mayer et al., 2007; *Pereira et al., 2000*; *Roach et al., 2009*; *Shea-Budgell et al., 2014*) met the eligibility criteria of the second phase and were therefore included in the review.

Study characteristics

The characteristics of all the articles are described in Table 1. All studies were published in English in peer reviewed journals between 2000 and 2014. Six of the seven studies were performed in North America (USA and Canada), and one (*Crutzen et al., 2014*) was conducted in Europe (Netherlands). Four studies used on-site recruitment of participants visiting outpatient facilities for treatment or checkups (*Losken et al., 2005*; *Lussiez et al., 2017*; *Pereira et al., 2000*; *Shea-Budgell et al., 2014*). Two studies (*Mayer et al., 2007*; *Roach et al., 2009*) called patients at their homes, and one study (*Crutzen et al., 2014*) recruited participants online. All seven studies were cross-sectional. Five of the studies performed out to answer broad research questions, while two studies (*Lussiez et al., 2017*; *Roach et al., 2009*) formulated hypotheses. Three of the studies formulated the intention to describe the general internet use of patients with any type of cancer (*Losken et al., 2005*; *Pereira et al., 2000*; *Shea-Budgell et al., 2014*). One study intended to provide insights into user perceptions related to loyalty towards a specific Dutch cancer information website (*Crutzen et al., 2014*). The website offered tailored, hospital-specific information on oncological care and detailed information about health care professionals, and it was constantly reviewed and updated by professionals in oncology care. Another study aimed to describe differences between cancer survivors who do and do not seek cancer information off- or online (*Mayer et al., 2007*). The authors of the sixth and seventh study hypothesized that cancer patients are more likely to search for cancer information (*Lussiez et al., 2017*; *Roach et al., 2009*), higher income and education levels correlate with increased internet use for health information (*Lussiez et al., 2017*) and cancer patients are more likely to have an increased knowledge of cancer-related information sources than healthy individuals (*Roach et al., 2009*).

All but one study used one item scored on a 3- to 5-point scale to measure the participants' trust in information found on the internet (*Losken et al., 2005*; *Lussiez et al., 2017*; *Pereira et al., 2000*) or the internet as a medium of health information (*Mayer et al., 2007*; *Roach et al., 2009*; *Shea-Budgell et al., 2014*). The seventh study used 3 items scored on a 7-point Likert scale to measure patients' trust in one specific cancer information website (*Crutzen et al., 2014*). Convenience and purposive sampling methods were applied in five studies, while two studies (*Mayer et al., 2007*; *Roach et al., 2009*) applied stratified sampling with oversampling of minority groups. The sample sizes of cancer patients in the included studies ranged from 63 to 719 (median, 157).

Synthesis of the results

The study results were grouped into three themes based on the study goals: (1) characteristics of the included study samples; (2) cancer patients' trust in cancer- or health-specific online information, in internet websites as a source of cancer-related information or in the internet as a medium of cancer information; and (3) between-group comparison of patient characteristics (age, gender, education and cancer type). A full overview of the results is displayed in Table 2.

Sample characteristics of the included studies

In the five studies that reported the participants' age, the mean age was 56 years (range, 47–58). In the five studies that reported the participants' education levels, the largest group in each study was highly educated. Two studies did not report their participants' education levels (*Lussiez et al., 2017*; *Roach et al., 2009*).

Three studies (*Mayer et al., 2007*; *Roach et al., 2009*; *Shea-Budgell et al., 2014*) included cancer patients with various types of cancer, while three studies (*Losken et al., 2005*; *Lussiez et al., 2017*; *Pereira et al., 2000*) focused on particular types. Two studies (*Losken et al., 2005*; *Pereira et al., 2000*) focused on breast cancer patients, while one (*Lussiez et al., 2017*) focused on lung or esophageal cancer. One study did not report the cancer types of the included participants (*Crutzen et al., 2014*). Six of the seven studies that reported the participants' gender included more female than male participants (63% females among the 1,347 participants).

Cancer patients' trust in online cancer information

Approximately half of the 2,041 cancer patients who participated in all of the included studies combined appeared to trust online cancer information ($\bar{x} = 3.1$, SD = 1.4). A total of 1,054 patients reported having some or a lot of trust in cancer information obtained online, while 154 patients reported moderately trusting or being undecided about whether they should trust online health information, and 833 patients reported having no or a little trust in cancer-related information found on the internet or in the internet as a medium of cancer-related information.

Table 1 Study characteristics of the included cross sectional studies.

Study	Title	Year	Country	Study design	Recruitment strategy	Instruments to measure trust	Sampling method
Crutzen et al. (2014)	E-loyalty towards a cancer information website: applying a theoretical framework	2014	NL	CS	Online invitations to visit the website & asking visitors of the website to evaluate it	Three items scored on a 7-point Likert items (‘strongly disagree’ to ‘strongly agree’) to measure trust in one specific website	Nonprobability sampling: convenience sampling & purposive sampling
Losken et al. (2005)	Infonomics and breast reconstruction—Are patients using the internet?	2005	USA	CS	On-site recruitment (first postoperative visit)	One item scored on a 3-point item format (‘disagree’ to ‘agree’): “Did you trust the information” found in the internet	Nonprobability sampling: purposive sampling
Lussiez et al. (2017)	Internet usage trends in thoracic surgery patients and their caregivers	2015	USA	CS	On-site recruitment (outpatient clinic visit)	One item scored on a 3-point item format (‘not trustful’ to ’very trustful’) to measure the “level of trust subjects placed in the information they found” online	Nonprobability sampling: purposive sampling
Mayer et al. (2007)	Cancer survivors information seeking behaviors:	2007	USA	CS	Called via telephone	One item scored on a 4-point item format (‘not at all’ to ‘a lot’) to measure “how much they trusted different sources of information” (i.e., internet)	Stratified sampling with oversampling of minority groups

(*continued on next page*)

Table 1 (*continued*)

Study	Title	Year	Country	Study design	Recruitment strategy	Instruments to measure trust	Sampling method
Pereira et al. (2000)	Internet usage among women with breast cancer: an exploratory study	2000	Canada	CS	On-site recruitment (outpatient clinic visit)	One item scored on a 5-point Likert item ('completely disagree' to 'completely agree'): "I trust the medical information I found on the Internet."	Nonprobability sampling: purposive sampling
Roach et al. (2009)	Differences in cancer information-seeking behavior, preferences, and awareness between cancer survivors and healthy controls	2009	USA	CS	Called via telephone	One item scored on a 4-point item format ('not at all' to 'a lot') to "indicate how much they would trust cancer information obtained from the following sources" (i.e., internet).	Stratified sampling with oversampling of minority groups
Shea-Budgell et al. (2014)	Information needs and sources of information for patients during cancer follow-up	2014	Canada	CS	On-site recruitment (outpatient clinic visit)	One item scored on a 4-point item format ('not at all' to 'a lot' = 4) to measure "the level of trust in information sources"	Nonprobability sampling: purposive sampling

Notes.

CS, Cross-sectional; NL, Netherlands.

[a] Number of particpants included in the study.

Table 2 Outcomes of the included studies.

Study	Trust[a] (m, SD)	Sample characteristics					Differences in trust between groups (MD, [95% CI], Cohen's *d* effect size)			
		N[b]	Age[c] (m/SD)	Education	Cancer type	Gender (% female)	Female vs. male patients	Highly vs. low educated	Young vs. old patients	Cancer types
Crutzen et al. (2014)	3.8 (1.0)	45	53 (12)	46% high education; 40% intermediate education; 14% low education	NR	76	0.13, [−0.45, 0.71], $d = 0.14$	−0.58, [−1.64, 0.48], $d = 0.58$	NR	NR
Losken et al. (2005)	4.3 (1.0)	72	50 (30–70)	22% graduate; 43% college; 30% some college, 14% high school	Breast cancer patients	100	NR	NR	NR	NR
Lussiez et al. (2017)	3.9 (1.1)	192	54 (14–86)	NR	Lung or esophageal cancer	55	NR	High educated participants reported higher trust scores	NR	NR
Mayer et al. (2007)	2.9 (1.6)	597	58	44% more than high school; 38% high school; 18% less than high school	18 different cancer types[d]	65	NR	NR	NR	NR
Pereira et al. (2000)	3.5 (0.6)	32	47 (9)	66% college or university; 34% junior or senior high school	Breast cancer patients	100	NR	NR	NR	NR
Roach et al. (2009)	3.0 (1.6)	692	NR	NR	Different cancer types[e]	NR	NR	NR	NR	NR
Shea-Budgell et al. (2014)	3.1 (1.2)	411	NR	33% high school or less; 21% post–high school; 33% college or university; 10% postgraduate; 4% not specified	Seven different types/group of cancer types reported	53	NR	NR	NR	No significant associations between cancer site and level of trust

Notes.

m, mean; SD, standard deviation; MD, mean difference; NR, not reported.

[a] Average trust in online information reported on a 5-point item format.

[b] The number participating of cancer patients.

[c] Age reported in years.

[d] Breast and cervical were most frequent reported types of cancer.

[e] The most common initial diagnoses were gynecologic, non-melanoma skin, and breast cancers.

Regarding the individual results of each study, two points are apparent. In all studies but one (*Roach et al., 2009*), the majority of the participants reported having some or a lot of trust in online cancer information. Additionally, 55% of breast cancer patients in outpatient treatment stated that they were undecided about whether to trust online information (*Pereira et al., 2000*).

Three of the included studies indicated that the internet appears to be the second-most-trusted medium of cancer information after health care professionals (*Mayer et al., 2007*; *Roach et al., 2009*; *Shea-Budgell et al., 2014*). Patients were more likely to trust online information than information from newspapers, magazines, the radio, family or friends or the television.

Between-group comparisons of patient characteristics

Two of the seven studies reported between-group comparisons of characteristics that might influence patients' trust in online health information. One study found that participants were more likely to be very trustful of information found online if they had a higher education level (*Lussiez et al., 2017*). The authors of the second study stated that no significant associations were detected between cancer site and level of trust (*Shea-Budgell et al., 2014*). The conclusions of both studies could not be verified or replicated because the necessary descriptive data were not reported.

Furthermore, the corresponding author of one study (*Crutzen et al., 2014*) provided his entire data set, which made it possible to calculate two additional results. The MD of the reported trust between patients with high and low education levels was −0.58 (95% confidence interval (CI): −1.64, 0.48) with a medium effect size; between female and male patients, the MD was 0.13 (95% CI [−0.45, 0.71]), with a small effect size (*Crutzen et al., 2014*).

Additionally, two studies reported between-groups comparisons of patients' trust as related to patient characteristics that were not part of the secondary research question. The MDs in the reported trust between cancer patients and healthy control groups were −0.03 (95% CI [−0.33, 0.27]) (*Roach et al., 2009*) and −0.07 (95% CI [−0.21, 0.06]) (*Crutzen et al., 2014*), with a small effect. The MD between patients who had personally sought cancer information and those who had not was 1.14 (95% CI [0.88, 1.40]), with a large effect size (*Mayer et al., 2007*).

Quality assessment

The detailed methodological quality ratings of the included studies are displayed in Table 3. An estimation of the selection bias is covered by questions one to three. The inclusion criteria did not vary across individuals in three of the included studies (question 1). However, four studies failed to report the inclusion criteria (*Crutzen et al., 2014*; *Lussiez et al., 2017*; *Mayer et al., 2007*; *Roach et al., 2009*). None of the studies used different recruitment measures across individuals (question 2). The selection of an appropriate comparison group was not relevant to the included studies as none of them included a comparison group (question 3).

Question six gives an indication of the detection bias of the included studies. Three studies (*Crutzen et al., 2014*; *Mayer et al., 2007*; *Roach et al., 2009*) used valid and reliable

Table 3 Risk of bias appraisal using the RTI item bank.

Study	Selection bias/confounding			Detection bias	Selective outcome reporting	Confounding	Overall Assessment
	Q1	Q2	Q3	Q6	Q9	Q11	Q13
Crutzen et al. (2014)	NR	No	NA	Yes	No	Yes	No
Losken et al. (2005)	No	No	NA	No	No	Yes	Yes
Lussiez et al. (2017)	NR	No	NA	No	No	Yes	No
Mayer et al. (2007)	NR	No	NA	Yes	No	Yes	No
Pereira et al. (2000)	No	No	NA	No	No	Yes	No
Roach et al. (2009)	NR	No	NA	Yes	No	Yes	No
Shea-Budgell et al. (2014)	No	No	NA	NR	No	Yes	Partially

Notes.
Q1, Do the inclusion criteria vary across the participants of the study?; Q2, Does the strategy for recruiting participants into the study differ?; Q3, Is the selection of the comparison group inappropriate?; Q6, Were valid and reliable measures used?; Q9, Are any important primary outcomes missing from the results; Q11, Are results believable taking study limitations into consideration?; Q13, Were the important confounding variables taken into account in the design?; NR, not reported; NA, not applicable.

instruments, while the remaining four studies used self-developed questionnaires that were not psychometrically validated. Question nine asks whether the researchers were selective in their outcome reporting. None of the seven studies failed to report the results of any of the important primary outcomes. Confounding was accounted for in all studies by believably taking study limitations into consideration (question 11). Question thirteen asks whether important confounding variables were taken into account in the design and/ or the analysis. Five of the studies did take important confounding variables into account. One study reported the descriptive results of possible confounders such as age or education, but did not investigate whether any of the confounders had an influence on the measured outcome (Losken et al., 2005). Another study did not state whether the types of information the patients sought varies by any socioeconomic factors (Shea-Budgell et al., 2014).

DISCUSSION

This review includes seven studies that describe cancer patients' trust in cancer-related online information. Overall, approximately half of the cancer patients in the included studies reported that they trusted cancer-related online information, internet websites as a source of cancer-related information or the internet as a medium of cancer-related information.

There appears to be differences in the results of the seven included studies. The lowest trust scores were reported in the three studies with the largest samples of cancer patients with various types of cancer (Mayer et al., 2007; Roach et al., 2009; Shea-Budgell et al., 2014). In these studies, the participants were asked to appraise their trust in the internet as a medium of cancer-related information. In three of the other four studies (Losken et al., 2005; Lussiez et al., 2017; Pereira et al., 2000), the participants were asked how much they trusted the cancer- or health-specific information they found online. The seventh study measured patients' trust in one specific cancer information website (Crutzen et al., 2014). Possible explanations for the differences in trust reported by the groups of participants in these studies might be the formulation of the items that measured patients' trust or the gender of the study participants. When patients are asked to report how much they trust the information they find online, they might be more likely to interpret the question as a rating of their information literacy (*Shenton, 2009*) or eHealth literacy (*Norman & Skinner, 2006*), which are defined as the skills needed to find, retrieve and analyze information in general (information literacy) or health information online (eHealth literacy) and use it appropriately. The potential bias that occurs when patients rate their own information literacy or eHealth literacy is that people are likely to overestimate their own abilities (*Merritt, Smith & Di Renzo, 2005*; *Mohmood, 2016*; *Van der Vaart et al., 2011*). Furthermore, two of the studies with higher reported trust scores (*Losken et al., 2005*; *Pereira et al., 2000*) mainly focused on breast cancer patients. These studies reported mean trust levels of 4.3 and 3.5, which is in line with prior research that stated that female consumers are more likely to trust online information (*Kim, 2016*; *Sbaffi & Rowley, 2017*). Nevertheless, a between-group comparison within the studies showed no difference between female and male patients.

The internet appears to be the second-most-trusted cancer information medium behind health care professionals (*Mayer et al., 2007*; *Roach et al., 2009*; *Shea-Budgell et al., 2014*). Patients are more likely to trust online information than information from newspapers, magazines, the radio, family or friends or the television. A possible explanation might be that the internet offers information that has greater relevance to the consumer and therefore is considered more trustworthy (*Song & Zahedi, 2007*). Magazines, radio and television present information that might target cancer patients or patients with a certain cancer type, whereas the internet allows cancer patients to search for information that is relevant to their individual situation or question.

The number of breast cancer patients in one of the included studies (*Pereira et al., 2000*) that reported that they were undecided regarding whether they should trust the medical information they found online was higher than expected. A possible explanation might be the varying quality of online information, which makes it difficult for cancer patients to make well-informed medical decisions (*Al-Bahrani & Plusa, 2004*; *Borgmann et al., 2016*; *Bruce et al., 2015*; *Hargrave, Hargrave & Bouffet, 2006*; *Liebl et al., 2015*; *Nghiem, Mahmoud & Som, 2016*; *Ni Riordain & McCreary, 2009*; *Wasserman et al., 2014*). Physicians and oncologists should adopt an intermediary role when they discuss internet information with their patients. They should be able recommend reliable online information sources to their patients and help them understand and discuss the information found there (*Halwas, Griebel & Huebner, 2017*). Patients who search for information should not be viewed as a threat (*Helft, Hlubocky & Daugherty, 2003*) but as an opportunity to increase communication and shared decision-making ability (*Kehl et al., 2015*).

It was not possible to answer the secondary research question: Does trust in online health information differ between cancer patients with different ages, genders, health status or education levels? Most of the included studies did not examine how patients' characteristics influence the amount of reported trust in online health information as measuring trust was not their main research goal. The results of the included studies that did examine within-group differences did not always confirm the results of recent systematic reviews that identified consumer characteristics that might influence the reported trust in health information websites (*Kim, 2016*; *Sbaffi & Rowley, 2017*): In one study, as expected, female patients reported higher levels of trust (*Crutzen et al., 2014*). The effect size for the MD between females and males was quite small. The results of the comparisons between patients with higher and lower education levels within the studies were mixed. One study (*Lussiez et al., 2017*) reported the expected difference, while the other study (*Crutzen et al., 2014*) stated that patients with lower education levels were more likely to trust online information. There appears to be no explanation for the higher mean trust scores of the low-education patient groups compared with the high-education patient groups. However, the study sample of cancer patients with low education levels only included five individuals (*Crutzen et al., 2014*) and therefore may not represent the entire population of cancer patients with low education levels. A within-study comparison indicated that cancer type appeared to have no influence on the reported trust in online cancer information (*Shea-Budgell et al., 2014*). The absence of a difference among different cancer types did not contradict any study findings. Cancer type was added to the list of possible confounding variables because a difference in reported trust was expected due to differences in attitudes towards eHealth among patients with different types of cancer (*Jansen et al., 2015*). The MD in reported trust between patients who had personally sought cancer information and those who had not had a large effect size. This effect may be explained by differences in research findings. Patients who are searching for cancer information are more likely to have completed a higher level of education (*Ramanadhan & Viswanath, 2006*), which is again associated with a higher tendency to trust online information (*Kim, 2016*; *Sbaffi & Rowley, 2017*). Additionally, experienced users are more confident in the internet and less concerned over the risks entailed in its use, both of which have a positive influence on trust (*Kim, 2016*).

In terms of the methodological quality of the included studies, it should be noted that the assumptions of this review are exclusively based on the results of cross-sectional studies, which are likely to have different biases (*Viswanathan & Berkman, 2012*). Overall, the assessment of the included studies with the RTI item bank indicated that estimations of selective outcome reporting, confounding and overall assessment gave a positive impression of the methodological quality of the included studies. However, four studies failed to report whether the inclusion criteria varied across participants. Due to the lack of information on inclusion criteria, a selection bias cannot be ruled out which may limit the generalizability of the study results (*Hernán, Hernández-Díaz & Robins, 2004*). However, not reporting the inclusion criteria only allow conclusions to be drawn about the reporting quality of the included studies, but not about the quality of the studies (*Margulis et al., 2014*). Additionally, only three of the studies used valid and reliable instruments, which is an indicator for detection bias (*Viswanathan et al., 2013*). Additional research needs to be conducted using a validated instrument to measure patients' trust in cancer-related information websites.

Six of the studies only used one item to measure the primary outcome of trust, creating a possible source of bias. Latent variables are usually complex and not easily measured. The use of multiple items helps to average out errors that are inherent in single items and therefore have higher reliability and criterion validity than a single item (*Sarstedt*

& Wilczynski, 2009). Single items have practical advantages, such as parsimony and ease of administration (Bergkvist & Rossiter, 2009), and they usually promote higher response rates (Bergkvist & Rossiter, 2007). However, they only perform as well as multi-item scales under very specific conditions (Diamantopoulos et al., 2012). Under these conditions, the construct should be unidimensional and unambiguous to the respondent (Wanous, Reichers & Hudy, 1997). Examples of these types of constructs are job satisfaction (Wanous, Reichers & Hudy, 1997) and attitude towards advertisement and brand in marketing (Bergkvist & Rossiter, 2007; Bergkvist & Rossiter, 2009). Because assessing trust in information always will contain a certain degree of heuristics (Lucassen et al., 2013), it appears as if one item might provide a sufficient indication of whether cancer patient trust online information or the internet as an information source. Nevertheless, there appears to be a need for validated questionnaires that measure consumers' trust in online health information.

Strengths and limitations

This systematic review has some limitations. Its main limitation is the lack of knowledge of the webpages that formed the basis of the study participants' trust assessments. As stated in the introduction, the quality of the cancer-related information that can be accessed on the internet is highly variable (Al-Bahrani & Plusa, 2004; Borgmann et al., 2016; Bruce et al., 2015; Hargrave, Hargrave & Bouffet, 2006; Liebl et al., 2015; Nghiem, Mahmoud & Som, 2016; Ni Riordain & McCreary, 2009; Wasserman et al., 2014). When participants had a negative prior experience with cancer websites, they were more likely to report low levels of trust (Kim, 2016). Furthermore, only studies written in German and English were included in the study. Therefore, studies in other languages that examine cancer patients' trust in cancer-related online information might be missing from this systematic review. Another limitation could be that six of the seven included studies were conducted in North America, and only one was conducted in Europe, although there appears to be only small differences in the reported internet utilization of these populations (Poushter, 2016). We can therefore only draw conclusions about North American cancer patients. No gray literature was included in the review. Therefore, we missed the opportunity to minimize the effects of publication bias and to represent the entire evidence base as studies that show statistically significant, positive results have a better chance of being published (Blackhall & Ker, 2007; Hopewell et al., 2007).

In addition to the limitations, this review also has distinct strengths. First, because the authors aimed to provide a broad picture of cancer patients' trust in online health information, the study used a systematic search strategy of five electronic databases, which resulted in a heterogeneous sample of studies and did not exclude studies due to their design or quality. Additionally, the search strategy used appeared to be successful as only four additional studies could be identified through manual searches of the reference lists of studies that fulfilled the eligibility criteria of the first selection phase, and none of these four studies was included in the review. A further strength is the methodological quality assessment of the included papers, which was independently performed by two researchers according to the reporting guidelines of the PRISMA statement (Moher et al., 2009). Finally, this systematic review was registered in PROSPERO to achieve transparency.

CONCLUSIONS

This systematic review included seven cross-sectional studies out of 7,314 citations obtained from a search. The results of the included studies indicate that approximately half of cancer patients appear to trust information found on the internet, internet websites as a source of cancer-related information or trust the internet itself as a medium of cancer information. However, the small number of included studies, high heterogeneity of participants, methods and outcomes, and the diverse quality of the included studies call for further systematic research.

Further research on cancer patients needs to be conducted using a validated instrument to measure patients' perceived trust and the credibility of health information websites, especially for groups of patients such as older adults and those with a low socioeconomic status, who appear to have lower online information searching skills and tend to be less likely to trust cancer information found online.

Furthermore, it is important to understand that cancer patients' decision making is influenced by online information and that even if the physician remains the most trusted medium of advice, patients do and will increasingly use cancer-related websites to search information concerning their disease and its treatment. Therefore, physicians, nurses and other health care providers should provide more support and advice to patients seeking health information. Additionally, patients should be encouraged to ask their doctors questions and to discuss the results of their online information searches with them to ensure that false information is not included.

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The authors declare there are no competing interests.

Author Contributions

- Lukas Lange conceived and designed the experiments, performed the experiments, analyzed the data, contributed reagents/materials/analysis tools, prepared figures and/or tables, authored or reviewed drafts of the paper, approved the final draft.
- Mona Leandra Peikert performed the experiments, analyzed the data, contributed reagents/materials/analysis tools, authored or reviewed drafts of the paper, approved the final draft.
- Christiane Bleich and Holger Schulz conceived and designed the experiments, authored or reviewed drafts of the paper, approved the final draft.

Data Availability

The following information was supplied regarding data availability:

The raw data are available at Figshare: Lange, Lukas (2019): RAW Data Systematic Review.xlsx. figshare. Dataset. https://doi.org/10.6084/m9.figshare.7701014.v1.

Supplemental Information

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7.2 Publikation 2

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Original Paper

Patients With Cancer Searching for Cancer- or Health-Specific Web-Based Information: Performance Test Analysis

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Abstract

Background: Searching the internet for cancer-related information helps patients with cancer satisfy their unmet information needs and empowers them to play a more active role in the management of their disease. However, to benefit from the search, patients need a sufficient level of skill to search, select, appraise, and apply web-based health information.

Objective: We aim to study the operational, navigational, information, and evaluation skills and problems of patients with cancer performing cancer-related search tasks using the internet.

Methods: A total of 21 patients with cancer were recruited during their stay at the rehabilitation clinic for oncological rehabilitation. Participants performed eight cancer-related search tasks using the internet. The participants were asked to think aloud while performing the tasks, and the screen activities were recorded. The types and frequencies of performance problems were identified and coded into categories following an inductive coding process. In addition, the performance and strategic characteristics of task execution were summarized descriptively.

Results: All participants experienced problems or difficulties in executing the tasks, and a substantial percentage of tasks (57/142, 40.1%) could not be completed successfully. The participants' performance problems were coded into four categories, namely operating the computer and web browser, navigating and orientating, using search strategies, and evaluating the relevance and reliability of web-based information. The most frequent problems occurred in the third and fourth categories. A total of 90% (19/21) of participants used nontask-related search terms or nonspecific search terms. A total of 95% (20/21) of participants did not control for the source or topicality of the information found. In addition, none of the participants verified the information on 1 website with that on another website for each task.

Conclusions: A substantial group of patients with cancer did not have the necessary skills to benefit from cancer-related internet searches. Future interventions are needed to support patients in the development of sufficient internet-searching skills, focusing particularly on information and evaluation skills.

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KEYWORDS

telemedicine; eHealth; eHealth literacy; digital literacy; internet; web-based; health information; health education; cancer; mobile phone

Introduction

Background

Searching the internet for cancer-related information enables patients with cancer to satisfy their unmet information needs and empowers them to play a larger role in the management of their disease. Unmet information needs are one of the most frequently reported unmet supportive care needs of patients with cancer (6%-93%) during the treatment and posttreatment phases [1]. Patients with cancer prefer to receive as much information as possible about their disease [2,3]. The most common topics of cancer-related information sought on the web are information regarding the diagnosis, prognosis, disease stage, treatment options, or side effects of treatment [4-6].

The percentage of patients with cancer who use the internet to search for cancer-related information is high. In 1 Swedish, 1 American, and 1 Dutch sample, 63%-75% of the participants used the internet to search for cancer-related information or general health information [4,7,8]. The prevalence will continue to rise in the future owing to the increasing use of the internet worldwide [9].

Patients with cancer have various reasons for searching cancer-related web-based information. They use the internet to develop questions to discuss with their physician, verify information given by their physician, or seek alternative treatments [4]. Moreover, they feel that the amount of information they receive from their physician is insufficient [10].

Searching the internet for cancer-related information is positively associated with patient-reported outcomes and socioeconomic characteristics of patients with cancer. Patients with cancer who search the internet for cancer-related information are more involved in medical decision-making [11], feel better informed about their disease [7], have a higher level of self-reported health [12] and quality of life [13], are more likely to have a partner [8], and are younger and more educated [4,8,13] than patients who do not search the internet. In addition, internet health information seeking can improve the patient-physician relationship of patients with acute or chronic conditions, depending on whether the patients discuss the information with their physicians [14].

Nevertheless, to benefit from cancer-related internet searching, cancer-related web-based information must be reliable, and patients with cancer need a sufficient level of skills to search, select, appraise, and apply web-based health information [15,16]. However, the quality of cancer-related web-based information varies widely [17-23]. Information on websites is often incomplete and does not provide a basis for well-informed medical shared decision-making [17-23]. Only half (52%) of the patients with cancer trust the internet as a source of cancer-related information [24]. A total of 3 previous studies [15,25,26] analyzed essential skills to properly search the internet for health-related information. These 3 studies used performance tests and observed participants while executing health-related search tasks on the internet. The essential skills observed during task execution can be divided into 2 categories. First, people need operational and navigational skills to use a computer and web browser, that is, using a keyboard, mouse, or touch screen; navigating forward and backward between websites; and maintaining orientation on a website [15,25]. Second, they need information and evaluation skills to search, find, and assess web-based information, that is, formulate adequate search terms, choose a relevant search result, or check the source of information [15,25]. The results of the first study indicated that approximately one-third of the participants had severe problems in using operational and navigational skills [25]. Similar to the first study, the sample in the second study had, on average, a sufficient level of these skills [15]. The third study did not evaluate these 2 skills [26]. The levels of information and evaluation skills observed in the 3 studies seemed to be much lower [15,25,26]. Many participants reported problems choosing relevant search terms (14/15, 93%), selecting a reliable search result (13/15, 87%), and not checking the source of information (14/15, 93%) in at least 1 task [25]. Furthermore, none of the participants controlled the source of information, the topicality of the information, or how the information had been compiled [26].

Thus far, research on internet searching skills has focused on general healthy populations [15,26] or patients with rheumatoid arthritis [25]. The internet-searching skills of patients with cancer have not yet been studied.

Objective

Therefore, the primary goal of this study is to gain insight into the operational, navigational, information, and evaluation skills and problems of patients with cancer performing cancer-related search tasks using the internet.

Methods

Study Design

A performance test was conducted to obtain in-depth insight into the operational, navigational, information, and evaluation skills and problems of patients with cancer using the internet to search for cancer-related information on the web. Three qualitative methods of data collection were used: (1) the think-aloud method [27] combined with (2) the study administrator’s *real-time* notes and (3) video and audio data of the participants’ screen activity.

The report of this study followed the recommendations of the Standards for Reporting Qualitative Research, consisting of 21 items that aimed to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research (Multimedia Appendix 1) [28].

The study protocol for this qualitative study is freely available at the Open Science Framework [29] and was published before the recruitment of the first participant.

Setting, Participants, and Recruitment

The participants were recruited during the first week of their 3-week stay at a rehabilitation clinic for oncological inpatient rehabilitation. Recruitment was conducted by the medical director (GE) of the clinic who approached the participants during the patient consultations. Patients were included if they had been diagnosed with any type of cancer and if they had sufficient oral and written proficiency in the German language. An appointment for the performance test was scheduled within the following week, and the participants received informed consent forms. Informed consent included information about the study goal, potential risks and benefits of the study, the voluntary nature of participation, and the type and duration of data storage. The participants were instructed to sign the informed consent before data collection. All appointments occurred at the rehabilitation clinic and were conducted by the same researcher (LLD). The sample size in this study was based on the concept of theoretical saturation [30], which is defined as the point when no new information, themes, or topics emerge from the data. Saturation, in the context of this study, indicates that no new performance problems were observed among the participants.

Procedure and Materials

Each appointment started with a short questionnaire to collect the following data: (1) the participants' socioeconomic characteristics (age, gender, education, and marital status); (2) their medical characteristics (cancer type, time since cancer diagnosis, and self-perceived health status measured using the second-to-last items of the German version of the EORTC QLQ C-30 [European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-30] [31], with response options ranging from 1=very poor to 7=excellent); and (3) their general and cancer-related internet usage characteristics (internet experience, daily time spent on the internet, internet use for cancer-related topics, frequency of health-related internet use, and self-perceived internet searching skills). The participants had to evaluate their internet searching skills on four 5-point scales (ranging from *very bad* to *very good*) that measured the participants' self-perceived ergonomic skills, navigational skills, evaluating information reliability skills, and determining relevance skills [16].

Performance tests were started when all the items were completed. The patients executed 8 cancer-related internet search tasks (Textbox 1) based on the most common topics of cancer-related information sought on the web [4,5]. The order of the tasks was randomized for each participant because a learning effect was expected to affect the performance of subsequent tasks. The tasks were pilot tested with 4 patients with cancer to ensure comprehensibility and applicability. The participants of the pilot study were recruited from the Outpatient Clinic for Psycho-Oncology of the University Medical Center Hamburg-Eppendorf. The pilot study contained 10 search tasks. Two tasks were deleted because none of the participants were able to complete these tasks independently.

Textbox 1. Description of the cancer-related internet search tasks.

Description of the Cancer-Related Internet Search Tasks

- Imagine that you have noticed the following effects on your physical and mental well-being during your cancer treatment: listlessness, physical and mental exhaustion that does not improve even by sleep or rest. Search the internet for the symptom's name.
- Please search the internet for treatments or methods of treatment for chronic or persistent "fatigue" (this task always came after task 1).
- Please search the internet for various providers who offer psycho-oncological counseling in the Hamburg area (postcode: 22529).
- Formulate a disease-related question you have had in the past and show how you would approach this on the internet.
- Please search the patient guidelines of the German Cancer Society for your specific type of cancer.
- Search for the information sheet of the Cancer Information Service "Cancer on the internet: Surf safely."
- With the help of information from the internet, please name 5 possible side effects or symptoms of the specific cancer therapy (eg, chemotherapy and radiotherapy) that you received.
- With the help of information from the internet, please name possible ways that you could change your diet to promote your well-being or reduce side effects.

The performance tests were recorded using *Open Broadcaster Software* (version 26.1.0), which generated video and audio data. The participants were asked and trained to think aloud while performing the tasks. The verbalization of the participants' thoughts allowed the researcher to gain insight into the participants' cognitive processes while searching for web-based information [32]. In addition, the researcher present observed the participants and recorded real-time notes to identify problems with the hardware operation.

Each performance test was conducted using the same hardware (laptop, mouse, and keyboard) with identical settings. The laptop was connected to an active internet connection and was programmed with the 3 most popular web browsers (Internet Explorer, Mozilla Firefox, and Google Chrome). The participants were instructed to choose the web browser with which they had the most experience. All web browsers began with a blank page. To prevent the participants from being influenced by previous participants' search activities, the web browser was reset after each participant by removing the web browser history and cookies using CCleaner version 5.44 (Avast Software). If the participants were unable to perform the task, help was offered by the researcher present. The participants received €15 (US $17.70) for participating in the study.

Data Analysis

Statistical analyses were conducted using SPSS Statistics (version 25, IBM SPSS Inc). The participants' sociodemographic characteristics, medical characteristics, and general and cancer-related internet usage were summarized descriptively.

Video and audio data, as well as the researcher's real-time notes, were analyzed to (1) identify participants' performance problems, (2) evaluate the participants' performance, and (3) identify performance and strategic characteristics of task execution.

To identify participants' performance problems, the researchers followed an inductive coding process [33]. Participants' behavior or statements were initially coded and subsequently grouped into categories and subcategories that were then named. The category names were partly based on categories from previous research [25]. The number of problems encountered per task was then determined.

The evaluation of the participants' performance per task and the difficulty of the tasks were based on two variables: (1) could the participants complete their task *completely independently*, *with help,* or *not able to complete* the task at all, and (2) the time needed to perform the task (the more time needed to complete a task, the higher the difficulty of the task).

The execution and strategic characteristics of task execution were described by six variables: (1) the used web browser (Internet Explorer, Mozilla Firefox, or Google Chrome), (2) the starting point (eg, a specific website or a search engine), (3) the position of the opened website in the Google search listings from top to bottom (the position of the opened website in the search listings is an indicator of whether participants look beyond the first search results), (4) the number of words per search query (the use of a single search term was considered too unspecific; it is more important for the successful completion of a task to use task-related search terms than a large number of search terms), (5) the number of times a search query needed to be adjusted (a higher number of adjustments per task indicated a higher difficulty of the task), and (6) the name of the opened websites (Do the most often opened websites have a good content ranking and a commercial interest?) [21].

The influence of the participants' education (>10 years of school education vs ≤10 years of school education), age (above vs below median), self-perceived internet skills (above vs below median), internet experience (above vs below median), and time since cancer diagnosis (above vs below median) on the participants' average number of problems per task and percentage of successfully completed tasks were analyzed using 2-tailed t tests for independent groups. For additional interpretation, effect sizes were calculated: the values of Cohen d for small, medium, and large effects were 0.2, 0.4, and 0.8, respectively [34]. The α level of significance was set at α=.05.

Ethics Statement

The study was conducted in accordance with the Code of Ethics of the Declaration of Helsinki and was surveyed by the Ethics Committee of the Medical Association (Hamburg, Germany). Written informed consent was obtained from all the participants before participation.

Results

Participants' Characteristics and Participants' Internet Use

Slightly more women (12/22, 55%) than men participated in the study (Table 1). The participants' ages ranged between 25 and 81 years (mean 57 years, SD 11.9 years). Almost three-fourths of the participants lived with a partner (16/22, 73%). Most (13/22, 59%) of the sample had 10 years or less of schooling, whereas 27% (6/22) had a university degree. Breast (6/22, 27%), colon (4/22, 18%), and prostate cancer (3/22, 13%) were the most frequently reported cancer diagnoses. The participants received their diagnosis, on average, 28 (SD 57.8) months prior. The average self-perceived health status score was 4.5.

Table 1. Medical and sociodemographic characteristics of the participants (N=22).

Participant characteristics	Values
Age (years), mean (SD; range)	56.8 (12; 25-81)
Gender (female), n (%)	12 (55)
Marital status, n (%)	
Living alone	6 (27)
Living with a partner	16 (73)
Highest educational achievement, n (%)	
University degree	6 (27)
13 years of school education	3 (14)
10 years of school education	9 (41)
9 years of school education	4 (18)
Cancer type, n (%)[a]	
Breast cancer	6 (27)
Colon cancer	4 (18)
Prostate cancer	3 (13)
Lung cancer	2 (9)
Kidney cancer	2 (9)
Other	8 (32)
Time since cancer diagnosis (months), median (range)	6 (1-207)
Self-perceived health status, mean (SD)	4.5 (1.0)

[a] Multiple selection.

The participants' mean internet experience was 15 years (Table 2). Most of the participants (13/22, 59%) used the internet for less than 1 hour per day. The most common cancer-related activities on the internet were searching for cancer-related information (14/22, 64%) and communication with relatives (14/22, 64%). More than half (14/22, 64%) of the participants used the internet less than once a month for health care reasons. The participants rated their ergonomic skills, evaluating information reliability skills, navigation skills, and determining information relevance skills as *medium* to *good*.

Table 2. General and cancer-related internet usage of participants (N=22).

Participant characteristics	Values
Internet experience (years), mean (SD; range)	15.4 (7.7; 0-30)
Daily time spent on the internet (minutes), n (%)	
No utilization	1 (5)
0-30	5 (23)
30-60	7 (32)
60-120	6 (27)
>120	3 (15)
Types of internet use for cancer-related topics, n (%)[a]	
Obtaining general information about my cancer (ie, treatment information)	14 (64)
Communication with relatives or friends	14 (64)
Search for treatment options	12 (55)
Search for health care professionals	8 (36)
Verifying information received from health care professionals	7 (32)
Contact health care professionals (ie, oncologist)	4 (18)
Contact pharmacist	3 (14)
Contact other patients	3 (14)
Search for alternative treatment options	3 (14)
Search scientific data (ie, Google Scholar)	3 (14)
Frequency of internet use as a part of health care, n (%)	
Never	2 (9)
Rarely	12 (54)
More than once a month	3 (14)
More than once a week	4 (18)
Daily	1 (5)
Self-perceived internet-searching skills	
Value, range	1-5
Different self-perceived internet-searching skills, mean (SD)	
Ergonomic skills	3.5 (1.4)
Navigation skills	3.2 (1.3)
Evaluating information reliability skills	3.5 (0.7)
Determining information relevance skills	3.5 (0.8)

[a] Multiple selection.

Execution of Cancer-Related Tasks and Problems Encountered

Search Strategy and Effectiveness of Searches

Performance tests of the 21 participants were included in the analysis. The performance of participant 22 was excluded because the participant could not execute the tasks due to stress. On average, the participants executed 6.8 tasks. Participants 1 and 21 performed only 2 tasks. A total of 57% (12/21) of participants executed all 8 tasks. All data on task execution and performance problems are available in Figshare [35].

None of the participants used medical websites as a starting point. All search tasks were started using the Google search engine. On average, the participants successfully completed 59.9% (85/142) of all the tasks. Task F (Search the information sheet of the Cancer Information Service) had the highest rate of successful completions (14/18, 78%) and took participants, on average, the shortest time to execute (Table 3). Task E (Search the patient guideline for your cancer type) had the lowest rate of completion (6/19, 32%). The longest mean time (mean 323 seconds) to execute a task was observed for task D (retrieve previously searched disease information). A total of 86% (18/21%) of participants used the same web browser for all the tasks. Google Chrome was used in 80.2% (114/142) of search queries. The participants opened 192 webpages (the same website was counted every time it was opened) from 61 different websites during their 142 search queries (Multimedia Appendix 2). The 2 most frequently opened websites were provided by professional associations with generally good content rankings [21]. The participants usually selected one of the first websites from Google search listings. Of the 192 opened webpages, 163 (84.9%) webpages were ranked among the first 5 Google search results. Websites from the second page of Google search listings were opened 4 times (4/192, 2.1%). On average, the participants used 4.2 search terms per task. A single search term was used for 4.9% (7/142) of search queries. In addition, in 27.5% (39/142) of search queries, the participants decided to adjust the search terms to improve the Google search results.

Table 3. Performance and strategic characteristics of the task execution (n=21).

Tasks	A[a] (n=19)	B[b] (n=17)	C[c] (n=17)	D[d] (n=17)	E[e] (n=19)	F[f] (n=18)	G[g] (n=17)	H[h] (n=18)
Task completion, n (%)								
Completed independently	12 (63)	10 (59)	10 (59)	11 (65)	6 (32)	14 (78)	12 (71)	10 (55)
Completed with help	1 (5)	2 (12)	0 (0)	0 (0)	0 (0)	1 (6)	0 (0)	1 (6)
Not completed	6 (32)	5 (29)	7 (41)	6 (35)	13 (68)	3 (16)	5 (29)	7 (39)
Time per task (seconds)								
Value, mean (SD; range)	195 (121; 58-461)	220 (105; 68-467)	253 (207; 81-843)	323 (188; 116-696)	209 (117; 63-411)	177 (177; 44-746)	228 (146; 36-529)	235 (149; 91-489)
Web browser used, n (%)								
Google Chrome	16 (84)	15 (87)	13 (76)	13 (76)	16 (84)	14 (78)	14 (82)	13 (72)
Mozilla Firefox	3 (16)	2 (13)	4 (24)	4 (24)	3 (16)	3 (16)	3 (18)	3 (17)
Internet Explorer	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	1 (6)	0 (0)	2 (11)
Position of website[i,j], n (%)								
First search result	11 (41)	11 (42)	6 (27)	9 (36)	15 (63)	12 (57)	7 (33)	5 (19)
Second to fifth search result	13 (48)	14 (54)	9 (41)	8 (32)	9 (37)	9 (43)	10 (48)	15 (58)
Sixth to tenth search result	3 (11)	1 (4)	7 (32)	8 (32)	0 (0)	0 (0)	4 (19)	2 (8)
Second page of Google listings	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	4 (15)
Words per search query								
Value, mean (SD)	5.6 (4.7)	3.3 (2.2)	4.8 (3.5)	3.4 (2.3)	2.8 (0.6)	3.8 (1.6)	3.4 (1.2)	3.9 (2.8)
Single search term, n (%)	0 (0)	2 (8)	1 (5)	2 (8)	0 (0)	2 (10)	0 (0)	0 (0)
Adjustments of a search query, n (%)								
Amount	6 (22)	2 (8)	5 (23)	6 (24)	4 (17)	6 (29)	6 (29)	4 (15)

[a] Identify the symptom fatigue.

[b] Search treatment methods for cancer-related fatigue.

[c] Search service providers who offer psycho-oncological counseling.

[d] Retrieve previously searched disease information.

[e] Search the patient guideline for your cancer type.

[f] Search the information sheet of the Cancer Information Service.

[g] Search for five symptoms of the treatment you received.

[h] Search for options to change your diet.

[i] Position of opened websites in the Google search listings from top to bottom.

[j] In some cases, participants opened more than one website. The position in the Google search listings of each website is listed here.

The participants' performance problems were coded into four categories concerning internet searching skills (Table 4): (1) operating the computer and web browser, (2) navigating and orientating, (3) using search strategies, and (4) evaluating the relevance and reliability of web-based information. In addition, problems in understanding the task and focusing on the task were observed.

Table 4. Performance problems and number of participants experiencing those problems for each task.

Tasks	A[a] (n=19)	B[b] (n=17)	C[c] (n=17)	D[d] (n=17)	E[e] (n=19)	F[f] (n=18)	G[g] (n=17)	H[h] (n=18)	Total[i] (n=21)
Operating the computer or web browser, n (%)									
Operating the keyboard	5 (26)	4 (24)	3 (18)	3 (18)	5 (26)	4 (22)	4 (24)	4 (22)	7 (33)
Controlling the mouse	6 (32)	2 (12)	2 (12)	2 (12)	5 (26)	5 (28)	3 (18)	6 (33)	8 (38)
Using the scroll bar	0 (0)	0 (0)	0 (0)	0 (0)	2 (11)	1 (6)	0 (0)	0 (0)	3 (14)
Operating the web browser	2 (11)	1 (6)	3 (18)	3 (18)	0 (0)	1 (6)	3 (18)	3 (17)	11 (48)
Reading difficulties	0 (0)	1 (6)	0 (0)	0 (0)	0 (0)	0 (0)	1 (6)	0 (0)	2 (10)
Participants with >1 problem per task	5 (26)	0 (0)	2 (12)	3 (18)	3 (16)	3 (18)	2 (12)	4 (22)	6 (29)
Navigating and orientating, n (%)									
Keeping orientation on a website	0 (0)	1 (6)	0 (0)	0 (0)	1 (6)	1 (6)	1 (6)	2 (11)	5 (29)
Using and understanding a PDF file	1 (5)	0 (0)	0 (0)	0 (0)	3 (11)	0 (0)	0 (0)	0 (0)	3 (14)
Using dropdown lists	0 (0)	1 (6)	0 (0)	0 (0)	1 (6)	0 (0)	0 (0)	0 (0)	2 (10)
Orientation in the Google search engine	1 (5)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	1 (5)
Participants with >1 problem per task	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	1 (6)	1 (6)	1 (6)	2 (10)
Using search strategies, n (%)									
Too broad search query	0 (0)	2 (12)	1 (6)	2 (12)	0 (0)	2 (12)	0 (0)	0 (0)	5 (24)
Nonspecific or nontask-related search query	9 (47)	5 (29)	9 (53)	1 (6)	5 (26)	4 (22)	4 (24)	2 (11)	19 (90)
Spelling and grammatical errors in search query	2 (11)	1 (6)	5 (29)	2 (12)	5 (26)	4 (22)	2 (12)	0 (0)	11 (52)
Adjusting the search query	1 (5)	0 (0)	1 (6)	0 (0)	2 (11)	0 (0)	1 (6)	1 (6)	6 (29)
Selection of task-related search results	0 (0)	0 (0)	3 (18)	2 (12)	0 (0)	4 (22)	4 (24)	3 (16)	11 (52)
Selecting physician instead of patient guidelines	N/A[j,k]	N/A[k]	N/A[k]	N/A[k]	8 (42)	N/A[k]	N/A[k]	N/A[k]	N/A[k]
Participants with >1 problem per task	3 (16)	0 (0)	5 (29)	0 (0)	5 (26)	2 (12)	1 (6)	1 (6)	9 (43)
Evaluating relevance and reliability, n (%)									
Controlling the source of information	19 (100)	17 (100)	17 (100)	17 (100)	18 (95)	18 (100)	17 (100)	17 (94)	21 (100)
Searching in commercial websites	1 (5)	0 (0)	2 (12)	2 (12)	0 (0)	0 (0)	3 (18)	6 (33)	8 (38)
Verifying the information	17 (89)	15 (88)	16 (94)	16 (94)	N/A[l]	N/A[l]	14 (82)	17 (94)	21 (100)
Scanning a website for relevant information	2 (11)	1 (6)	0 (0)	0 (0)	0 (0)	1 (6)	0 (0)	5 (28)	6 (29)
Participants with >1 problem per task	17 (89)	15 (88)	15 (88)	16 (94)	0 (0)	1 (6)	15 (88)	18 (100)	21 (100)
Understanding of the task and keeping focus, n (%)									
Understanding the task	4 (21)	2 (12)	0 (0)	0 (0)	1 (5)	2 (12)	3 (18)	0 (0)	7 (33)
Forgetting the task	0 (0)	2 (12)	1 (6)	1 (6)	3 (16)	3 (17)	0 (0)	0 (0)	9 (43)
Keeping focus	2 (11)	1 (6)	1 (6)	3 (18)	0 (0)	1 (6)	1 (6)	0 (0)	5 (24)

[a] Identify the symptom fatigue.

[b] Search treatment methods for cancer-related fatigue.

[c] Search service providers who offer psycho-oncological counseling.

[d] Retrieve previously searched disease information.

[e] Search the patient guideline for your cancer type.

[f] Search for the information sheet of the Cancer Information Service.

[g] Search for five symptoms of the treatment you received.

[h] Search for options to change your diet.

[i] Number of participants who experienced this problem during the execution of at least one task.

[j] N/A: not applicable.

[k] The problem was task-specific (task 5).

[l] Verifying the information was not applicable for this task because participants were instructed to search for a particular website.

Operating the Computer and Web Browser

A total of 62% (13/21) of participants had at least 1 problem using computer hardware (keyboard and mouse) or problems using basic web browser functions.

In total, 33% (7/21) of participants had problems using the keyboard, especially locating keys while typing search terms or searching for the *enter* key. In addition, 38% (8/21) of participants had problems controlling the mouse, mainly the double-clicking of icons (eg, web browser). A total of 14% (3/21) of participants experienced difficulties with the scroll bar. A total of 52% (11/21) of participants had problems operating the web browser. Frequent problems included finding the web browser icon on the desktop and closing and reopening the web browser to adjust the search terms instead of using the web browser's *back* button. Furthermore, 10% (2/21) of participants had problems reading the text of a website because of the small font size.

Overall, the operational problems were not task-specific. Most of the operating problems (94/122, 77%) were experienced by the same 6 participants. After completing several tasks, the present researcher observed that the participants became increasingly frustrated with the recurring operational problems.

In addition, 2 behaviors were observed but were not coded as operational problems. A total of 81% (17/21) of participants closed the web browser after every individual task and reopened the browser for the next task. Furthermore, 71% (15/21) of participants used a single tab for all searches.

Navigating and Orienting

A total of 33% (7/21) of participants experienced at least one problem with navigation and orientation in web browsers and on websites. Problems often occurred when the websites had complex structures, such as different graphical control elements (ie, dropdown lists or anchor links).

A total of 24% (5/21) of participants had problems maintaining their orientation on a website. They lost their orientation for various reasons. Twice, the participants felt confused by the browser's starting page (eg, "This is not where I wanted to be" [Participant 8]). Two other times, the participants did not understand the function of the anchor link at the top of the website, which would have helped them jump to the relevant information in the text. A total of 14% (3/21) of participants could not distinguish an opened PDF file from a website. In total, 10% (2/21) of participants did not find relevant information on websites because they could not use the websites' dropdown lists. One participant lost orientation due to the Google option *related searches* (eg, "I did not write that" [Participant 8]).

Notably, most of the orientation and navigation problems (94/122, 77%) were experienced by the same group of 6 participants who encountered most of the operational problems.

Using Search Strategies

A total of 95% (20/21) of participants experienced at least 1 problem using search strategies. Most of the problems occurred in the first stage when the participants formulated the search terms.

A total of 24% (5/21) of participants used only single search terms that were too broad to successfully complete the tasks. In total, 90% (19/21) of participants used nontask-related search terms or nonspecific search terms. For example, Participant 5 used the search terms *patient Hamburg* to find the patient guidelines of the German Cancer Society (task 5; nontask-related). Participant 11 searched for *psychological support* instead of *psycho-oncological support* (task 3; unspecific search). In total, 52% (11/21) of participants made spelling or grammatical errors in their search queries. These participants (9/11, 81%) usually did not adapt the search terms, and the Google option *did you mean* was not used to correct the errors.

The use of nontask-related, nonspecific, or grammatically incorrect search terms made the participants adjust their search terms or select a nontask-related webpage from Google search listings. A total of 29% (6/21) of participants experienced problems adjusting the search terms. For example, Participant 9 adjusted the original search query from *side effect of cancer therapy* to *side effect of cancer*, a query that was still not task-related (task 1: identify the symptom fatigue). A total of 52% (11/21) of participants selected nontask-related websites from the search listings. Many of these participants (5/11, 45%) randomly opened one of the first search results ("I am going on a random website; usually I don't like to pick the first website" [Participant 14]; task 2). They did not look at the URL or Google snippet (short description of the website's content) to be informed about the website's content.

To complete task 5, the participants had to find the patient guidelines (PDF file) of their specific cancer type. A total of 38% (8/21) of participants selected clinical practice guidelines instead of the patient guidelines. Both types of guidelines can be found on the same website.

Evaluating Relevance and Reliability

All participants experienced at least 1 problem while evaluating their relevance and reliability. None of the participants controlled the source or topicality of the information, except for Participant 19. Furthermore, none of the participants verified the information on 1 website with that on another website for each task. Most of the participants only opened a second website when they were not satisfied with the information on the first website. A total of 19% (4/21) participants made critical comments regarding the reliability of commercial websites; for example:

> *The first search result is an advertisement. Therefore, I will not consider that webpage.* [Participant 7]

Nevertheless, 38% (8/21) of participants selected and searched the providers' websites with a commercial interest. In total, 4 of these participants even opened websites marked as ads by Google. A total of 29% (6/21) of participants did not scan the selected websites for relevant information to complete the task. They read the websites' headings and then completed the task because they were convinced that the information they were looking for could be found on the website.

Notably, 71% (15/21) of participants made comments regarding the following: (1) the reliability of certain websites; for example:

> *I got offers. Here, from yelp.com. I have problems with opening this website because for me that is dubious information.* [Participant 17]

(2) the reliability of certain types of websites; for example:

> *What I would not read are patient forums. Where some laymen write what they did...I would rely on medical tips.* [Participant 2]

or (3) the internet as a source of cancer-related information; for example:

> *The internet in general is way too superficial. I read a book to gather information about that.* [Participant 4]

Understanding the Task and Staying Focused

A total of 33% (7/21) of participants experienced problems understanding the tasks ("I don't know what I am supposed to search" [Participant 14]; task 1), usually (10/12, 83%) resulting in nontask-related search queries. A total of 43% (9/21) of participants forgot the task during execution and had to reread it. A total of 24% (5/21) of participants were distracted by other nontask-related information. For example, Participant 3 became distracted by a brochure about *sexuality and cancer* while executing task 6.

Relationship Between Patient Characteristics and Performance Parameters

Participants 1 and 21 were not included in this analysis because they executed fewer than 3 tasks. The participants who were younger (mean 2.7, SD 1.0) and had higher self-perceived internet skills (mean 2.9, SD 1.1), on average, encountered significantly fewer (t_{17}=–2.78, *P*=.01, Cohen *d*=1.30; t_{17}=–2.33, *P*=.03, Cohen *d*=1.07) performance problems per task than those who were older (mean 4.6, SD 1.8) and had lower self-perceived internet skills (mean 4.5, SD 1.8; Multimedia Appendix 3). Both the differences had a large effect size. In addition, participants with higher self-perceived internet skills (mean 75.6, SD 18.1) completed a significantly higher percentage of tasks successfully (t_{17}=2.65; *P*=.02; Cohen *d*=1.23) than those with lower self-perceived internet skills (mean 44.9, SD 30.2). In addition, differences with a large, medium, and small effect size can be found: (1) younger participants completed a higher percentage of tasks successfully (Cohen *d*=0.87); (2) participants with more internet experience completed a higher percentage of tasks successfully (Cohen *d*=0.87) and had fewer performance problems (Cohen *d*=0.66) than patients with less experience; (3) participants with higher education completed a higher percentage of tasks successfully (Cohen *d*=0.46) and had fewer performance problems (Cohen *d*=0.40) than participants with a lower education; and (4) participants who had more time since diagnosis completed a higher percentage of tasks successfully (Cohen *d*=0.30) and had fewer performance problems (Cohen *d*=0.40) than participants with a lower education.

Discussion

Principal Findings

This study examined the level of operational, navigational, information, and evaluation skills of a sample of patients with cancer performing 8 cancer-related search tasks using the internet. The results indicate that a substantial group of patients with cancer did not have the necessary operational, navigational, information, and evaluation skills to benefit from cancer-related internet searches. A total of 29% (6/21) of participants had major problems with the operation of the hardware, operation of the computer and web browser, and with navigation and orientation in web browsers and on websites. These participants produced three-fourths (94/122, 77%) of the operational and navigational problems. These problems caused great frustration among the participants and often resulted in tasks not being completed successfully. A total of 6 participants completed only 29% (12/42) of their tasks successfully. Although the operational and navigational skills of most participants (15/21, 71%) seemed to be sufficient for searching the internet, the information and especially the evaluation skills were much lower. Many participants struggled with formulating a task-related search query (19/21, 90%), selecting a task-related search result (11/21, 52%) of a provider without a commercial interest (8/21, 38%), and browsing the website to find the answer to the task (6/21, 29%). Strikingly, only 19% (4/21) of participants verified the information on 1 website with that on another website, and only 5% (1/21) of participant informed himself about the provider of the website. The remaining participants seemed to take no interest in the source or topicality of the information. These findings are alarming because previous research has shown that the quality of cancer-related web-based information varies widely [17-23].

Comparison With Previous Work

Our results are consistent with those of previous studies that used performance tests to analyze the internet-searching skills of healthy participants [15,26] and patients with rheumatoid arthritis [25]. Operational and navigational problems occurred in only approximately one-third of the samples [15,25]. In addition, almost all the participants of this study and three similar studies had problems with information and evaluation skills [15,25,26]. Owing to the similarity of the results, we believe that the identified internet searching problems can also be found in patients with other health conditions and in the healthy population. In addition to the National Action Plans that plan to increase the health literacy of the entire population in the future [36,37], further web-based interventions are needed to increase the internet-searching skills of patients with low skills presently [38-40].

The rate of search queries with single search terms was the main difference between the search strategies used in 2002 [26] and those used in this study. In 2002, 65% of all search queries comprised a single search term [26] compared with 4.9% (7/142) in this study. The longer average internet experience of our sample (15.4 years vs 2.5 years) could be a possible explanation for choosing to use more search terms. However, information skills did not seem to grow with years of internet experience [41].

An exploratory analysis of our data indicated that younger age, higher self-perceived internet skills, more internet experience, and higher education were associated with encountering fewer performance problems and completing a higher percentage of tasks successfully. In addition, more time since diagnosis was associated with fewer performance problems and a slightly higher percentage of successfully completed tasks. The results of our exploratory analysis should be interpreted carefully because our sample size (n=19) was too small to make assumptions about the population of patients with cancer. However, previous research on internet-searching skills using performance tests confirmed that younger age, a higher level of education, more internet experience, and higher self-perceived internet skills are associated with more successful task completion [25,41]. Younger participants have higher operational and navigational skills but particularly poor performance regarding evaluation skills [41,42]. Education and self-perceived internet skills are associated with operational, navigational, information, and evaluation skills, whereas internet experience only has a positive influence on operational and navigational skills [41]. In addition, we analyzed the influence of time since cancer diagnosis on the participants' test performance, assuming that patients who had more time looking for cancer-related information on the web may know of more reliable providers of web-based cancer information than patients who recently received their diagnosis. A possible explanation for the lack of a stronger association with participants' performance might be that having more time since diagnosis may only be associated with patients' evaluation skills but not their operational, navigational, and information skills. Future performance tests with larger sample sizes are needed to examine this question.

Limitations

This study had several limitations. First, the participants performed the tasks in an artificial research setting under experimental conditions. They may have felt more nervous than if they had been in a natural setting. For example, Participant 22 did not start the performance test because of stress. In addition, the participants may have felt time pressure to perform the tasks and may have focused less on evaluating the reliability or topicality of the websites. We tried to minimize the pressure to perform and time pressure by explicitly reminding participants to take their time and that there were no right or wrong answers. Second, some participants had to use unfamiliar hardware as they accessed the internet exclusively with their smartphones or tablets [9]. This may have increased the number of operational problems experienced. Asking the participants what type of digital device they use to access the internet would have helped to distinguish among the users. Future performance studies should also consider enabling participants to perform tasks on a smartphone or tablet. Third, to ensure that the tasks were related to the interests and needs of patients with cancer, we formulated search tasks that covered the most common topics of cancer-related information sought on the web [4,5] and pilot-tested the tasks. However, compared with a real setting, answering our cancer-related questions had no direct effect on the treatment or well-being of the participants. Therefore, the participants may have been less motivated to evaluate the website's reliability or to verify the information found on a second website. Fourth, the study sample was small and most likely nonrepresentative. No national or international studies with representative samples have been conducted yet that allow statements on the internet searching skills of entire population groups or patients with cancer [43]. However, we expect that our sample had higher skills than the population of patients with cancer for the following three reasons: (1) the participants volunteered to participate in the study; (2) the participants' average internet experience in years (mean 15.4 years) was high, and operational and navigational skills grew with years of internet experience [41]; and (3) the participants were often highly educated (28% had a university degree), with a high level of education being related to high internet searching skills [41]. Future performance test studies should concentrate on older, lesser-educated patients with cancer with little internet experience. Additional important performance problems may be identified because these patient characteristics are associated with low internet-searching skills [25,41]. Fifth, using the concept of data saturation [30] also captures the risk of missing additional important performance problems [44]. Previous studies have indicated that even if no new concepts emerge, the possibility of further uncovered concepts in the population cannot be excluded [45,46]. We cannot completely exclude the possibility that we missed certain internet searching problems. Nevertheless, by giving the participants sufficient time to express all of their thoughts and the similarity between our results and those of previous performance tests [15,25], we are convinced that we have identified most of the important problems of patients with cancer using the internet to search for cancer-related information on the web.

Conclusions

A substantial group of patients with cancer did not have the necessary skills to benefit from cancer-related internet searches. The problems included operating the hardware, navigation and orientation in web browsers and on websites, and in particular formulating a task-related search query and critically evaluating and verifying web-based content. Given the high number of participants with higher education and relatively high internet experience, the need for future interventions or programs to increase the internet-searching skills of patients with cancer may be underestimated in this study. Additional important performance problems may be identified in future studies that concentrate on older, low-educated patients with little internet experience.

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Authors' Contributions

LLD was responsible for conceptualization, data curation, formal analysis, investigation, methodology, project administration, resources, validation, visualization, writing—original draft and review and editing. HS was responsible for the investigation, methodology, supervision, validation, and writing—review and editing. CB was responsible for conceptualization, investigation, methodology, supervision, validation, and writing—review and editing. GE was responsible for the recruitment of the sample, project administration, and writing—review and editing. All authors reviewed the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Standards for Reporting Qualitative Research checklist.
[DOCX File , 21 KB-Multimedia Appendix 1]

Multimedia Appendix 2

Names of websites and the number of times they were opened.
[DOCX File , 19 KB-Multimedia Appendix 2]

Multimedia Appendix 3

Completed tasks and number of encountered problems per assignment related to education level, age, self-perceived internet skills, internet experience, and time since diagnosis.
[DOCX File , 17 KB-Multimedia Appendix 3]

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Abbreviations

EORTC QLQ C-30: European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-30

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Association of the Extent of Cancer Patients' Internet Use with Social Support among Patients and Change in Patient-reported Treatment Outcomes during Inpatient Rehabilitation: Cross-Sectional and Longitudinal Study.

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Association of the Extent of Cancer Patients' Internet Use with Social Support among Patients and Change in Patient-reported Treatment Outcomes during Inpatient Rehabilitation: Cross-Sectional and Longitudinal Study.

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Abstract

Background: Association of the Extent of Cancer Patients' Internet Use with Social Support among Patients and Change in Patient-reported Treatment Outcomes during Inpatient Rehabilitation: Cross-Sectional and Longitudinal Study.

Objective: We hypothesized that the extent of cancer patients' internet use would be negatively related to social support among patients during their clinical stay as well as fewer improvements in patient-reported treatment outcomes from the first to the last day of the clinical stay.

Methods: Cancer patients participated during their inpatient rehabilitation. Cross-sectional data, such as the extent of participants' internet use and perceived social support among patients, were collected during the last week of the clinic stay. The treatment outcomes, i.e., participants' levels of distress, fatigue and pain were collected on the first and last day of the clinic stay. We used multiple linear regression analysis to study the association between the extent of cancer patients' internet use and social support among patients. We used linear mixed model with repeated measures analysis to study the association between the extent of cancer patients' internet use and the change in patient-reported treatment outcomes.

Results: Of the 323 participants, 279 participants (86.4%) reported that they use the internet. During their clinical stay, 71% (198/279) of the internet users used the internet daily, and 30 of the 279 (10.8%) internet users never used the internet. The extent of participants' internet use during their clinical stay (t315=0.78, P=.43) was not significantly associated with the perceived social support among patients during their clinical stay. Additionally, the extent of participants' internet use during their clinical stay was not negatively associated with the change in participants' levels of distress (F1, 306.08=0.29, P=.59), fatigue (F1, 308.89=0.02, P=.90), and pain (F1, 306.31=1.84, P=.18) from the first to the last day of the clinical stay.

Conclusions: The extent of cancer patients' internet use during their clinical stay does not seem to be negatively associated with the perceived social support among patients or with the change in patients' levels of distress, fatigue or pain from the first to the last day of patients' clinical stay.

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Original Paper

Association of the Extent of Cancer Patients’ Internet Use with Social Support among Patients and Change in Patient-reported Treatment Outcomes during Inpatient Rehabilitation: Cross-Sectional and Longitudinal Study.

Abstract

Background: Given the increasing number of cancer survivors and rising survival rates, rehabilitation plays an increasingly important role. Social support among patients is an essential element of inpatient and day care rehabilitation. The internet can empower cancer patients to be more active health care consumers and facilitate information and supportive care needs. On the other hand, therapists suspect that high internet use during rehabilitation may severely limit social interactions between patients, thus interfering with the patients’ rehabilitation program and jeopardizing treatment success.

Objective: We hypothesized that the extent of cancer patients’ internet use would be negatively related to social support among patients during their clinical stay as well as fewer improvements in patient-reported treatment outcomes from the first to the last day of the clinical stay.

Methods: Cancer patients participated during their inpatient rehabilitation. Cross-sectional data, such as the extent of participants’ internet use and perceived social support among patients, were collected during the last week of the clinic stay. The treatment outcomes, i.e., participants’ levels of distress, fatigue and pain were collected on the first and last day of the clinic stay. We used multiple linear regression analysis to study the association between the extent of cancer patients’ internet use and social support among patients. We used linear mixed model with repeated measures analysis to study the association between the extent of cancer patients’ internet use and the change in patient-reported treatment outcomes.

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Conclusions: The extent of cancer patients’ internet use during their clinical stay does not seem to be negatively associated with the perceived social support among patients or with the change in patients' levels of distress, fatigue or pain from the first to the last day of patients’ clinical stay.

Keywords

internet; online; internet use; social support; perceived social support; perceived social support; inpatients; Patient Reported Outcome Measures

Introduction

Background

Cancer survivors can suffer from the long-term physical and psychological consequences of cancer and its treatment [1-3]. Fatigue, pain, and distress are among the most frequently reported symptoms during and after primary cancer treatment [4-9]. Given the increasing number of cancer survivors and rising survival rates resulting from progress in early detection, treatment, and cancer management [10, 11], rehabilitation is playing an increasingly important role.

Different rehabilitation approaches are being used for cancer patients worldwide. Based on the biopsychosocial model of the World Health Organization (WHO), these programs are based on a similar, multidisciplinary understanding of cancer rehabilitation [12-14]. In Germany, after primary treatment, every cancer patient is legally entitled to participate in a three-week combined multidisciplinary treatment program consisting of physical therapy, patient education, relaxation training, functional training, psycho-oncological treatment, nutrition counseling, and occupational counseling depending on the patient’s functioning and needs as assessed at the beginning of the rehabilitation [12, 15]. A special feature is that in Germany, cancer rehabilitation is mainly carried out in inpatient clinics [12]. Uncontrolled before-and-after studies showed that cancer rehabilitation patients can improve their somatic status, psychosocial status, and quality of life and reduce their anxiety, depression, and distress from the beginning to the end of inpatient rehabilitation [16-18].

Two essential elements of inpatient and day care rehabilitation are social support from other cancer rehabilitation patients and physical activity [12]. Social support has been recognized as an important factor in overall well-being [19, 20] and has been positively associated with both improvement in cancer-related stress [21] and posttraumatic growth in cancer patients [22]. In inpatient and day care, cancer rehabilitation patients receive social support from other rehabilitation patients with a cancer diagnosis (peer support) during therapist-guided group treatment sessions and unguided peer support during leisure time activities. Three main attributes of peer support are (1) emotional support by discussing personal difficulties, (2) informational support by providing knowledge relevant to problem solving, and (3) appraisal support such as encouragement to persist in problem solving and reassurance that efforts will lead to positive outcomes [23]. Previous research found gender and age differences for seeking and providing social support. Women seem to provide more emotional support to both men and women, and they seem to receive more help in return [24]. Older people (age 60+) are less likely to explicitly ask for emotional support than younger people [25]. Systematic reviews that explored the benefit of one-on-one and group peer support interventions for cancer patients conducted analog and online showed mixed results. Peer support interventions increased breast cancer patients’ emotional well-being, quality of life, and treatment-related compliance [26], as well as cancer patients’ psychosocial functioning [27]. However, unmoderated and unstructured group peer support interventions conducted online without peer training had no effect or even adverse effects on some psychosocial outcomes [26, 28]. In the absence of moderation, or group structure, expressions of anger and fear increased, as did discussions about death and dying [28, 29].

E-Health applications and the internet can empower cancer patients to be more active health care consumers and facilitate information and supportive care needs [30-33]. First, cancer patients can search the internet for health- or cancer-related information or solicit medical advice from their physicians by email. Intensive searches revealed that there is no publication on the prevalence of cancer-related internet searching during inpatient or day care rehabilitation. However, the prevalence of cancer patients in a Dutch sample, two American samples and a Swedish sample who used the internet ranged from 60.2% to 79.8% [31, 34-36]. In advanced economies, 87% of the population uses the internet at least occasionally [37]. The internet can help cancer patients fulfill their needs for information regarding their diagnosis, prognosis, or treatment options [34, 38, 39]. Cancer patients who search the internet for cancer-related information are younger and more highly educated than patients who do not search the internet [34-36]. Second, cancer patients can use virtual communication and virtual communities for social support. Online, cancer patients can access the internet anytime and from almost anywhere [40], anonymously if desired, and even patients with rare cancer types can find other patients with the same cancer type to share experiences [41]. The online peer support programs used in a study setting can have a positive influence on cancer patients’ psychosocial well-being, including quality of life and distress [26, 42]. Third, e-Health programs are used as independent treatment measures or to improve or assist health care services in various phases of cancer treatment [43-46]. E-Health cancer rehabilitation and aftercare programs especially address logistically challenged populations and commonly use elements such as education, self-monitoring, self-management training, personalized exercise programs, communication with health care providers, and communication with fellow patients [45, 46].

To date, there has been little research on the relationship between the extent of internet use and perceived social support. Initial studies suggest that there is no overall relationship between these two variables [47, 48]. One of the studies reported that individuals who report greater use of internet activities such as gaming and instant messaging receive more social support than individuals who reported lower use of these internet activities [47], whereas the second study found no association between type of internet activity and perceived social support in patients with spinal cord injuries [48].

Objective

The starting point of the present study was observations by health care professionals of the cooperating oncological rehabilitation clinic that a high level of internet use between and after rehabilitation sessions reduced social interactions between patients during their clinic stay and interfered with the patients’ rehabilitation program. Therefore, they hypothesized that reducing an essential element of inpatient rehabilitation, i.e., real-life social interactions negatively impact patients' rehabilitation outcomes. Hence, the study addressed the following research questions: (1) Is the extent of cancer patients’ internet use during their clinical stay negatively associated with the perceived social support among cancer patients during their clinical stay? (2) Is the extent of cancer patients’ internet use during their clinical stay negatively associated with changes in distress, fatigue, and pain scores from the beginning to the end of inpatient cancer rehabilitation, with distress being the primary outcome?

Additionally, we aimed to describe the extent and purpose of cancer patients’ internet use during their clinical stay and at home and explore their preferences for the future use of eHealth or web-based services for their health care.

Methods

Study Design

In the cross-sectional part of the study, we obtained data using a paper-pen questionnaire to gain insight into the extent and purpose of rehabilitant internet use, their preferences for future use of eHealth or web-based programs, their perceived social support from other patients, and their physical activity during the clinic stay. For the longitudinal part of the study, medical data and three Patient Reported Outcome Measures (PROMS) were collected on the first and the last day of the clinic stay.

The report of this study followed the recommendations of the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement. The STROBE statement contains eighteen items that are common to cohort, cross-sectional, and case–control studies. Four checklist items (Items 6, 12, 14, and 15) have specific variations according to the study design [49] (Multimedia Appendix 1).

The study protocol for this study is freely available at the Open Science Framework [50] and was published before the recruitment of the first participant.

The study was conducted in accordance with the Code of Ethics of the Declaration of Helsinki and was surveyed by the Ethics Committee of the local Medical Association (Schleswig-Holstein, Germany, study ID 042/18 II).

Setting, Recruitment and Participants

The participants were recruited during their third week of their three-week inpatient cancer rehabilitation stay at a German rehabilitation clinic. Potential participants were approached during the patient consultation. Rehabilitation patients were recruited between September 2018 and February 2020. Recruitment occurred in random time samples. During the random time samples, all eligible patients were asked to participate. Patients were included if they had been diagnosed with any type of cancer, were 18 years of age, and had sufficient oral and written proficiency in the German language. First, the patients received informed consent forms. The consent forms contained information about the study goal, potential risks and benefits of study participation, the voluntary nature of participation, and the type and duration of data storage. Participants were informed that medical data would be included in the evaluation of the study. Medical data are routinely collected on the first and last day of the clinic stay. Afterward, the medical director distributed the pen-and-paper questionnaire to the participants, which the participants completed and handed to their treating physician within the next day.

Measures and data source

Cross-sectional questionnaire

Sociodemographic and medical characteristics

The questionnaire during the last week of the clinic stay included multiple choice items designed to describe sociodemographic (age, gender, years of schooling, professional situation, current living situation) and medical characteristics (type of cancer) of the participants.

The Extent and Purpose of Patients’ Internet Use

We used an adapted version of the questionnaire used by Drewes et al. [51] to measure the internet use of patients during their clinic stay and at home as well as their interest in future interaction with new media. First, participants reported whether they use the internet. Participants who indicated not using the internet were instructed to skip all questions about the extent and purpose of internet use.

The frequency of internet use at home and during the clinic stay was self-reported by responses on a 4-point response scale from 'never' to 'daily'. Two items about the daily time spent online during the clinic stay and at home were answered on a 5-point response scale from ‘none’ to ‘more than 120 minutes’. Furthermore, participants were asked which device they use to access the internet at home and during their clinic stay. To indicate the most common online activities during the clinic stay and at home, participants could select one or more of ten predefined activities options and could enter an activity themselves.

Preferences for Future Use of eHealth or Web-Based Programs

Participants’ interests in future interaction with new media or web-based services in health care were determined by rating the following 6 statements on a 4-point Likert scale from ‘I strongly disagree’ to ‘I strongly agree’: “I wish to use a smartphone for my health care”, “I would like to receive therapy assistance via smartphone”, “I would like to receive therapy assistance via personal computer (PC) or laptop, “I would like to receive therapy assistance via telephone”, “I would like to document symptoms and side effects of my disease and treatment online”, and “I would like to document symptoms and side effects of my disease and treatment in a mobile application”.

Patients' Views on Internet use during Clinic Stay.

Participants rated the following statements on a 4-point Likert scale from ‘I strongly disagree’ to ‘I strongly agree’: “The availability of Wireless LAN (WLAN) in the rehabilitation clinic is very important to me”, “I would like to receive online support during treatment”, “I feel distracted from rehabilitation by using the internet during rehabilitation”, “I can fulfill my information needs by using the internet during my rehabilitation stay”, and “I was absent from the clinic's leisure time activities because I spent the time on the internet”.

Perceived Social Support between Patients during Clinic Stay

To measure the perceived social support between patients during the clinic stay, the questionnaire on social support between patients (F-SozU-P) was used [52]. The F-SozU-P is an adaptation of the German self-report questionnaire for the assessment of social support (F-SozU) [53], which is the long version of the brief form for assessing social support (F-SozU K-6) [54]. Both the order and the sentence structure of the F-SozU items were retained in the F-SozU-P. However, words such as "people, relatives, family" in the F-SozU were replaced by "fellow patients" or "patients" in the F-SozU-P. All 54 items were scored on a five-point Likert scale ranging from 1 = ‘I strongly disagree’ to 5 = ‘I strongly agree’. In the validation study, the global scale (WasU-P) had high values for internal consistency (α =.93) [52].

Physical Activity during Clinic Stay

Physical activity during the clinical stay was measured with the German version of the Godin-Shephard Leisure-Time Physical Activity Questionnaire (GSLTPAQ) [55]. The GSLTPAQ is commonly used for classification purposes in oncology [56]. Participants reported how often and how long (in minutes) they engaged in low-, moderate- and high-intensity physical activity in the past week. The frequency at each intensity is multiplied by 3, 5, and 9 metabolic equivalents (METs) and then multiplied by the duration divided by sixty and summed. Scores derived from the GSLTPAQ represent the time of physical activity during the clinic stay in the form of METs time hours within the last week [56].

Longitudinal Questionnaire

The Longitudinal questionnaire included three validated PROMS. First, the German version of the Distress Thermometer (DT) [57] consists of a single item scale from 0 = no distress to 10 = extreme distress, indicating how much stress the participant has felt in the last week, including today. A score of 5 is internationally recommended as an indicator that a patient is distressed and may need support [57]. Second, the German version of the numeric rating scale (NRS) for pain [58]. The NRS for pain is an 11-point numeric scale (NRS 11) from 0 = no pain to 10 = worst pain imaginable [58]. The instrument is commonly used to measure pain in cancer patients [7]. Third, participants completed the German version of the Brief Fatigue Inventory (BFI) [59]. The BFI is used for the specific assessment of fatigue in patients with oncological diseases. The questionnaire contains ten items. Three items ask patients to rate the severity of their fatigue at the average, at its worst and right now, with 0 = no fatigue and 10 = fatigue as bad as you can imagine. In addition, six items measure the extent to which patients’ fatigue interferes with general activity, mood, walking, work, relationships with others, and enjoyment of life. These items are rated on a scale of 0 = does not interfere to 10 = completely interferes [59]. A score between 3 and 4 points indicates medium-severity fatigue in tumor patients.

Pilot Testing

We pilot tested the complete set of items in March 2018 in six rehabilitation patients. The pilot participants were recruited from the same German rehabilitation clinic as the respondents in the following study. The inclusion criteria for participation in the pilot test were identical to those of the main study. Participants were instructed to think aloud while completing the questionnaires to identify how participants interpreted items, whether instructions were easy to understand, whether problems occurred and whether participants understood the items in the way they were intended [60]. The pilot study showed satisfactory results and revealed that participants generally understood the set of items well. The completion of the questionnaire took between 25-50 minutes.

Data Analysis

We used SPSS Statistics (version 25, IBM SPSS Inc.) for the statistical analyses. The participants’ sociodemographic characteristics, medical characteristics, the extent and purpose of rehabilitant internet use, and their preferences for future use of eHealth or web-based programs were summarized descriptively (i.e., means, standard deviations (SD), frequencies, percentages).

For further analysis, we excluded cases with more than 30% of the F-SozU-P items missing [61]. We used multiple linear regression analysis to determine the association between the extent of participants' internet use (independent variable) and perceived social support among patients during their clinical stay (dependent variable) (research question 1). To control for potential confounding variables, we included physical activity during the clinical stay (GSLTPAQ score), age, education (more than 10 years of school education vs. less than or equal to 10 years) and sex as additional independent variables. Categorical variables were dummy coded. The variable extent of internet use was the product of the two factors time spent online during the clinic stay and frequency of internet use during the clinic stay. Missing values of the F-SozU-P and the independent variables extent of internet use during rehabilitation, GSLTPAQ, age, and education were imputed using the EM algorithm [62].

We used three linear mixed models with repeated measures to determine the association between the extent of participants' internet use during inpatient rehabilitation (independent variable) and the change in distress as the primary outcome as well as the secondary outcomes fatigue and pain (dependent variables) from the beginning to the end of inpatient rehabilitation (research question 2). To answer the research question, we included the interactions between the extent of participants' internet use during their clinical stay and time (second measurement point as the reference category) in the model. We included the interaction between social support among patients and time and the interaction between the extent of internet use during the clinical stay, the extent of patients' internet use, and time in the model. We included the two interactions to test whether social support moderated the association between the extent of participants' internet use and the three PROMS. Additionally, we tested the main effects of social support among patients, time, and the interaction effect of the extent of participants' internet use and social support among participants. The overall fit of the models was evaluated by the -2 log likelihood (-2LL). We ran the three models first with and then without a random intercept. We evaluated the difference in the model fit by a test of differences in –2LL over the difference in degrees of freedom by using an ordinary Chi-square distribution. If the random intercept did not result in a significantly better model fit, we selected the fixed intercept model. We used the constrained maximum likelihood (REML) method to estimate the parameters in all three models [63]. For our models, we chose the heterogeneous first-order autoregressive (ARH(1)) covariance structure. We expected that the variance in distress, pain and fatigue would be greater on the first day than on the last day of the clinical stay [64].

For the planned multiple regression analyses, we conducted an a priori power calculation by using G*Power [65]. Based on this analysis, we concluded that study data from 352 patients should be available. This number of patients is sufficient to demonstrate a correlation with a small to medium effect size of R=.20 (corresponding to an f-square=.0417) with 80% power and a level of significance set at alpha =.05 in a multiple linear regression analysis with seven predictor variables.

Results

Cross-Sectional Results

Participants Sociodemographic and Medical Characteristics

A total of 323 rehabilitation patients participated. Nine hundred rehabilitation patients were asked to participate, which resulted in a response rate of 36%. The participants' ages ranged from 29 to 88 years (Table 1). More female (172/323, 53.3%) than male patients participated in the study. Approximately one-third (111/323, 34.4%) of the participants had more than 10 years of school education. Almost half (146/323, 48.3%) of the participants were retired. Seventy percent (226/323) of the participants were married or lived in a committed relationship. Colon (69/323, 17.5%), breast (66/323, 16.7%) and prostate (49/323, 12.4%) cancer were the most common types of cancer among participants.

Table 1. Medical and sociodemographic characteristics of participants (N=323).

Participant characteristics		Values
Age (years), mean (SD; range)		62.3 (11.2; 29-88)
Sex, n (%)		
	Female	172 (53.3)
	Male	150 (46.4)
	Missing values	1 (0.3)
Highest educational achievement, n (%)		
	13 years of school education	111 (34.4)
	10 years of school education	110 (34.1)
	9 years of school education	93 (28.8)
	No degree	2 (0.6)
	Other	3 (0.9)
	Missing values	4 (1.2)
Professional situation, n (%)[a]		
	Retired	146 (45.2)
	Working full-time	97 (30.0)
	Working part-time	49 (15.2)
	Unemployed	24 (7.4)
	Housewife/Househusband	18 (5.6)
	Other	6 (1.9)
	Missing values	0 (0)
Current living situation, n (%)		
	Living with partner or living with partner and children	222 (68.7)
	Living alone	83 (25.7)
	Living alone with kids	11 (3.4)
	Other	3 (0.9)
	Missing values	4 (1.2)
Cancer type, n (%)[a]		
	Colon	69 (21.4)
	Breast	66 (20.4)
	Prostate	49 (15.2)
	Lung	27 (8.4)
	Non-Hodgkin	24 (7.4)
	Kidney	18 (5.6)

	Mouth, throat, esophagus	15 (4.6)
	Pancreatic	14 (4.3)
	Other	83 (25.7)
	Missing values	0 (0)

[a]Multiple selection, percentages of respondents

The Extent and Purpose of Patients' Use of the Internet during their Clinic Stay and at Home

Of the 323 participants, 279 participants (86.4%) reported that they use the internet. These participants are referred to as "internet users" in the following section. During their clinical stay, 71% (198/279) of the internet users used the internet daily. At home, 85% (237/279) of the internet users used the internet daily (Table 2). Thirty of the 279 (10.8%) internet users never used the internet during their clinic stay. During their clinic stay, 27 of the 279 internet users (9.8%) used the internet for more than one hour per day, compared to 84 of the 277 participants (30.3%) at home. The smartphone was the most frequently used device for internet access during the clinic stay (219/279, 78.4%) and at home (215/279, 77.1%). During the clinic stay and at home, social media use (192/279, 68.9%; 208/279, 74.6%) and emailing (143/279, 51.3%; 228/279, 81.7%) were among the three most frequently reported online activities.

Table 2. The extent and purpose of patients' use of the internet during their clinical stay and at home (N=279).

Participant characteristics	**Setting**	
	During clinic stay	**At home**
Frequency of internet use, n (%)		
Daily	198 (71.0)	237 (84.9)
> once a week	16 (5.7)	22 (7.9)
> once a month	0 (0)	5 (1.8)
Rarely	23 (8.2)	11 (3.9)
Never	30 (10.8)	2 (0.7)
Missing values	12 (4.3)	2 (0.7)
Daily time spent online in minutes, n (%)		
> 120	7 (2.5)	28 (10.0)
60-120	20 (7.2)	56 (20.0)
30-60	84 (30.1)	118 (36.5)
0-30	115 (42.6)	71 (42.3)
None	38 (13.6)	3 (1.1)
Missing values	11 (3.9)	3 (1.1)
Devices used to access the internet, n (%)[a]		
Smartphone	219 (78.5)	215 (77.1)
Tablet	69 (24.7)	118 (42.2)
Laptop	62 (22.2)	152 (54.5)
PC	4 (1.4)	130 (46.6)
None	26 (9.3)	4 (1.4)
Other	7 (1.4)	5 (1.8)
Missing Values	4 (1.4)	1 (0.3)
Online activities during rehabilitation, n (%)[a]		
Using social media	192 (68.9)	208 (74.6)
Communication with relatives	148 (53.0)	154 (55.2)

	Writing emails	143 (51.3)	228 (81.7)
	Other (news, online games, shopping on eBay/amazon, erotic)	106 (38.0)	205 (73.5)
	Searching for health-related information	68 (24.0)	173 (62.0)
	Reading	54 (19.4)	92 (33.0)
	Working	14 (5.0)	74 (26.5)
	Learning/Studying	12 (4.3)	88 (31.5)
	Looking for treatment support	11 (3.9)	22 (7.9)
	Participation in online courses for private education/qualification	3 (1.1)	22 (7.9)
	Other	12 (4.3)	25 (9.0)
	Missing Values	7 (2.5)	2 (0.7)

[a]Multiple selection, percentages of respondents

Internet Users' Views on Internet use during the Clinic Stay.

9.3% (26/279) of internet users did feel distracted from rehabilitation by using the internet during their clinical stay (46/279, 16.5%), and 1.8% (5/279) reported having missed their clinic's leisure time activities because they spent time on the internet (Multimedia Appendix 2). Approximately four-fifths (219/279, 78.5%) of the internet users reported that the availability of Wi-Fi in the clinic was very important to them. Approximately one-third of internet users reported that they would like to receive online support during treatment (60/279, 21.5%) and that they could fulfill their information needs by using the internet during the clinic stay (95/279, 34.1%).

Patients’ Interests in Future Interaction with New Media or Web-based Services in Health Care

Approximately 35.9% (116/323) of the participants wanted to use a smartphone for their health care in the future (Multimedia Appendix 3). Approximately one-third of the participants would like to receive support via smartphones, PCs or laptops. A total of 11.2% (36/323) of participants would like to receive therapy support via telephone. Furthermore, 23.8% (77/323) of the participants agreed to document the side effects of their disease online, and 18.3% (59/323) agreed to do so via a mobile application.

Association between the Extent of Internet Use and Social Support Among Rehabilitants During Rehabilitation

Seven cases (2.2%) were excluded from the multiple regression analysis because more than 30% of the F-SozU-P items were missing. The mean perceived social support between patients during their clinical stay was 3.2 (SD 0.7).

The extent of participants’ internet use during their clinic stay (t_{315}=0.78, *P*=.43) was not significantly negatively associated with the perceived social support among patients (Table 5). Participants who were younger (t_{315}=-6.01, *P*<.001) and were female (t_{315}=2.02, *P*=.04) perceived significantly more social support from other cancer patients during their clinic stay than older and male participants, controlling for all other predictors in the model. Seventeen percent (R^2=.17) of the variance in perceived social support among rehabilitation patients during rehabilitation was explained by the model.

Table 4. Parameters of the multiple regression analysis with perceived social support as the dependent variable (n=316).

Variables	**b**	**SE b**	**t test**	**P value**	**95% CI**

Intercept	4.31	0.30	14.17	< .001	3.71, 4.90
Time spent online during clinic stay	0.00	0.01	0.78	.43	-0.01, 0.02
Age	-0.02	0.00	-6.01	<.001	-0.03, -0.02
Sex (male vs. female)	0.14	0.07	2.01	.04	0.00, 0.28
GSLTPAQ	0.00	0.00	0.82	.42	-0.00, 0.01
Education (> 10 years vs. ≤ 10 years of school education)	-0.04	0.07	-0.56	.58	-0.18, 0.10

GSLTPAQ = the Godin-Shephard Leisure-Time Physical Activity Questionnaire.
R^2 =.17; P <.001

Longitudinal Results

Participants’ mean level of distress decreased from 5.2 (SD 2.4) to 2.7 (SD 2.1) from the beginning to the end of rehabilitation (Table 5). The mean fatigue decreased from 3.2 (SD 1.9) to 2.1 (SD 1.6) from the beginning to the end of rehabilitation. The mean pain decreased from 2.4 (SD 2.8) to 1.2 (SD 1.9) from the beginning to the end of rehabilitation.

Table 5. Descriptive data for outcomes for both measurement points (N=323).

Questionnaire	**First measurement point**	**Second measurement point**
	Mean, (SD), n	Mean, (SD), n
DT	5.2, (2.4), 315	2.7, (2.1),311
BFI	3.2 (1.9), 315	2.1 (1.6), 311
NRS for pain	2.4 (2.8), 316	1.2 (1.9), 315

DT=distress, BFI=Brief Fatigue Inventory, NRS=numeric rating scale

Association Between the Extent of Internet Use and Changes in Distress from the First to the Last Day of the Clinic Stay (Primary Outcome)

The interactions between the extent of participants’ internet use during their clinic stay and time ($F_{1, 306.08}$=0.29, P=.59) and the interaction between perceived social support among patients and time ($F_{1, 306.15}$=0.99, P=.32) were not negatively associated with changes in participants’ distress levels (Multimedia Appendix 3). The interaction between the extent of participants’ internet use during their clinic stay and perceived social support among patients and time ($F_{1, 306.02}$=0.17, P=.68) was not significantly associated with changes in the participants’ distress levels. Additionally, participants' distress levels did not significantly change ($F_{1, 306.48}$=2.08, P=.15) from the first to the last day of their clinic stay, controlling for all other fixed effect predictors in the model.

Association Between the Extent of Internet Use and Changes in Fatigue and in Pain from the first to the last day of the clinic stay (Secondary Outcomes)

The interactions between the extent of participants’ internet use during their clinic stay and time ($F_{1, 308.89}$=0.02, P=.90) and the interaction between perceived social support among patients and time ($F_{1, 308.99}$=0.08, P=.78) were not significantly negatively associated with changes in participants’ fatigue levels (Multimedia Appendix 4). The interaction between the extent of participants’ internet use during their clinic stay and perceived social support among patients and time ($F_{1, 308.79}$=0.00, P=.99) was not significantly associated with changes in the participants’ fatigue levels. Additionally, participants' fatigue levels did not significantly change ($F_{1, 309.29}$=2.97, P=.09) from the first to the last day of their clinic stay, controlling for all other fixed effect predictors in the model.

The interactions between the extent of participants' internet use during their clinic stay and time ($F_{1, 306.31}$=1.84, P=.18) and the interaction between perceived social support among patients and time ($F_{1, 306.31}$=1.52, P=.22) were not significantly negatively associated with changes in participants' pain levels (Multimedia Appendix 4). The interaction between the extent of participants' internet use during their clinic stay and perceived social support among patients and time ($F_{1, 306.09}$=1.79, P=.18) was not significantly associated with changes in the participants' pain levels. Additionally, participants' pain levels did significantly decrease ($F_{1, 307.34}$=7.71, P=.006) from the first to the last day of their clinic stay, controlling for all other fixed effect predictors in the model.

Discussion

Principal Findings

The study results do not support the study hypotheses. The extent of participants' internet use during their stay at the oncological rehabilitation clinic was not negatively associated with the perceived social support among cancer patients during their clinic stay. Additionally, the extent of participants' internet use during their clinical stay was also not negatively associated with the change in the three PROMS distress (primary outcome), pain, and fatigue from the first to the last day of the clinical stay.

Furthermore, the results of the multiple linear regression analysis indicate that participants who were younger and female perceived significantly more social support from other cancer patients during their clinical stay than older and male participants.

The descriptive study results indicate that more than four-fifths of the participants were internet users. During the clinic stay, 71% of internet users used the internet daily. Approximately 10% of the internet users never used the internet during their clinic stay. At home, 85% of internet users used the internet daily. During their clinical stay, participants seemed to be interested in using the internet to communicate with relatives, followers and strangers and seemed less interested in using it for health-related activities. Only a quarter of internet users searched the internet for health-related information during rehabilitation or wanted to receive online support during treatment. At home, almost three times as many internet users searched the internet for health-related information.

Few participants showed interest in using eHealth or web-based services for their future health care. Approximately one-third of participants intended to use their smartphone, PC or laptop for therapy support in the future or to use a smartphone for their health care in the future. Cancer patients' interest in future therapy support via telephone was even lower.

Comparison with Previous Work

The assumption before the study start was that a high level of internet use during rehabilitation could reduce social interaction between patients and therefore the perceived social support among cancer patients during their clinic stay. This assumption was based on the observations of health care professionals and not on previous study results. Finding no association between the extent of participants' internet use and perceived social support is consistent with the results of studies that examined internet use in healthy individuals [47] and in patients with spinal cord injuries [48]. Additionally, only 2% of internet users reported missing out on clinic leisure time activities because they spent time on the internet. Finding female sex to be associated with more perceived social support from other patients in the clinic fits the results of the validation study of the F-SozU-P, in which female psychosomatic patients in inpatient rehabilitation perceived more social support than male patients [52]. Women seem to provide more emotional support to both men and women, and they seem to receive more help in return [24]. A positive association between younger age and higher perceived social support for cancer patients may be partially explained by the findings of a previous study that reported that older adults reported seeking less explicit social support but reported using a similar amount of implicit social support seeking to cope with their stressors [21]. In an unfamiliar environment with initially unfamiliar fellow patients, explicitly asking for emotional support seems to be associated with higher perceived social support.

Finding no association between the extent of participants’ internet use and the change in participants’ levels of distress, pain and fatigue from the first to the last day of their clinic stay is consistent with participants’ perceptions of the relationship between internet use and rehabilitation activities. Only 9% and 2% of internet users, respectively, reported that they felt distracted from the rehabilitation program or that they missed recreational activities at the clinic because they spent time on the internet. Additionally, social support did not moderate the association between the extent of participants’ internet use and change in the three PROMS.

This study is the first to present data on the extent and purpose of patients' internet use during inpatient cancer rehabilitation. The prevalence of internet use among participants (86.4%) was higher than in previous studies with cancer patients (60.2% to 79.8%) [31, 34, 35] and very similar to the prevalence (87%) in the population of advanced economies [37]. The higher prevalence compared to previous studies with cancer patients may be explained by the samples in the earlier studies being recruited in 2005 [31], 2007 [34], and 2015 [35] and the increasing internet access among cancer patients [66].

The high interest in using the internet to communicate with relatives, followers and strangers and the low interest in using it to search for health-related information during the clinic stay could be explained by the circumstance that most patients are geographically too far away to meet their relatives in person and therefore need to use communication technology during the clinic stay. In addition, to satisfy their information needs during rehabilitation, they have daily contact with the medical staff to ask health-related questions instead of using the internet.

Cancer rehabilitation patients’ interest in using eHealth or web-based services for their future health care was lower than in previous studies. Participants’ interest in future therapy support via smartphone (99/323, 30.7%) was similar to a previous study of cancer survivors (42/168, 25%) [51]. However, interest in future therapy support via PC or laptop (29% vs. 67%) and interest in therapy support via telephone (11% vs. 74%) was considerably lower than in the previous study [51]. Interest in future symptom monitoring via the internet (24% vs. 55% vs. 44%) was also lower compared with two previous studies [32, 51]. Two explanations for the differences could be patient characteristics and the recruitment method. Participants in the previous study were younger (mean 62.3 vs. 54.6 years) [51], with younger age associated with a higher likelihood of cancer-related internet use [31, 34-36]. Additionally, in a previous study, cancer patients were recruited during a 4-day meeting with advanced training for breast cancer patients and physicians. These patients possessed a particularly high level of interest in their health [51]. Although participants' interest in future interaction with web-based health services, as measured in this study, was low, we do not believe this should discourage implementation of web-based services for therapy support in cancer rehabilitation. For the planning of future web-based interventions or services, it is more important to evaluate the needs and values of the participants toward this specific new web-based service [67].

Limitations

The first limitation concerned the low participation rates, which could be an indicator that our sample had a nonresponse bias [68]. However, the scores of the study participants who experienced fatigue differed only slightly from the scores of all cancer patients (n= 1204) treated at the analyzed oncological rehabilitation clinic in 2019, indicating that our sample was representative of the patients of the rehabilitation clinic.

Second, we were unable to find comprehensively validated instruments to measure perceived social support between patients, the extent and purpose of rehabilitating patients’ use of the internet and patients’ interest in future interactions with web-based services. The F-SozU-P was validated as part of a dissertation project and showed good values for internal consistency and convergent and discriminant validity [52]. The items we used to measure the extent and purpose of rehabilitating patients’ use of the internet and patients’ interest in future interactions with web-based services were obtained or adapted from a previous study by Drewes, Kirkovits [51]. We pilot tested all instruments of the questionnaire to assess the experiences of cancer patients while they were completing the instruments. The results of the pilot study showed that the participants generally understood the questions well, and no adjustments to the questionnaire had to be made.

Third, 7.7 (25/323) - 12.0% (39/323) of the values for the items measuring patients’ interest in future interaction with web-based services were missing. The missing values can be partially explained by the fact that participants who reported not using the internet were instructed to skip all questions about the extent and purpose of internet use. Nine of 44 (20.5%) noninternet users additionally skipped the last six questions of the questionnaire about their interest in future interactions with web-based services.

Conclusions

The extent of cancer patients’ internet use during their clinical stay does not seem to be associated with the perceived social support among patients or with the change in patients' level of distress, fatigue or pain from the first to the last day of patients’ clinical stay. Therefore, we recommend that clinics offer their patients a free, easily accessible and fast WLAN connection.

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Conflicts of Interest

None declared.

Abbreviations

BFI: Brief Fatigue Inventory
DT: Distress Thermometer
F-SozU-P: The questionnaire on social support between patients
GSLTPAQ: Godin-Shephard Leisure-Time Physical Activity Questionnaire
NRS: Numeric Rating Scale
PC: personal computer
PROMS: Patient Reported Outcome Measures
WLAN: Wireless Local Area Network

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Supplementary Files

Multimedia Appendixes

The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Statement.
URL: http://asset.jmir.pub/assets/86748f1a5235c98b23dc087ac90597fd.docx

Internet users' views on internet use during the clinic stay.
URL: http://asset.jmir.pub/assets/2071ec6b40cb23e69015992128f55924.docx

Participants’ interests in future interaction with new media or web-based services in health care.
URL: http://asset.jmir.pub/assets/d3f34b6813315941314325f4bca60bd9.docx

Parameters of the linear mixed model analysis with distress as the dependent variable.
URL: http://asset.jmir.pub/assets/b72b5117633af82855684c29254557e1.docx

Parameters of the linear mixed model analysis with the fatigue as the dependent variable.
URL: http://asset.jmir.pub/assets/ae51da3765017542899bf6703700e7b5.docx

Parameters of the linear mixed model analysis with pain as the dependent variable.
URL: http://asset.jmir.pub/assets/8f90c365484afff7ef58144884de52f7.docx

8 Zusammenfassung

Hintergrund: Die Suche nach krebsbezogenen Informationen im Internet hilft Krebspatient(inn)en, ihren ungedeckten Informationsbedarf zu befriedigen, und versetzt sie in die Lage, eine aktivere Rolle im Umgang mit ihrer Krankheit zu spielen. Die Entscheidung der Patient(inn)en, ob Sie die gefundenen Informationen nutzen, hängt stark von der Vertrauenswürdigkeit der Informationen und des Mediums ab. Außerdem müssen die Patient(inn)en über ein ausreichendes Maß an Bedienungs-, Navigations-, Informations- und Bewertungsfähigkeiten verfügen, um von den Informationen zu profitieren. Die soziale Unterstützung der Krebspatient(inn)en untereinander ist ein wesentliches Element der stationären und teilstationären Rehabilitation. Therapeut(inn)en vermuten, dass ein hohes Maß an Internetnutzung während der Rehabilitation die sozialen Interaktionen zwischen den Patient(inn)en stark einschränken kann, wodurch das Rehabilitationsprogramm der Patient(inn)en gestört und der Behandlungserfolg gefährdet wird.

Ziel: Ziel dieser Dissertation war es, zu untersuchen, inwieweit Krebspatient(inn)en Vertrauen in krebsbezogene Online-Informationen haben. Darüber hinaus wollten wir die Bedienungs-, Navigations-, Informations- und Bewertungsfähigkeiten von Krebspatient(inn)en untersuchen. Wir stellten die Hypothese auf, dass das Ausmaß der Internetnutzung von Krebspatient(inn)en negativ mit der sozialen Unterstützung unter Patient(inn)en während ihres Klinikaufenthalts sowie mit geringeren Verbesserungen der von den Patient(inn)en berichteten Behandlungsergebnisse vom ersten bis zum letzten Tag des Klinikaufenthalts assoziiert ist.

Methode: Wir führten eine *systematische Übersichtsarbeit* durch. Eingeschlossen wurden Studien jeglicher Art, die das Vertrauen von Krebspatient(inn)en in Online-Gesundheitsinformationen messen. Die Qualität der Studien wurde anhand der Item-Bank des Research Triangle Institute (RTI) bewertet. Die eingeschlossenen Studien wurden in einer narrativen Synthese zusammengefasst.

21 Krebspatient(inn)en führten *acht krebsbezogene Suchaufgaben* im Internet durch. Die Teilnehmenden wurden gebeten, laut zu denken, während sie die Aufgaben ausführten, und die Bildschirmaktivitäten wurden aufgezeichnet. Die Arten und Häufigkeiten von

Leistungsproblemen wurden ermittelt und nach einem induktiven Kodierungsverfahren in Kategorien eingeteilt.

Querschnittsdaten, wie das Ausmaß der Internetnutzung der Teilnehmenden und die von den Teilnehmenden wahrgenommene soziale Unterstützung unter Patient(inn)en, wurden in der letzten Woche des Aufenthalts der Krebspatient(inn)en in der Rehabilitationsklinik erhoben. Die Behandlungsergebnisse, d. h. der Distress-, der Müdigkeits- und der Schmerzlevel der Teilnehmenden, wurden am ersten und letzten Tag des Klinikaufenthalts erhoben. Mit Hilfe einer multiplen linearen Regressionsanalyse untersuchten wir die Assoziation zwischen dem Ausmaß der Internetnutzung durch Krebspatient(inn)en und der sozialen Unterstützung unter Patient(inn)en. Wir verwendeten eine lineare Gemischte Analyse mit wiederholten Messungen, um die Assoziation zwischen dem Ausmaß der Internetnutzung durch Krebspatient(inn)en und der Veränderung der von den Patient(inn)en berichteten Behandlungsergebnisse zu untersuchen.

Ergebnisse: Von den 7.314 Publikationen, die bei der Suche identifiziert wurden, wurden sieben Querschnittsstudien in die Synthese eingeschlossen. Insgesamt 1 054 Patient(inn)en gaben an, dass sie ein gewisses oder großes Vertrauen in Online-Krebsinformationen haben; 154 Patient(inn)en gaben an, dass sie mäßiges Vertrauen in solche Informationen haben; und 833 Patient(inn)en gaben an, dass sie kein oder wenig Vertrauen in Online-Krebsinformationen, Internet-Websites als Quelle für krebsbezogene Informationen oder das Internet als Medium für krebsbezogene Informationen haben. Die methodische Qualität der eingeschlossenen Studien war unterschiedlich.

Alle Teilnehmenden hatten Probleme oder Schwierigkeiten bei der Ausführung der Aufgaben. Die Performanceprobleme der Teilnehmenden wurden in vier Kategorien eingeteilt, nämlich (1) Bedienung des Computers und des Webbrowsers, (2) Navigation und Orientierung, (3) Verwendung von Suchstrategien und (4) Bewertung der Relevanz und Zuverlässigkeit von webbasierten Informationen. Die häufigsten Probleme traten in der dritten und vierten Kategorie auf. Insgesamt 90 % (19/21) der Teilnehmenden verwendeten nicht aufgabenbezogene Suchbegriffe oder unspezifische Suchbegriffe. Insgesamt 95% (20/21) der Teilnehmenden kontrollierten nicht die Quelle oder die Aktualität der gefundenen Informationen.

Von den 323 Teilnehmenden gaben 279 Teilnehmende (86,4 %) an, dass sie das Internet nutzen. Während ihres Klinikaufenthalts nutzten 71 % (198/279) der Internetnutzer(innen) das Internet täglich. Das Ausmaß der Internetnutzung der Teilnehmenden während ihres Klinikaufenthalts (t_{315}=0,78, P=.43) war nicht signifikant mit der wahrgenommenen sozialen Unterstützung unter Patient(inn)en während ihres Klinikaufenthalts assoziiert. Darüber hinaus war das Ausmaß der Internetnutzung der Teilnehmenden während des Klinikaufenthalts nicht negativ mit der Veränderung des Distreslevels ($F_{1, 306.08}$=0.29, P=.59), des Fatiguelevels ($F_{1, 308.89}$=0.02, P=.90) und des Schmerzlevels ($F_{1, 306.31}$=1.84, P=.18) der Teilnehmenden vom ersten bis zum letzten Tag des Klinikaufenthalts verbunden.

Schlussfolgerungen: Die Ergebnisse der eingeschlossenen Studien deuten darauf hin, dass etwa die Hälfte der Krebspatient(inn)en krebsspezifischen Online-Informationen, Internet-Websites als Quelle für krebsbezogene Informationen oder dem Internet als Informationsmedium vertrauen. Die geringe Anzahl der eingeschlossenen Studien und die große Heterogenität der Studienteilnehmenden, Methoden und Ergebnisse erfordern jedoch weitere systematische Forschung. Eine beträchtliche Gruppe von Krebspatient(inn)en verfügte nicht über die notwendigen Fähigkeiten, um von krebsbezogenen Internetrecherchen zu profitieren. Künftige Maßnahmen sind erforderlich, um Patient(inn)en bei der Entwicklung ausreichender Fähigkeiten zur Internetsuche zu unterstützen, wobei der Schwerpunkt auf Informations- und Bewertungskompetenz liegen sollte. Darüber hinaus scheint das Ausmaß der Internetnutzung von Krebspatient(inn)en während ihres Klinikaufenthalts nicht negativ mit der wahrgenommenen sozialen Unterstützung unter den Patient(inn)en oder mit der Veränderung des Distress-, Fatigue- oder Schmerzlevels der Patient(inn)en vom ersten bis zum letzten Tag des Klinikaufenthalts verbunden zu sein.

9 Abstract

Background: Searching the internet for cancer-related information helps patients with cancer satisfy their unmet information needs and empowers them to play a more active role in the management of their disease. Patients' decisions regarding whether to act upon the information they find strongly depend on the trustworthiness of the information and the medium. Additionally, to benefit from the information, patients need a sufficient level of operational, navigational, information, and evaluation skills. Social support among patients is

an essential element of inpatient and day care rehabilitation. Therapists suspect that high Internet use during rehabilitation may severely limit social interactions between patients, thus interfering with the patients’ rehabilitation program and jeopardizing treatment success.

Objective: The objectives of this dissertation were to examine the extent to which cancer patients’ trust in cancer-related online information. Additionally, we aimed to study the operational, navigational, information, and evaluation skills and problems of patients with cancer. We hypothesized that the extent of cancer patients’ internet use would be negatively related to social support among patients during their clinic stay as well as less improvements in patient-reported treatment outcomes from the first to last day of the clinic stay.

Method: A *systematic review* was conducted using five databases. Studies of any kind were included if they measured cancer patients’ trust in online health information. Study quality was assessed using the Research Triangle Institute (RTI) item bank. A narrative synthesis was undertaken to examine the included studies.

21 cancer patients *performed* eight cancer-related search tasks using the internet. The participants were asked to think aloud while performing the tasks, and the screen activities were recorded. The types and frequencies of performance problems were identified and coded into categories following an inductive coding process.

Cross-sectional data, like the extent of participants’ internet use and participants’ perceived social support among patients, were collected during the last week of cancer patients' stay at the rehabilitation clinic. The treatment outcomes, i.e. participants’ levels of distress, fatigue and pain were collected on the first and last day of the clinic stay. We used multiple linear regression analysis to study the association between the extent of cancer patients’ internet use and social support among patients. We used linear mixed model analysis with repeated measures to study the association between the extent of cancer patients’ internet use and the change in patient-reported treatment outcomes.

Results:

Of the 7,314 citations obtained by the search, seven cross-sectional studies were included in the synthesis. A total of 1,054 patients reported having some or a great deal of trust in online cancer information; 154 patients reported moderately trusting such information; and 833 patients reported having no or little trust in online cancer information, internet websites as a source of cancer-related information or the internet as a medium of cancer-related information. The methodological quality of the included studies was diverse.

All participants experienced problems or difficulties in executing the tasks. The participants' performance problems were coded into four categories, namely (1) operating the computer and web browser, (2) navigating and orientating, (3) using search strategies, and (4) evaluating the relevance and reliability of web-based information. The most frequent problems occurred in the third and fourth categories. A total of 90% (19/21) of participants used nontask-related search terms or nonspecific search terms. A total of 95% (20/21) of participants did not control for the source or topicality of the information found.

Of the 323 participants, 279 participants (86.4 %) reported that they use the internet. During their clinic stay, 71% (198/279) of the internet users used the internet daily. The extent of participants' internet use during their clinic stay (t_{315}=0.78, P=.43) was not significantly associated with the perceived social support among patients during their clinic stay. Additionally, the extent of participants' internet use during their clinic stay was not negatively associated with the change participants' levels of distress ($F_{1, 306.08}$=0.29, P=.59), fatigue ($F_{1, 308.89}$=0.02, P=.90), and pain ($F_{1, 306.31}$=1.84, P=.18) from the first to the last day of the clinic stay.

Conclusions: The results of the included studies indicates that approximately half of cancer patients appear to *trust* cancer-specific online information, internet websites as a source of cancer-related information or the internet as an information medium. However, the small number of included studies, high heterogeneity of participants, methods and outcomes calls for further systematic research. A substantial group of patients with cancer did not have the necessary *skills* to benefit from cancer-related internet searches. Future interventions are needed to support patients in the development of sufficient internet-searching skills, focusing particularly on information and evaluation skills. Additionally, the extent of cancer patients' internet use during their clinic stay does not seem to be negatively associated with the perceived social support among patients or with the change in patients' level of distress, fatigue or pain from the first to the last day of patients' clinic stay.

10 Erklärung des Eigenanteils an den Publikationen

Ich bin bei allen drei Publikationen Erstautor. Für alle drei Publikationen habe ich die Experimente konzipiert und geplant, die Experimente durchgeführt, die Daten analysiert, Analysewerkzeuge beigesteuert, Abbildungen und Tabellen erstellt, Entwürfe der Arbeit geschrieben und überprüft und den endgültigen Entwurf genehmigt.

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